Monitoring the Worker and the Community for Chemical Exposure and Disease: Legal and Ethical Considerations in the United States

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ABSTRACT

Biomonitoring of workers and communities raises important legal and ethical concerns, but the two contexts are different. Monitoring workers is usually done by, or at the instigation of, the employer who in law is responsible for their health and safety. Whenever worker monitoring leads to the removal of workers, difficult issues emerge affecting labor-management relations, labor law and discrimination law. Resulting legal and ethical questions are usually framed within the context of the employment contract or labor relationship. In contrast, public health or environmental officials may be the driving force behind biomonitoring of the community. No employer-employee relationship exists, and the doctor-patient relationship may be tenuous. The community may often initiate the request for biomonitoring, but the situation is no less contentious. On the basis of an historical view of monitoring events within the U.S. context, mechanisms are suggested that would promote positive interactions between employers and workers, and between individuals and groups in the monitoring of chemically contaminated communities. These suggestions should have relevance to experience in other countries.

INTRODUCTION

Biomonitoring of workers and of communities at large raises important legal and ethical concerns, but the two contexts are different. Monitoring workers is usually done by, or at the instigation of, the employer who in law is responsible for their health and safety. Whenever workplace monitoring leads to the removal of workers, difficult issues emerge affecting labor-management relations, labor law and discrimination law. Resulting legal and ethical questions are usually framed within the context of the employment contract or relationship.

In contrast, public health or environmental officials may be the driving force behind biomonitoring of the community. No employer-employee relationship exists, and it is doubtful whether a doctor-patient relationship is present. The local community itself may initiate the request for biomonitoring, but the situation is no less contentious.

The identification of DNA-or protein-carcinogen adducts, and other markers of exposure to chemicals and their effects on health raises new and challenging questions for application of the emerging science of molecular epidemiology in the workplace and community. While most attention for possible applications has been focused on the workplace, the eventual use of biomarkers in the context of contaminated communities or consumers exposed to chemicals can

also be anticipated. The new science may well have relevance for chemical regulation, workers' compensation, and damage suits in the courts.

This article brings together two research efforts conducted by the author and his colleagues at the Massachusetts Institute of Technology. The first focused on monitoring in the workplace ($\underline{1}$) and the second on monitoring in the contaminated community ($\underline{2}$). Clearly the emphasis and the examples refer to the United States, but the underlying principles have general applicability.

Human monitoring in the workplace, sometimes referred to as medical screening, is a collation of practices that focuses on the workers as an indicator that (1) disease may result on exposure to a toxic substance, radiation, or other traumas (medical surveillance), (2) a toxic substance has been absorbed into the body (biological monitoring), (3) a particular worker may be especially predisposed to disease (genetic screening or other probes of sensitivity), and (4) a preclinical disease states exist, indicating that potentially harmful exposure has occurred (genetic monitoring). These monitoring practices, especially when required or carried out by a government agency or the employer, raise serious and complex legal and ethical concerns (1,3).

Monitoring in the context of the contaminated community is unlikely to involve genetic or sensitivity screening but may go beyond physical examinations or the collection and analysis of biological samples to include surveys of self-reported symptoms or searches of medical records.

The legal and ethical problems of disease detection and the communication of information in the context of the patient and personal physician relationship are thorny enough: workplace and community monitoring complicate the issue even further. This article seeks to construct a philosophic framework for examining the adequacy of law as an embodiment of ethical values concerning worker and community monitoring and for identifying possible solutions to the attendant legal and moral dilemmas. In the workplace, the analysis necessarily focuses on three sets of activities involving distinct participants: workers, employers, corporations, physicians either in-house or under contract, and the government. The sets of activities deserving separate consideration are as follows: (1) requiring the worker to submit to monitoring tests, (2) disseminating the results of the tests, and (3) using the test results. Because the different kinds of monitoring address different stages of the process from exposure to disease, and because what is monitored affects different groups of workers differently, specification of exemplar problems and a case-by-case analysis are essential, lest we face useless generalities at the end.

Community monitoring involves a different set of actors and activities than are encountered in the workplace. Community residents and public health/environmental officials are the key players. Monitoring the community for chemical exposure and disease involves eight stages: (1) recognition of a potential hazard to health; (2) decision to monitor a particular population for exposure or for particular health endpoints or indicators; (3) design of the monitoring study; (4) actual conduct of the monitoring; (5) evaluation and interpretation of the scientific data, i.e., the scientific study; (6) dissemination of the results; (7) decisions to act, or not to act, in response to the results; and (8) actions (or inaction). Whilst workers may have little potential choice in participating in decisions related to workplace monitoring, community residents can in principle demand participatory roles in all eight activities in exchange for their agreement to be the subjects of monitoring.

TOWARDS AN ETHICAL THEORY FOR HUMAN MONITORING

The moral and legal enquiry in the area of human monitoring addresses the behavior of particular actors engaged in the decision to undertake monitoring tests, and in their design and conduct in the evaluation and dissemination of the test results; and in the use of the information. Ladd (4) argues that it is important to distinguish ethics from law, custom, institutional practices, and positive morality (the body of accepted popular beliefs of a society about morality): ethics is concerned with what ought to be. Moral problems emanating from conflicts concerning human monitoring may be categorized as: (1) conflicts arising from differences in legitimate interests of different actors/institutions; (2) conflicts in moral and legal duties of each actor/institution; and (3) conflicts among actors/institutions arising from different perceptions of what is right or wrong, fair or unfair. In addition to conflicts, other problems arise during the eight stages of monitoring activity, including the perennial problem of how much (information, safety, precaution etc.) is enough to justify intervention, and the difficulty of responding responsibly to events and information when people are experiencing stress and misperception.

Certain rights are possessed by individuals, and those rights impose (moral) obligations on others. Rights and obligations must be viewed together in the context of particular relationships (5). Ladd and others have argued that people have a general duty to support the fulfillment of the moral requirements of relationships, whether their own or those of others. Some of what is necessary to carry out this duty is embodied in rights and obligations, which may sometimes be given the force of law.

... the concept of rights, as a cluster of claims on society and its institutions on the part of the individual, derives its principal moral warrant from the concept of moral integrity. This concept, unlike the concept of simple self-determination, focuses on the integrity of personal relationships, concerns, and responsibilities. Everyone in society has a duty, individually and collectively, to defend, support, and nourish these moral relationships both personally and in others. The concept of rights provides an effective social and conceptual instrument for carrying out this general duty (5).

The delineation of rights and duties gives rise to certain expectations or hopes on the part of society concerning human behavior. In imposing rules or legal principles on individuals and institutions, the law often embodies societal attitudes, values, and expectations. Sometimes, but not always, this occurs when a significant societal consensus has been reached on a particular moral question derived from human conflicts. The law establishes legal rights, whose violation may be illegal, and the law provides remedies to correct their violation. But the law also recognizes that conflicts of legitimate interests, conflicts of legal duties, and differences in perception of what is right or wrong, fair or unfair, require a balancing in the fashioning of remedies. Indeed, there are both legal remedies (usually of statutory origin) and equitable remedies that give great discretionary power to the courts or adjudicating institutions, such as the Equal Employment Opportunity Commission in the United States. Rules are embodied in legislation and regulations; legal principles guide, but do not unequivocally settle, other conflicts. In examining of questions of conflict, the law does indeed view behavior in the context of relationships. Justifiable expectations which one party has of another are translated into the legal concept of reliance. Thus, the law will sometimes find a physician-patient relationship between worker and company physician - when none was intended by the physician

- because it was reasonable that the worker expected certain behavior or transmission of information from the physician. Similarly, although the legal construct of the modern corporation in many countries bestows limited personal liability on corporate officers or employees ($\underline{6}$), the courts will "pierce the corporate veil" when corporate behavior violates the ethical norm. Discrimination law is replete with discretionary justice ($\underline{7}$).

The law, of course, does not always serve the ethical interests of the society so nobly. Legislation and legal institutions can be compromised by powerful special interests. In addition, if there is a lack of societal consensus or interest about a moral issue, the law may either not address that issue or fail to give helpful guidance concerning the boundaries of fair or equitable behavior. This is currently the case concerning the problems encountered in community monitoring. Thus, it is important to engage in both a legal and ethical enquiry concerning human and institutional behavior.

In the context of the transfer of medical information resulting from workplace monitoring and discrimination resulting from its use, the legal and ethical norms are in a great state of flux. Conflicts of interest and conflicts of duty (for example, for the company physician or government official) abound. Moreover, given the arguable scientific validity of many screening tests and of resulting data, questions of what actions to take or not to take reflect differences in perceptions of fairness and risk-adverseness. The worker would rather be safe and keep his or her job; the employer wants to limit his or her legal and economic liability. In the face of great uncertainty, the actors prefer to take few chances so that very divergent solutions are pursued concerning both the transmission of uncertain information and its use.

On the other hand, some employers may be motivated to undertake medical screening solely out of a genuine concern for the health of their employees and may even feel a moral obligation to do so. In this case, there may be no conflict if care is taken concerning the dissemination and use of the monitoring results.

LEGAL AND ETHICAL PROBLEMS IN WORKPLACE MONITORING

1. Requiring Workers to Submit to Human Monitoring

Personal privacy is an important issue. In the abstract sense, an employee may always refuse to be the subject of human monitoring. Thus the U.S. Occupational Safety and Health Administration (OSHA), the U.S. National Institute of Occupational Safety and Health (NIOSH), and the employer have no authority to compel employees to cooperate. Refusal to participate, however, may mean loss of a job, so that the relevant enquiry is the extent to which the employer may predicate employment on such cooperation. For example, may an employer require a prospective employee to submit to genetic or biologic screening as a precondition to employment? May he or she require a current employee to submit to periodic biologic monitoring or medical surveillance? These questions raise important issues of confidentiality and discrimination. Apart from these issues, however, the question of the employer's general authority to require human monitoring of employees needs to be considered.

Monitoring in Response to Agency Directive. At the outset, a distinction must be made between the human monitoring that OSHA, NIOSH, or the U.S. Environmental Protection Agency (EPA) may require and the monitoring that the employer implements on his or her own initiative. When a federal agency requires that monitoring be done, the worker has a valid

objection only if he or she asserts a statutory or constitutional violation. The U.S. Congress was mindful of constitutional considerations in developing human monitoring programs. For example, it specifically acknowledged the need for a balancing of interests when an employee asserted a religious objection to a monitoring procedure. Human monitoring can also impinge on the worker's constitutional right to privacy. In the case of human monitoring, the right to privacy may be articulated in two ways: the right to physical privacy, and the right to withhold information likely to prove detrimental to one's self-interest.

If an employee does not wish to comply with a monitoring procedure required by agency regulation, imposing that procedure as a condition of employment may invade that employee's constitutional right to physical privacy. Depending on the nature of the procedure, it may infringe the right to be free from unwelcome physical intrusions and the right to make decisions regarding one's own body. Although these rights are obviously related, the former is grounded in the fourth amendment's proscription against unreasonable search and seizure, whereas the latter is closely associated with the rights of personal privacy commonly identified with the ninth and tenth amendments. Although protected by the U.S. Constitution, these rights of privacy are not inviolate.

U.S. courts have recognized a general need to balance the privacy interests of the individual with the public health interests of society. In certain situations, the former will be deemed to outweigh the latter, but in others, intrusion will be permitted in the name of public health. To date, no reported judicial decision has mentioned an asserted constitutional right to refuse participation in human monitoring as a condition of employment. Nevertheless, one can identify the factors that would bear upon an evaluation of that right.

The public health significance of human monitoring, when properly used, is difficult to deny. Gathering information through human monitoring to develop standards for the protection of workers' health, or for the enforcement or evaluation of existing standards, serves an important public health purpose. Furthermore, although the U.S. Constitution protects against government paternalism, the fact that this public health interest parallels the affected worker's own interest in a healthy workplace may make monitoring a less onerous invasion of privacy than it would be otherwise. [Indeed, Bayer (8) raises the question of whether workers may actually have a moral obligation to cooperate in such monitoring for the collective good. He argues that without safeguards, coercive monitoring is unfair.] To the extent that monitoring serves a legitimate public health purpose, a limited intrusion of physical privacy appears constitutionally permissible. The less the accuracy, reliability, or predictive value of a particular intrusion, however, the weaker the case for violating physical privacy.

At some point, the degree of risk or intrusiveness of monitoring may be sufficiently compelling to outweigh the public health interests. Some forms of human monitoring may simply be too risky or too intrusive to be constitutionally permissible. Furthermore, even if a monitoring procedure is not constitutionally impermissible per se, the worker may have a right to insist on an alternative, less intrusive procedure that adequately fulfills public health purposes. To survive constitutional challenge, a regulation requiring human monitoring should be reasonably related to a legitimate public health goal and should impose the least intrusive method necessary to achieve that goal.

An additional and critical question is whether the employee may refuse to participate in a program of agency-directed monitoring when he or she believes that the employer may use the

resulting information as a basis for termination of employment. For example, the worker who suffers chromosomal damage as a result of workplace exposure may fear that medical screening will reveal this condition to the employer and thus induce job loss or reassignment (i.e. removal). Thus, participation in a monitoring program can be tantamount to self-incrimination.

This form of self-incrimination conflicts with the right to personal privacy. If there is a constitutional right to preserve the confidentiality of information pertaining to one's health, there may also be a right to retain that information within one's body. Stated differently, there may be a limited constitutional right to refuse to comply with physical procedures that result in the initial disclosure of confidential information. Although this right is not absolute, damage to the employee can be substantial if health data are likely to affect employment status adversely. A worker's interest in preserving his employment status may rise to the level of property protected by the fifth amendment.

In developing monitoring requirements, an agency should seriously consider the constitutional dimensions of human monitoring. To avoid a challenge on a self-incrimination basis, OSHA and NIOSH might consider including mandatory Medical Removal Protection (MRP) programs as part of their human monitoring requirements. MRP provides earnings protection and employment security during medical removal. Properly used, an MRP program would help to ensure employee cooperation with monitoring.

Monitoring in the Absence of Agency Directive. Under common law, employers can require their employees to comply with reasonable programs of human monitoring. The U.S. Congress did not intend the Occupational and Safety and Health Act (OSHAct) to "preempt the field" by authorizing the implementation of human monitoring requirements. One of the Act's express purposes is to "stimulate employers ... to institute new and to perfect existing programs for providing safe and healthful working conditions." Congress intended that employers take the initiative on a number of fronts, including human monitoring, in developing health and safety programs. As long as it promotes "safe and healthful working conditions," employer-initiated human monitoring would appear to be allowed. Similarly, nothing in the Act precludes employers who are subject to OSHA monitoring requirements from implementing additional programs. Further, it could be argued that employers have a moral obligation to initiate monitoring if they suspect their employees are at risk. To date, however, this moral obligation has not been translated into a legally enforceable duty to undertake medical screening.

If an employer institutes a human monitoring program in the absence of agency directive, he or she is still subject to applicable restrictions under state common law, state statute, and federal labor law. Common law requires that human monitoring be implemented in a reasonable fashion. Determining reasonableness involves balancing the benefits gained by monitoring against the risk, discomfort, and intrusiveness of the monitoring procedure. The U.S. National Labor Relations Act may also require such balancing. In a given jurisdiction, the balance might be affected by a state statute defining a right of personal privacy.

Informed consent is also an important issue in the context of workplace monitoring. Assuming that a human monitoring program is permissible, there are limitations on the manner in which an employer may implement the program. In general, one who undertakes the performance of monitoring procedures has a duty to perform those procedures properly and will face liability for damages caused by the negligent administration of a monitoring procedure.

A troublesome question arises, however, with regard to the applicability of the doctrine

of informed consent. Strictly speaking, informed consent is a medico-legal concept, and stems from a belief that persons have a right to make decisions governing their bodies and health. Thus, a medical professional is said to have a duty to inform the patient honestly and accurately of the potential risks and benefits of a proposed medical procedure so that the patient can make an informed choice whether to consent to that procedure. All human monitoring procedures are medical or quasi-medical in nature. Commonly, they are performed by medical professionals: physicians, physician assistants, nurses, or nurse practitioners. Thus, the concept of informed consent appears at first glance to be applicable. The differences between human monitoring and medical treatment, however, are not insignificant, and they raise serious questions as to whether and to what extent the traditional doctrine of informed consent has meaning in the occupational setting.

Initially, one may enquire to what extent the relationship between the worker and the medical professional who administers the monitoring procedure can be characterized as a physician-patient relationship. Quite often, neither the employee nor the workers' union selects the occupational physician. Rather, the employer selects and often directly employs the physician. Accordingly, some courts have held that the performance of a physical examination, which would clearly establish a physician-patient relationship in a purely medical context, does not create that relationship if it is a pre-employment examination requested by the prospective employer. To the extent that the physician-patient relationship does not exist in the occupational setting, traditional notions of informed consent may not be applicable to human monitoring.

Similarly, the doctrine of informed consent is tied closely to the concept of medical treatment. It assumes that not only is the patient being requested to submit to a procedure designed for his or her own benefit, but also that the patient is in a position to make a voluntary choice to participate. Human monitoring calls both of these assumptions into question. Monitoring may not be "treatment" in the conventional sense of the word. In many cases, monitoring benefits the employer more than the employee. Furthermore, monitoring is usually compulsory in that it is a condition of continued employment. It may be meaningless to speak of "informed consent" if the worker/patient is not free to reject the proffered procedure without jeopardizing his job. In this light, the applicability of informed consent appears particularly dubious in the case of agency-directed monitoring. Neither the employee nor the employer has the discretion to discontinue monitoring.

Regardless of the applicability of informed consent in the traditional sense, a complete and accurate disclosure of risks seems an advisable adjunct to a program of human monitoring. Whether or not a physician-patient relationship exists, imposing a medical procedure on a person not fully informed of the risks of that procedure may still be regarded as a physical battery and may give rise to liability in tort. In addition, prudent social policy requires full disclosure of risks. If the employer is required to disclose all risks inherent in a program of human monitoring, employee and union scrutiny will act as an incentive for the employer to develop programs that use the safest and least intrusive techniques possible. Indeed, unions may have a right to demand such information as a part of the collective bargaining process. Recognition of a duty to disclose material risks seems as appropriate in the area of human monitoring as it is in the area of medical treatment.

A final question concerns the scope of the required disclosure of procedural risks. The employer should, of course, disclose all material physical risks. The most significant risk of all,

however, may be dismissal from employment. Should employers or occupational physicians be required to warn employees that one of the risks of submitting to a program of human monitoring may be the loss of jobs? The Code of Ethical Conduct (9) adopted in 1976 by the American Occupational Medical Association and the American Academy of Occupational Medicine states that physicians should:

... treat as confidential whatever is learned about individuals served, releasing information only when required by law or by over-riding public health considerations, or to other physicians at the request of the individual according to traditional medical ethical practice; and should recognize that employers are entitled to counsel about the medical fitness of individuals in relation to work, but are not entitled to diagnoses or details of a specific nature.

Under this formulation, although the physician may not disclose to the employer the specific results of human monitoring, the employee's job security may be endangered nonetheless. Employers are "entitled to counsel about the medical fitness of individuals in relation to work." A preferable alternative practice (10) would involve the worker in such discussions between the physician and the employer.

2. <u>Dissemination of Monitoring Results</u>

Employee's Right of Access. An employer may not limit or deny an employee access to his or her medical or exposure records. The OSHA regulation promulgated on May 23, 1980 grants employees a general right of access to medical and exposure records kept by their employer. Furthermore, it requires the employer to reserve and maintain these records for an extended period of time. [In the absence of OSHA regulation, employees would arguably still have a right of access under common law or state statute in many jurisdictions (11).] There appears to be some overlap in the definition of "medical" and "exposure" records, because both may include the results of biologic monitoring. The former, however, is generally defined as those records pertaining to "the health status of an employee," while the latter is defined as those pertaining to "employee exposure to toxic substances or harmful physical agents."

The employer's duty to make these records available is a broad one. The regulations provide that upon any employee's request for access to a medical or exposure record, "the employer shall assure that access is provided in a reasonable time, place, and manner, but in no event later that fifteen (15) days after the request for access is made." In addition to the right of access, there are duties to inform workers of exposure to occupational hazards (12).

Employees' Right to Confidentiality. Of all of the issues raised by human monitoring, employee confidentiality may have received the most attention (13). An employee's right to maintain the confidentiality of information regarding his body and health places a significant limitation on the ways in which others can use that information. As programs of human monitoring are developed, mechanisms must be found that maximize both the employee's interest in privacy and society's interest in promoting general workplace health and safety. In the final analysis, this may be more a technologic challenge than a legal or ethical one.

In a broad sense, private citizens do have a right to protect the confidentiality of their personal health information. With regard to governmental invasions of privacy, this right is created by the U.S. Bill of Rights and is one component of the right of personal privacy

discussed previously. With regard to private intrusions, the right is grounded in state law. In the medical setting, it grows out of the confidential nature of the physician-patient relationship, although rights of confidentiality exist outside this relationship as well. In essence, the recognition of a right of privacy reflects an ongoing societal belief in the need to protect the integrity of the individual.

This right to privacy, however, is not absolute and may be limited or waived. U.S. courts nonetheless remain vigilant in their attempts to protect individual privacy. They generally look for a reasonable middle ground when faced with legitimate interests on both sides of the confidentiality question. They prefer an approach that permits both the use of health information for a socially useful purpose and the protection of the privacy of the individual. The key is the development of information-based technology that will make that approach more readily available.

Notification of Workers at High Risk. Caldart (14) and Ashford and Caldart (15) have addressed the worker's right to information and the employer's duty to provide information concerning occupational risks without request. Recently, there has been increasing attention to the government's responsibility to notify workers if they have been identified as being part of a high-risk group based on epidemiologic studies. The reader is referred to the excellent works of Schulte and associates (16-18), which deal with the multitude of legal and ethical problems arising out of the right-to-know.

3. <u>Employer's Use of Human Monitoring Results</u>

Even if an employer obtains human monitoring data through a legitimate exercise of his right of access, the right to use such data is not absolute. In the United States, employers may not use health information to discriminate against employees on a basis deemed impermissible by federal or state law. Beyond discrimination, however, a more essential--and perhaps more difficult--question arises: to what extent may an employer use health or exposure information to limit or terminate the employment status of an individual employee or to deny employment to a prospective employee? Further, to what extent and under what conditions does the employer have an obligation to remove the worker? If removing a worker and rotating another employee to take his or her place reduces each worker's individual risk but increases the total number of diseased workers, what is the employer to do?

Common Law Limitations. In early common law [court-developed law through successive cases], an employer had the right to take an employee's health into account in determining whether to continue to employ that person. If the employment contract was "open," with no definite term, the employee could be discharged for any reason, including health status, at the will of the employer. If the contract of employment was for a definite term, the employee could be discharged for "just cause." Typically, significant illness or disability constituted "just cause." Although federal labor law, workers compensation, and recent common law limitation on the doctrine of "employment at will" have profoundly affected the nature of employee-employer relations in this century, courts continue to recognize an employer's interest in discharging employees who cannot perform their work safely. Thus, if the worker has no statutory or contractual protection, an employer may retain a general common law right to

discharge the worker whose health status makes continued employment dangerous, or whose health status prevents him from performing his or her job. Workers compensation legislation, of course, facilitates termination of the jobs permanently disabled workers.

Human monitoring, however, places the issue in a somewhat different light. Monitoring designed to reveal whether an employee has been, or in the future may be, harmed by workplace hazards raises the question of whether the employer may discharge an employee merely because the employee was, or may be, harmed by a situation created by the employer. The rights of the employer to discharge the employee might not be as broad then as in the general case.

Suppose an employer is complying with an existing OSHA standard for a particular toxic exposure, and monitoring reveals that one of the firm's employees is likely to suffer serious or irreparable health damage unless he or she is removed from the workplace. In this situation, the employer is complying with public policy as enunciated by OSHA and, in the absence of a mandatory MRP provision, is arguably free to discharge the employee. If an employer fails to comply with applicable OSHA standards, however, or if no standard exists, and the employer permits workplace exposure levels that violate state and federal requirements to maintain a safe place of employment, then the employer is violating the public policy embodied in the OSHAct. Workers are only infrequently able to obtain compensation for disability due to occupational disease. In this case, to permit the employer to discharge the employee is to permit a further violation of public policy. An employer's use of human monitoring data for this purpose may well be impermissible as a matter of public policy, and employers may be obliged by common law to find safe assignments for the workers at comparable pay or bear the costs of their removal.

Limitations Under the OSHAct General Duty Clause. The use of monitoring data to limit or deny employment opportunities raises other issues under the general duty clause of the OSHAct. When monitoring information reveals that an employee risks serious health damage from continued exposure to a workplace toxicant, it may also indicate that the employer is in violation of the general duty clause. When a workplace exposure constitutes a recognized hazard likely to cause death or serious physical harm, an employer violates the general duty clause if he or she does not take appropriate steps to eliminate the hazard. In the case of a toxic substance, this would appear to require reduction of the exposure, not mere removal of presumptively sensitive employees from the site of exposure.

The issue is amenable to regulatory solution. The implementation of mandatory MRP for toxic substances exposure in general, as OSHA has done with its lead standard (19) might be accomplished by a generic MRP standard. An employer's compliance with a mandatory MRP provision for a particular exposure would remove the threat of a general duty clause citation.

Limitations Under the Anti-Discrimination Laws. In addition to potential liability under the common law and the OSHAct general duty clause, an employer who uses monitoring information to limit employment opportunities may also face liability under antidiscrimination laws. Although not all workplace discrimination is prohibited, U.S. state and federal laws forbid certain bases for discrimination. Many of these may apply to an employer's use of human monitoring information. A detailed discussion of the relevant discrimination laws is beyond the scope of this article, but an outline of their potential impact on human monitoring follows.

Section 11(c) of the OSHAct prohibits employers from discharging or otherwise

discriminating against any employee "because of the exercise by such employee on behalf of himself or others of any right afforded by this chapter." If an employee insists on retaining his job in the face of medical data indicating that continued exposure to a workplace toxicant will be likely to pose a danger to health, the employee may well be asserting a right afforded by the OSHAct. The Act's general duty clause imposes on employers a duty to maintain a workplace that is free of "recognized hazards" likely to cause death or serious physical harm. Inferentially, then, the Act vests employees with a concomitant right to insist that their workplace be free of such hazards. By insisting on retaining employment, the employee is asserting his right to a workplace that comports with the requirements of the general duty clause. Accordingly, an employer who discharges or otherwise discriminates against a worker because of perceived susceptibility to a toxic exposure arguably violates the prohibition of section 11(c). When an employer asserts that an employee cannot work without injury to health, the employer tacitly admits that the workplace is unsafe. That admission triggers the remedial provisions of the OSHAct.

An OSHA regulation, issued under section 11(c) and upheld in an unanimous U.S. Supreme Court decision (20) gives individual workers a limited right to refuse hazardous work when there is a situation likely to cause "serious injury or death" (21). The employer may not take discriminatory action against the employee by discharging the employee or by issuing a reprimand to be included in the employment file. According to the district court to which the issue was remanded for consideration, withholding the employee's pay during the period in which the employee exercises the right is also prohibited.

As a worker may be absent from a hazardous work assignment under certain conditions without loss of pay or job security, it seems anomalous to allow an employer to discharge or remove the employee without pay because of the same hazardous condition. This would make the employee's status depend on whether he or she asserted a right to refuse hazardous work before the employer took action to discharge him from employment.

Handicap Discrimination. Employees may be able to assert further rights against discriminatory use of human monitoring data under laws protecting the handicapped/disabled. U.S. Congress and most states have passed laws barring discrimination against handicapped/disabled individuals in certain employment situations. The laws, which vary widely among the jurisdictions, all place potential limitations on the use of human monitoring data. Although the courts have adopted a case-by-case approach, the worker who is denied employment opportunities on the basis of monitoring results often falls within the literal terms of many handicap discrimination statutes. In general, two issues will be determinative regarding disability: whether the workplace in question is covered by a state or federal handicap act; and if so, whether the worker in question is handicapped/disabled under the act.

At present, the general applicability of handicap/disability discrimination statutes to the use of human monitoring information remains unclear. Examining the definitional criteria in the federal act, on which many of the state statutes are based, will illustrate the issues facing courts--and the potential range of logical interpretations. The U.S. National Rehabilitation Act of 1973 as well as the Americans with Disabilities Act (ADA) of 1990 defines a handicapped/disabled individual as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.

In the great majority of cases, persons facing reduced employment opportunities as a result of human monitoring data do not presently have a substantially debilitating medical condition and thus do not satisfy either the first or second clauses of the federal definition. Rather, they are perceived as having an increased risk of developing such a condition in the future. The Act seems designed primarily to protect the seriously handicapped, but its wording is broad enough to cover discriminatory practices based on data obtained through human monitoring.

Even in cases in which handicap/disability discrimination is established, an employer may escape liability if the discriminatory practice is reasonably necessary for efficient operation of the business. The U.S. National Rehabilitation Act provides employers with no affirmative defense, but does require the handicapped/disabled individual to prove that he is "qualified" for the job. Thus, if a handicap/disability prevents a worker from safely or effectively performing the job, an exclusionary practice may be permissible under the Act. Most state handicap statutes include some form of affirmative defense. Although these vary among jurisdictions, many appear analogous to the familiar defenses that have developed under Title VII of the U.S. Civil Rights Act of 1964.

<u>Civil Rights and Age Discrimination</u>. Employers who exclude workers on the basis of monitoring information may also run afoul of the more general laws against discrimination. Title VII of the Civil Rights Act prohibits employment discrimination on the basis of race, color, religion, sex, or national origin. The scope of the Act is substantially broader than that of the federal handicap discrimination act, and it affords protection for the great majority of American employees. In addition, many states extend similar protection to employees not covered by the federal act. The Age Discrimination in Employment Act of 1967 and some state acts provide protection of comparable breadth against discrimination on the basis of age.

As with handicap discrimination, the applicability of these laws to the use of human monitoring information is not yet clear. The practical impact of an exclusionary practice, however, may fall disproportionately on a particular race, sex, ethnic or age group.

The U.S. Supreme Court has long held that a claim of disparate impact states a viable cause of action under the Civil Rights Act. A similar rationale has been applied in the area of age discrimination. In a 1975 decision, the Court held that job applicants denied employment on the basis of a pre-employment screen can establish a prima facie case of racial discrimination if they demonstrate that "the tests in question select applicants for hire or promotion in a racial pattern significantly different from that of the pool of applicants." Proof of disparate impact thus requires statistical analysis demonstrating a "significantly" disproportionate effect on a protected class. The cases provide no clear guidance, however, as to the level of disproportion that is required before an effect is deemed significant.

The potential for disparate impact is inherent in many uses of human monitoring data. A genetic screen for sickle-cell anemia, for example, will disproportionately exclude blacks and certain ethnic groups because they have a much higher incidence of this trait than does the general population. Similarly, tests that consistently yield a higher percentage of positive results in one gender than the other may give rise to exclusionary practices that discriminate on the basis of sex. The permissibility of fetus protection policies, which exclude women of child bearing capacity from the workplace to avoid exposure to reproductive hazards, is beyond the scope of this article, as it does not involve discrimination on the basis of monitoring data; for a brief

discussion of this issue, see Ashford and Caldart (12).

Finally, a wide variety of exclusionary practices based on monitoring data may have a disparate impact on older workers. Older workers are likely to have been in the workforce longer and usually have been exposed to hazardous work environments much more often than their younger colleagues. Their prior exposure may have impaired their health or left them more vulnerable to current workplace hazards. They may, for example, have a preexisting illness as a result of previous workplace exposures or on account of age alone.

When the plaintiff establishes a prima facie case of disparate impact, the employer will have an opportunity to justify the alleged exclusionary practice by showing that its use constitutes a "business necessity." If such a showing is made, the practice will withstand a charge of disparate impact discrimination. The U.S. Supreme Court has characterized the defense of business necessity as requiring "a manifest relation to the employment in question." In the works of an often cited opinion, this means that the practice must be "necessary to the safe and efficient operation of the business." Further, if the plaintiff can establish that another, less discriminatory practice will accomplish the same purpose, the defense of business necessity will not stand.

The defense of business necessity is available only in cases of disparate impact. If a practice is discriminatory on its face or involves disparate treatment, the employer may avoid liability only by demonstrating that the basis of the discrimination constitutes a bona fide occupational qualification (BFOQ). This defense is available under the Civil Rights Act for discrimination based on sex, national origin, or religion (but not for discrimination based on race or color) and under the Age Discrimination in Employment Act. The BFOQ defense requires the employer to establish that the discriminatory practice is "reasonably necessary to the normal operation of business." The U.S. Supreme Court has characterized the defense as an "extremely narrow" one.

There are two principal reasons why business necessity may be difficult to establish for exclusionary practices based on human monitoring data. The first is that most of these practices are not designed to protect the health and safety of the public or of other workers. Instead, their business purpose is the protection of the excluded worker and, not incidentally, the protection of the employer from the anticipated costs associated with the potential illness of that worker (22). That position may well encounter a chilly judicial reception. As noted in one analysis, "the courts are usually skeptical of an employer's argument that it refuses to hire qualified applicants for their own good, and they often require a higher level of justification in these cases than in cases in which public safety is at stake (23). Another, and potentially more serious, obstacle to the successful assertion of a defense of business necessity is the unreliability of the screening procedures themselves. If the exclusion of susceptible (high risk) individuals truly is a business necessity, its rationale disappears if the test used as the basis for such exclusion cannot provide reasonable assurance that those excluded are actually susceptible i.e. at high risk. Indeed, without such assurance, the test becomes little more than an instrument for arbitrariness and only adds to the discriminatory nature of the exclusionary practice. As many screening tests are currently far from reliable, the availability of the business necessity defense is questionable.

The foregoing discussion of discrimination has presupposed that the screened worker will be excluded from the workplace. Employers, however, may have another option. In many cases, they may be in a position to provide these workers with other jobs in workplaces that do not

involve exposures to the substances from which they may suffer adverse health effects. If such alternative positions were supplied, at benefit levels comparable to those of the positions from which exclusion was sought, employers might avoid the proscriptions of the various discrimination laws. Providing an alternative position would certainly remove much of the incentive for filing a discrimination claim. Further, even if such a claim were filed, courts might find that an adequate MRP program obviated the charge of discrimination. This could be one area in which good law and good social policy coincide.

4. The Use of Monitoring Data in Tort and Workers' Compensation Cases

From a legal perspective, the most important impact of human monitoring information may be its use as evidence in tort and workers' compensation cases. Although its potential in this area is still to be realized, the science of biological markers may eventually serve to answer the evidentiary question that has plagued most compensation cases involving human exposure to toxic substances: how do we know whether a *particular* exposure caused a *particular person's* medical condition? At present, the problem remains a major one, except for exposure to a few substances, such as vinyl chloride and asbestos.

Obviously, to the extent that increased use of human monitoring adds to the existing database on the observed correlations between particular diseases and particular chemicals, it will provide increased evidence for use in compensation proceedings generally. More than this, though, human monitoring has the potential to bring about a change in the nature of the evidence used in these cases.

Typically, the evidence offered to prove causation in chemical exposure cases is premised on a statistical correlation between disease and exposure. Whether the underlying data are from epidemiologic studies, from toxicological experiments, or from the results of a complicated risk assessment model, they are usually population-based. This places the plaintiff at the mercy of the attributable risk (expressed as the percentage of cases of the disease attributable to the exposure) for the study population. Unless the attributable risk is greater than 50%--that is, unless the incidence rate among those exposed to the chemical is more than double the background rate--the plaintiff cannot prove on the basis of the available statistical evidence, that it is more likely than not that his or her particular case of the disease was caused by the chemical exposure.

The developing science of human monitoring may offer a way to distinguish individual claimants from the population at risk. Conceivably, the data generated by various human monitoring procedures will:

- o increase our knowledge of the "sub-clinical" effects of toxic substances, thus permitting us to track the effect of a chemical exposure over time, and also expanding the universe of "medical conditions" for which compensation may be provided;
- o eventually enable us to establish that a particular person has been exposed to a particular chemical (or class of chemicals); and
- o eventually enable us to establish that a particular person's medical condition (or subclinical effect) was caused by exposure to a particular chemical (or class of

chemicals).

Already, human monitoring data are being used in some situations to identify sub-clinical changes thought to be associated with particular chemical exposures. This can have many applications in toxic substance compensation cases. In the long term, evidence of sub-clinical changes occurring between the time of exposure and the time of disease may be a way of distinguishing those whose disease was caused by the exposure from those who contracted the disease because of other factors. Such evidence may also give rise to more immediate legal relief. There is a growing trend toward allowing those who can establish that they have been exposed to a toxic substance--and thus that they have been placed at increased risk of future harm--to recover the costs of medical surveillance from the responsible party. Proof of certain sub-clinical effects, such as DNA damage, would tend to support an allegation of increased risk, and would make the claim for medical surveillance all the more compelling. Further, such evidence may support a separate claim for damages for having been put at increased risk of future harm, although it is not clear that such a claim would be viable in most states.

Finally, some evidence of "sub-clinical" effects may give rise to a right to recover compensation for those effects themselves. For example, human monitoring can detect certain changes in the immune system. There is a body of literature suggesting that chemical exposures can harm the immune system (24), and evidence of immune system damage has been offered in recent cases involving toxic substance exposure (25). Thus far, allegations of immune system damage have met with mixed success in the courts, both because the relationship between chemical exposure and immune system damage is not yet clear, and because the evidence of immune system damage was not always considered persuasive. Although human monitoring may not be able to tie particular immune system deficiencies to particular exposures, it should be able to establish with greater certainty whether immune system damage has, in fact, occurred.

Looking farther to the future, it is quite possible that further developments in the science of biomarkers will permit the identification of "chemical fingerprints"--a distinctive change in the DNA that can be linked with exposure to a particular chemical or class of chemicals. At the very least, this should make it much easier to distinguish those who have been exposed to a particular chemical in the workplace from those who have not, and to identify which of the many potential defendants was responsible. More importantly, it should eventually permit the correlation of particular cases of diseases such as cancer with exposure to particular chemicals (or classes of chemicals). To the extent that this happens, it will narrow the scope of the evidence from the population to the individual, and will place the deliberations in these cases on firmer scientific footing.

POSITIVE USES OF HUMAN MONITORING IN THE WORKPLACE

The strategies used for human monitoring must be fashioned on a toxicant-specific basis because the state-of-the-art techniques differ from substance to substance. In general, medical surveillance and biologic or genetic monitoring for populations should be used only in combination with environmental monitoring. In the case in which a specific harmful substance cannot be identified, however, and the workplace is suspected of being unsafe, medical surveillance may indicate whether a problem exists. In the future, genetic monitoring may serve as an early indicator that exposure to a certain chemical has occurred in a worker population.

However, the use of that kind of screening for this purpose is in its infancy. Genetic screening focuses on removal of the worker before exposure and is preventive for that worker only.

Human monitoring should be used only if: (1) given the specific workplace problem, monitoring serves as an appropriate preventive tool; (2) it is used in conjunction with environmental monitoring; (3) the test is accurate and reliable and the predictive value is high; (4) monitoring is not used to divert resources from reducing the presence of the toxic substance in the workplace or from modifying the hazardous technology; and (5) medical removal protection for earnings and job security is provided. New solutions involving both technologic innovation and job redesign may obviate the necessity of human monitoring. Conflicts now arise only because, with existing technology, workers continue to be exposed to toxic substances.

If conditions one through five are met, the question remains whether the employer is obligated to remove the worker from the workplace. It would seem so, since the employer owes that duty of care to his or her employees. But what if the monitoring test is unreliable? The extent of the obligation would appear to be less, although the dissemination of the test results to the worker arguably would still be required. Is the employer under a greater or lesser obligation to remove the worker if he or she provides no earnings and job security protection--greater, because it costs him or her nothing to protect the worker, or lesser because the worker is economically disadvantaged?

Finally, if a particular workplace cannot be made safer and the removal (and rotation-replacement) of workers results in lower individual risk but greater total disease, is this morally defensible? Exposure to radiation or some carcinogens can represent such a situation. These are difficult questions which deserve careful consideration.

SOLUTIONS TO THE LEGAL AND ETHICAL CONFLICTS IN THE WORKPLACE

The extensive discussion in the previous section reveals the complexity and difficulty with which the law balances competing interests and equities. In some cases, the law embodies the belief that de facto discrimination against certain protected classes of people (e.g. a minority race) is to be affirmatively avoided and cannot be justified by resulting health benefits. In other cases, such as those involving workers who are perceived as handicapped, the burdens to industry of providing protection may be relevant in deciding how much employment security to require. Discrimination law necessarily involves the exercise of discretion by courts and adjudicating institutions--with its attendant inconsistency and unpredictability.

Discriminatory practices and consequential tort suits, anti-discrimination suits, deterioration of labor-management relations, and agency sanctions may follow poorly conceived and poorly executed human monitoring programs. The weaker the scientific foundation for the monitoring test, the less secure are the legal grounds and defenses available to the employer. In light of the sometimes preliminary, unreliable and non-specific nature of many techniques used in human monitoring, the practice is a problematic activity itself in most instances.

With legal and ethical norms in flux, it is important to examine the policy options for dealing with future and continuing ethical dilemmas. The possible strategies which deserve consideration include:

1. Encouragement of ethical enquiry in the conduct and use of medical screening - that is, educating workers, management, and health professionals to think more seriously about

the problems. Indeed, ethicists should be consulted in designing the screening programs.

- 2. Use of legislative and regulatory means to clarify rights and duties, such as encouraging OSHA in the United States to promulgate a generic earnings and job security protection requirement for all cases of medical removal, or enacting legislation that requires workers to be notified of occupational risks and prohibits discrimination outright.
- 3. Encouragement of the use of self-help techniques by workers, such as union bargaining, the filing of discrimination complaints, and the right to refuse hazardous work.
- 4. Encouragement of better disposition of conflicts by improving procedural fairness in attempts at resolution, such as full and complete disclosure of information to workers, the better maintenance of confidentiality of worker records, or the use of corporate ombudspersons.
- 5. Encouragement of shared decision-making through joint health and safety committees.

These options differ in the extent to which the rights and freedoms of some are diminished to protect those of others. Regulatory or legislative fiats define acceptable behavior and in the process, decrease freedom of choice. On the other hand, freedom from harm and discrimination is preserved. Sharpening self-help mechanisms preserves choice, but fosters an adversarial solution. Education can persuade and enlighten; it can also sensitize the discriminated to assert their rights. Procedural fairness tends to right the imbalance of access to legal and political institutions.

The choice of options at any one time reflects the seriousness with which society wishes to address the moral and legal dilemmas. Thinking about these problems is a first and necessary step $(\underline{26-29})$.

LEGAL AND ETHICAL PROBLEMS IN COMMUNITY MONITORING

Experience with three contaminated communities in Love Canal, NY; Woburn, MA; and Michigan reveals a rich picture of conflicts and problems. In 1930, Love Canal was an open, abandoned trench in an empty field just to the southeast of the city of Niagara Falls, New York. In 1978, it was the notorious landfill that oozed toxic chemicals into the environment of a middle-class community. The trench that was Love Canal was filled with municipal and industrial wastes before it was covered in dirt and sold, as part of a larger parcel, to the Niagara Falls Board of Education. The Board built a school on the site and sold other portions to real estate developers who, over the next two decades, constructed single-family homes along its borders (2).

A relatively high incidence of leukemia among children in the neighborhood of Walker Pond initiated the episode at Woburn MA. Residents quickly focussed on the sometimes malodorous drinking water as the probable culprit; two wells that contributed to the supply in recent times had been closed when they were found to contain toxic organic compounds (2).

Sickly livestock, especially deformed and dying cattle, led to the discovery of toxic contamination in Michigan. Inadvertent mixing of a flame retardant with cattle feed and

subsequent distribution and use of the feed (and later of the contaminated dairy products, eggs, and meat), exposed virtually the entire population of Michigan to a variety of brominated organic compounds. Inadequate cleansing of the apparatus that mixed the chemicals with the feed and use of contaminated milk and new batches of animal feed resulted in continuous, although decreasing, toxic exposure to a variety of livestock and to human consumers for several years following the initial mix up (2).

Conflicts of legitimate interests among actors existed at every stage of monitoring activity, both early and late in the three episodes of contamination. The conflicts that gave rise to the most hostility occurred between agency personnel and community residents. The most critical of these conflicts related to the actors' intentions for use of monitoring information, often due to the agency's concern for the overall health of the entire public within their jurisdiction, versus the community's more parochial and environmental concerns and individuals' private concerns. For the same reason, agencies and citizens often have different interests with respect to the distribution of costs and benefits. Conflicts of interests also existed between government and the entity responsible for the contamination, and these were significant sources of discord during the first two monitoring stages ("Hazard Recognition" and "Decision to Monitor"), the next two stages ("Decision to Act" and "Action") and the fifth stage ("Evaluation of Monitoring Data"). Conflicts of interest between citizens who were activists (in favor of monitoring and remedial action) and people affiliated with the entity responsible for pollution were significant during the same five stages. Finally, the conflicts of legitimate interests between scientists and government (especially public health agencies) were prominent beginning with the third stage of monitoring activity ("Design of the Monitoring Study") and ending with the seventh stage ("Decision to Act").

In anticipation of possible criticism for omitting conflicts of interest with the news media, it should be noted that local media are included in the category of people affiliated primarily with the contaminated community. These individuals were indeed influential and helped to shape the course of events. However, their role appeared to be investigative and/or supportive of community activists rather than independent in character. The regional and national media were not observed to initiate conflict, and actually did not appear on the scene until late in the episodes. The exception to this rule occurs when a community is ignorant of the potential hazard and informed by media coverage, as, for example, has happened with respect to the pesticide commonly known as EDB (ethylene dibromide). In such cases, however, the national media actually assumes the more activist role of the local media in service of the potentially exposed community, which includes the entire population of the United States.

Internal conflicts among duties led to psychological distress and sometimes to unethical behavior. A particularly common internal conflict was observed in community residents who were torn between a duty to be well informed (so as to anticipate and respond appropriately to danger) and a duty to maintain their own peace of mind (which is conducive to rational thought) with a calm exterior for the benefit of their families. The latter duty prompted many residents to avoid distressing information or to deny its significance. Public health professionals experienced internal conflicts between their duties to prevent panic in the community and to warn the public of potential danger, as well as among the duties associated with their various roles as scientists, wage earners, public servants and employees of a particular branch, unit and level of

government. Other individuals who worked for governmental agencies experienced conflicts as a results of multiple roles as defenders and regulators of a particular client group--e.g. farmers. Private physicians were not spared internal conflict, for they suffered from the desire to help community members to cope with their fears, to protect the health of their patients, to maintain their professional standing in the community, and to avoid taking responsibility for decisions with regard to issues beyond their expertise. People affiliated with the entity that caused the contamination also faced conflicting duties--loyalty to the entity, obligation to the community (due to their special knowledge) and obligations to families, friends and the community as a whole if they resided locally. Most of these internal conflicts permeated all stages of monitoring activity, both early and late in the episodes, whenever the actors were directly involved.

Conflicts among values of different key actors centered around the relative significance of "subjective" versus "objective information" and the nature and degree of uncertainty, error, and/or risk that is tolerable or that should be addressed by managers of hazards. Residents and agency professionals disagreed even about which of these issues should be addressed by managers of hazards. Residents and agency professionals disagreed even about which of these issues was more important--i.e., about problem definition--and therefore about appropriate solutions. Residents worried about experts' ability to assess and control risk, while "experts" fretted about citizens' unreasonable demands for certainty. The views with regard to these matters were not universally held by actors affiliated with the same group. Rather, conflicts occurred between those who were trained and socialized in a technical field and those who identified more with humanistic traditions. These conflicts drove a wedge between actors, initially when they considered the need for monitoring and later for acting in response to monitoring results and when they evaluated monitoring data, but they also influenced the other monitoring stages.

The *problem* inherent in dealing with issues that are complex and surrounded by scientific uncertainty and that has been encapsulated by posing the question "How much information is enough?" fueled disputes during the "Design of Monitoring Studies" as well as, to a lesser extent, during "Hazard Recognition", "Decision to Monitor", "Evaluation of Monitoring Data", "Dissemination of Information", "Decision to Act" and "Action". Tied to this issue in every case, is the related question *"Who should decide?"*

Stress afflicted key actors who were faced with unprecedented situations, scientific uncertainty, and a need to make decisions quickly. In the years before the discovery of contaminated communities became common, people in government were subjected to enormous political and personal pressures and were placed in a "no-win" position. Today, professionals have the benefit of past experiences and specialized training that may help to prepare them for the experiences they will encounter. Nevertheless, due to the crisis mentality that often prevails, the political controversies that develop and the continuing scientific uncertainty, people affiliated in government still find their personal moral integrity threatened. For residents of contaminated communities, the situation is little different from the way it was in Love Canal or Woburn. Although they may have read about the events in other contaminated communities, their own episode of contamination usually is a novel personal experience. They generally are not prepared to cope well and can be expected to respond emotionally and with confusion. In such an aroused state, their behavior may be abusive or otherwise inappropriate. In short, they need to be regarded like any other victims of natural disasters or of crimes, with understanding,

patience and counseling. In addition, they need to be provided with adequate resources and a meaningful role in monitoring activities. Stress is a problem throughout the episode of contamination of residents, but it is most acute when they first learn about the potential adverse health effects. The Conduct of Monitoring stage in the first round of monitoring is particularly sensitive because inevitably, no matter how wide the press coverage, there will be some residents who have not heard about the contamination or who have not accepted the threat as real. To be asked for a biologic sample is a convincing and frightening way to learn about one's possible exposure to a toxic substance.

Finally, there is the problem of *misperceptions and misunderstanding* when actors observe the activities of people with a different frame of reference from their own. People afflicted within each group are liable to misconstrue the meaning of events, misinterpret verbal and written communications, and especially attribute negative motives to silence or to an unexpected absence of apparent activity. While each actor may be acutely aware of his/her own responsibilities and attitudes, he/she tends to be quite ignorant of the responsibilities and attitudes of others. The obvious solution to this problem is to increase opportunities for actors to get to know one another and to interact in a positive way. They need to discover common goals, to realize constraints that shape the attitudes and actions of other groups, and to form realistic expectations with regard to the timing and substance of monitoring activities. Ideally, communication between agencies and citizens would commence before a problem occurs, but if this is impossible, it should be initiated with vigor as early as possible, even before a hazard is given official status. Only through a convincing display of openness and respect for the abilities and trustworthiness of others will trust be reciprocated.

Four factors emerged as significant influences on the emergence and evolution of conflicts and problems in contaminated communities: resources, information, openness and trust.

Resources such as time, money, and (knowledgeable) personnel too often constrain the options available to key actors in contamination episodes. Agencies and community residents alike are forced to address concerns that are immediate and critical while ignoring other concerns of almost equal importance. Often, the relative availability of a particular resource determines the aspect of a multi-sided issue that actors are willing to address (30). Thus, for example, managers of prosperous industries are more willing to define an issue in terms of its complexity because that aspect emphasizes the value of the two resources most available to industry--money and expertise. Individuals such as the residents in contaminated communities are more apt to characterize issues as value conflicts over the distribution of costs and consequences, thus emphasizing the importance of public opinions and political input.

Information, its existence and availability to different groups of actors, is power. Biased or selected information or the lack and/or unavailability of information frustrates attempts to resolve disputes and forces opponents to rely on their values in making judgments. Scientific uncertainty also clearly influences risk perceptions.

Openness, in fact and in appearance, of actors' minds and of decision-making procedures is the antithesis of secrecy. Citizens in a democratic society insist on their right to observe government in action and, therefore, to hold public servants accountable for their part in decisions (31). Although the majority of citizens may never exercise their right, the knowledge that they may do so, and that some other citizens do watch over government, reassures everyone that democracy is safe. In contrast, the merest hint of secrecy by elected or appointed public

officials enrages many citizens unless a strong and reasonable argument exists that secrecy protects some other more basic right--e.g., to privacy for individuals. Demands for access to information about activities in the past asserts a citizen's right to retroactively "observe" decision makers.

Trust and trustworthiness are key attributes. There is one point, however, that stands out: a breakdown in trust between people or groups does not occur without reason; the behavior or communication of the party who is judged is at least as instrumental in destroying trust as is the tendency for the judge to pass judgment precipitously. If one is to learn from experience, it is necessary to evaluate available information. Indeed it is human nature to do so. If the only information available is a gesture or an ambiguous situation, one can either defer judgment and wait for more information or pass judgement based on previous analogous experience. Circumstances determine the relative cost of waiting versus judging. The circumstances that prevail in episodes of contamination strongly favor a decision to act, and to dispense with more waiting. To avoid loss of trust, actors must learn to radiate an aura of trustworthiness as well as to maintain their integrity in fact. Placing the blame on the other for drawing inaccurate conclusions is counter-productive and unfair to the other in turn.

THE NEED FOR NEW SOLUTIONS IN COMMUNITY MONITORING

Major U.S. national legislation was enacted during the 1970's and 1980's to address some of the issues that emerged at Love Canal, Woburn and in Michigan. For example, funds for emergency response actions were established at the Federal level and in many states. Citizens were granted the right to petition the Federal government to perform health studies of populations exposed to chemical wastes. And the U.S. Environmental Protection Agency now screens requests of industries that plan to produce, distribute or use newly synthesized chemicals and, if it determines that the chemical may pose an unreasonable risk, toxicity tests are required to be performed prior to the intended action. Toxic chemicals presenting an unreasonable risk may be banned, or their use may be strictly regulated.

Other issues have been resolved, or at least managed, as agencies have gained experience in dealing with releases of toxic substances. Training programs for staff provide constructive suggestions to improve community relations. Some citizens, too, have gained experience, and have formed organizations to provide advice to others.

Problems and conflicts and the external conditions that give rise to hostility still exist, however. Some legal issues that are unresolved include: definition and protection of the right to privacy for residents of monitored communities; lack of assurances that citizens are adequately informed prior to being asked for their formal consent to be monitored; the conditions which justify decisions to withhold research results or information about research methods; and confidentiality of individual's and group's test results. Ethical issues that require attention include: the need for counseling and support for individuals who experience stress in monitoring situations; the lack of sensitivity and respect among groups affiliated with the potentially responsible party, government and the community; the perception of undue delays and secrecy in government's response to citizens' concerns; the quality and quantity of public involvement in decision-making stages of monitoring activities; and the lack of knowledge about the substance and format of information that is needed or desired to empower residents to make personal and political decisions that are consistent with their values related to the local problem of

contamination and to the broader social issue of chemical controls.

Participation by members of the affected communities was seen as an essential element in constructing solutions. This participation can be facilitated, using a number of different mechanisms. The utilization of advisory panels warrants particular attention in the context of a participatory model for problem solving. We distinguish (and recommend for different purposes) five different types of committees, each with a different mission or purpose, level of involvement and degree of public representation.

- (1) For each state-level agency involved in monitoring, establish a *permanent,state-wide, institutional science advisory board* of independent experts to evaluate and advise generally on [monitoring] policies, protocols and priorities on a regular, periodic basis (cf. The Agency for Toxic Substances and Disease Registry's (ATSDR) obligation to utilize "disinterested experts").
- (2) Establish a *permanent, state-wide, advisory board of interested (or affected)* parties and citizens to evaluate and advise generally on [monitoring] policies, protocols and priorities on a regular periodic basis.
- (3) Establish a *permanent, state-wide, fact-finding, technical board of experts* (from multiple disciplines) with balanced representation (including citizens or their nominees) to review research, hold hearings, draw conclusions or studies *at particular sites*, i.e., a permanent, open "Blue Ribbon" review panel.
- (4) Establish an *ad hoc citizen (or worker) advisory board* or citizen (or worker) panel to represent citizen (or worker) concerns *in each putatively contaminated community*. [This has been advocated as a separate committee so as to avoid citizens' concerns of possible intimidation and the divulging of health-sensitive information to industry, insurance companies or employers.] Arguably this citizen panel would be involved at an early stage, i.e. hazard recognition or decision to monitor, and continue throughout the monitoring stages.
- (5) Establish a *permanent advisory board of interested (i.e., affected) parties* to represent all concerns in each community; this might be an expanded Local Emergency Planning Committee (LEPC), but it must include representatives of the contaminated area as well as of workers involved in remedial activity. Terms should be staggered and limited to prevent co-optation.

The distinction between the first committee and the second is that the first is restricted to "independent experts," whilst the second is representative and not required to be expert. Both are permanent and state-wide and perform the same functional tasks. The third committee is an expert review or evaluating committee that operates on a state-wide basis, but reviews studies at (many) particular sites. The fourth and fifth committees operate at the community level and perform similar functions, but differ as to composition.

Even with regard to citizen panels, there is wide variation in type. Renn et al. (32) advocate

utilizing 20-25 randomly chosen citizens. Whilst this may be "democratic," it may not ensure that serious differences within the community are sufficiently aired. Administrative selection, carefully overseen, inclusion of a range of affected groups (33), or election by the community [groups] might be preferable in the monitoring context. Of course, it should be recognized that a "group" may not be homogeneous, i.e., divergent views exist there, too.

Obviously, it may not be necessary to appoint all five types of committees. For example, a state could choose between the first and second, or ensure that the first includes recommendations for technical experts from the community or industry, thus making the need for the second committee less compelling. The different types of committees may be utilized (in different ways) at different stages of the monitoring process. For example, committee (3) is a committee that evaluates the *results* of monitoring studies.

In each case, committee membership should be balanced appropriately to reflect the range of reasonable political and/or scientific viewpoints. Members should be required to disclose any relationships they have that reveal allegiances or bias or that might influence their ability to function independently. In general, several citizen members, rather than one, should be on the committees. Citizens who serve on advisory committees, at every level of government, should be provided with training to participate effectively and with compensation for their time and effort and child care. We and others (34) argue that participation should occur as early as possible in the decision-making process.

In addressing the issues raised in this study, it is important to keep in mind that a variety of possible interventions is available with a continuum from specific laws to administrative processes. Within this taxonomy are included legislative directives or amendments: formal agency rulemaking with its constituent publication of proposed actions, comment periods and hearings; administrative policies/procedures for interacting with the public; and informal policies which may be altered unilaterally with every passing change in agency direction or administration. Administrative policies/procedures include agency guidelines, communication or educational initiatives, and citizen panels or technical panels that may advise an agency. Legislative provisions include citizen and state suits/petitions that may be brought against the agency and requirements for the agency to act or explain. In our suggesting the greater use of advisory panels, community monitoring impact statements (CMIS), and other measures, we are mindful of the danger of creating greater bureaucracy and paperwork requirements. Obviously, these measures should be utilized so as not to unduly impede rapid and timely action.

The generic nature of each process reflects a policy choice. In proposing mechanisms for addressing problems or for effective resolution of the conflicts between and within agencies and communities, we must be prepared to decide for each activity what mix of legal, political, and social mechanisms should be employed, and what sort of processes are the most appropriate.

It should be clear from our analysis that both new laws/institutions and ad hoc or informal mechanisms are needed to more fully involve the affected public and other key actors in monitoring. In general, the earlier that key actors are involved in the eight activities comprising human monitoring, the more effectively adverse effects and a loss of trust are likely to be avoided or minimized. Policy initiatives can be conveniently grouped into areas with specific measures that:

- o build skills and capability in the community;
- o build skills and capability in the agencies;
- o increase specific authority for (and obligations of) government;
- o provide increased community participation with the access to government decisions;
- o provide adequate incentives and motivation to agency personnel;
- o provide for more, more predictable, and better communication.

Communities are just beginning to explore ways to address the above activities. Law provides little structure at this time. Finally, it must be realized that community demands for health studies may be the community's means of getting governmental attention, and hopefully action - either to relieve the community of its concerns or to assist the community in dealing with a bona fide health problem. Many monitoring studies are unlikely to yield scientifically significant results because of a small population, low-dose exposures, latency periods, etc.; this problem partly explains the reluctance of some community residents to participate a monitoring.

The proper response of government, then, is either to decide it is willing to take remedial action even if a study does not reach statistical significance or have high power, or that action will be taken on the evidence of significant exposure alone.

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LIST OF ABBREVIATIONS

OSHA Occupational Safety and Health Administration

NIOSH National Institute for Occupational Safety and Health

EPA Environmental Protection Agency

OSHAct Occupational Safety and Health Act

MRP Medical Removal Protection

ADA Americans With Disabilities Act

BFOQ Bona Fide Occupational Qualification

LEPC Local Emergency Planning Committee

CMIS Community Monitoring Impact Statement