Bodies in Protest

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A New Body in the Courts, Federal Policies, the Market, and Beyond

If [a] plaintiff is successful in convincing a jury that the body’s shield against the disease has been lowered, then only a handful of complaints over the plaintiff’s lifetime may not be attributable to the chemical exposure. Therefore, the claim [of MCS] must be considered to be an extremely dangerous one in terms of the damage potential.

(Quoted in Bascom 1989, 35)

Legalizing the Multiply Chemically Sensitive Body

We can assume the term damage potential in the preceding is not referring to risk to human health and well-being but to the harm caused employers and manufacturers who must pay in the event they are found responsible for a plaintiff’s physical disability. Recognizing the grave potential in legal recognition of MCS, the Chemical Manufacturers Association called for a coordinated effort between insurance companies, the medical community, and consumer product manufacturers to resist the definition of MCS as an environmentally induced disease (Delicate Balance, spring/summer 1990; spring/summer 1991). The concern is understandable.

Also understandable, though for quite different reasons, is the official recognition of MCS by the Association of Trial Lawyers of America (ATLA). In 1987 the Consumer and Victims Coalition Com-
mittee of the ATLA proposed a resolution acknowledging EI and supporting the rights of environmentally ill victims. The resolution was accepted by the general membership (*Delicate Balance*, March 1987). The ATLA reconfirmed its recognition of MCS as a litigative issue in its 1994 national meeting, referring to it as “an emerging and potentially major public health problem” (Donnay 1996, 10).

We need not question the motives of the ATLA in recognizing the environmentally ill body; the point is that it does. Moreover, plaintiffs’ attorneys are assisted in their efforts to represent this body in the courts by two significant pieces of legislation: the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.

The Rehabilitation Act of 1973 prohibits discrimination against otherwise qualified persons with disabilities in any program or activity receiving federal funds, as well as in executive agencies and the Postal Service. The Americans with Disabilities Act (ADA) of 1990 states that reference to an individual disability means: “a. physical or mental impairment that substantially limits one or more of the major life activities of such individuals; b. a record of such an impairment; or c. being regarded as having such an impairment (42 USC, 12102, sec. 3).

Not surprisingly, the ADA is proving to be an effective resource for representing the chemically reactive body in courts. Its 1991 amendment, Regulation 1630, adds even more legal teeth to the ADA. Regulation 1630 requires employers to respond when employees report that one or more of their “major life activities,” including walking, breathing, seeing, and hearing, are impaired by workplace conditions (*Americans with Disabilities Handbook*, 1991). This expanded definition of disabilities might seem to some people to have been written with the chemically reactive in mind. That is certainly the case with the New Jersey State Bar Foundation, which offers a toll-free phone number to order printed information about both the ADA and MCS.

Framing the chemically reactive body in the language of the ADA does more than expand a potential client pool, however; it shifts attention from the more limited medical model to the far more inclusive...
model of disability. Since disability is not limited to conditions of medical pathology, the chemically reactive are less dependent upon medical experts to confirm their practical ways of knowing the relationships between bodies and environments. They can move quickly from their often complicated lay epistemologies to the more obvious and easily documented problems of physical impairment in such critical life activities as breathing, walking, talking, thinking, and so on. Insofar as the issue of disabilities attends to function and not cause, representing the chemically reactive body is more a matter of documenting its impairments, a far simpler task than confirming a disease etiology or pathophysiology. Once disability is documented, the search for cause in the legal arena is far more flexible than a similar search in the medical arena, as the following two cases illustrate.

In *Kallas Enterprises v. Ohio Civil Rights Commission* (No. 14282, 1990 Ohio App. Lexis 1683 [Ohio Ct. App. May 2, 1990]), the Ohio Court of Appeals ruled the plaintiff was dismissed from the work setting illegally because of a disability. The appellate court upheld a lower court decision regarding “occupational asthma,” finding that “hypersensitivity to [rustproofing] chemicals can be considered handicaps within the Ohio statutes for civil rights.” The case begins with the civil issue of disability and ends with a legal recognition of handicap that includes hypersensitivity to rustproofing chemicals.

Similarly, in *Kouril v. Brown* (912 F. 2d. 971 [8th Cir. 1990]), the Eighth Circuit Court decided in favor of a woman who claimed to be disabled by MCS. Once her disabilities were documented, the court acknowledged their source: exposures to common chemicals such as ink, perfume, tobacco smoke, and odors emitted from photocopiers. In both of these cases we can see the courts applying a more flexible criteria of etiology than those typically employed by most physicians. Disability rights legislation is creating a back door, if you will, for legal—not medical—recognition of the lay epistemologies of the chemically reactive.

In addition to or in combination with the ADA, attorneys can also use workers’ compensation laws to press for recognition of EI. Courts
and workers’ compensation boards in eight states have issued twelve separate rulings recognizing MCS as a physical disorder. In *Kehoe v. New Hampshire Department of Labor Compensation Appeals Board*, the New Hampshire Supreme Court found Denise Kehoe to be disabled by exposure to chemicals on her job site. Her symptoms include severe headaches, difficulty breathing, and allergies. The court decision includes the following legal endorsement for MCS: “[L]ittle doubt exists the multiple chemical sensitivity syndrome due to workplace exposure to chemicals is an occupational disease compensable under our workers’ compensation statute” (648 A. 2d 474 [N.H. 1994]).

In a second case a claimant is judged eligible to receive compensation benefits after it is determined that she is symptomatic only while at work. Chemicals offgassing from materials she works with, in combination with a warm temperature and poor ventilation, are determined to be the causes of her disability. According to the Oregon Court of Appeals, “she had shown by a preponderance of the evidence that the major contributing cause was her work environment . . . which exposed her to concentrations of chemicals much greater than she was ordinarily exposed to outside the course of employment” (*Robinson v. SAIF Corp.*, 717 P. 2d 1202–1206 [Or. Ct. App. 1986]).

A suit joining workers’ compensation laws to negligence laws was brought against the Boeing Company. A unanimous decision by the Supreme Court of the State of Washington found in favor of the plaintiffs. The court found sufficient evidence that Boeing engaged in deliberate intent to do harm to seventeen of its employees, exposing them needlessly to dangerous chemical exposures. This ruling allowed the plaintiffs to sue for civil damages in addition to their workers’ compensation benefits. The case was returned to a U.S. District Court and will be tried by jury (Supreme Court of the State of Washington, October 26, 1995, No. 62530-1).

More than a little irony is found in the negligence case of *Bahura v. S.E.W Investors* (1989). Several employees who worked on the third floor of the federal building housing the Environmental Protection
Agency claimed in a suit brought against the building contractors that formaldehyde offgassing from new carpet was the cause of mild to severe medical disabilities. The protectors of the environment themselves became victims of the spaces where work proceeds to protect the public. A jury found in favor of the plaintiffs.

If workers’ compensation and negligence laws make it possible to represent multiply chemically sensitive bodies in workplaces, the Fair Housing Amendment Act makes it possible to represent them in domestic places. In fact, a right to adequate housing was originally a part of the first version of the Americans with Disabilities Act (West 1993). It was later deleted from the ADA, however, when legislators determined that persons with disabilities can appeal to the Fair Housing Amendment Act (FHA) of 1988. The FHA requires owners of public and private housing to provide adequate accommodations for people with physical disabilities (West 1993).

A letter from HUD’S assistant secretary written in 1990 makes it clear this federal agency recognizes the environmentally ill body as a “‘disability entitling those with chemical sensitivities to reasonable accommodation under Section 504 of the Rehabilitation Act of 1973’ as well as ‘under Title VIII of the Fair Housing Amendment act of 1988’” (Donnay 1996, 6). This was followed in 1992 by a formal memorandum issued from the HUD deputy general counsel to all regional counsels stating that individuals disabled by MCS and EI can be handicapped within the meaning of the Act.

Attorneys writing for *Trial* magazine note:

The conclusion that MCS can be a handicap under the FHA greatly helps people with MCS. The act provides them with a right not to be discriminated against because of their handicap when buying or renting housing. It also provides them with the right to an equal opportunity to use and enjoy their dwellings. (Lieberman, DiMuro, and Boyd 1995, 28)

Not only does the FHA work in the concrete manner just described to represent the environmentally ill body in domestic environments; it also affirms the existence of this new body, giving it a tangible legal
identity. Joining the lay epistemologies of the chemically reactive to legislation and the courts bypasses the medical profession and expresses an alternative strategy for constructing a biomedical reality.

In *Lincoln Realty Management Co. v. Pennsylvania Human Relations Commission* (1991), Susan Atkinson filed a complaint against her landlord for failing to accommodate her physical disability. The commission summarizes her case:

Lincoln ejected Atkinson from her apartment solely because of her physical disability, and rejected any reasonable accommodations she proposed in violation of the provisions of the Pennsylvania Human Relations Act. . . . Atkinson, who is extremely sensitive to a variety of chemicals and chemical products, entered into a one year lease beginning February 1986. By letter dated May 6, 1986, Lincoln informed Atkinson that her lease would not be renewed for the upcoming year as Lincoln was unable to provide her with the special treatment and precautions her condition demanded. Atkinson did not vacate . . . at the expiration of the lease term . . . and filed a complaint with the Commission. (598 A. 2d 594 [PA. Commw. 1991], 596)

The commission received her complaint and set a hearing date. At the hearing Atkinson testified she suffered from multiple chemical sensitivity.

The hearing examiner found that Atkinson is handicapped within the meaning of the Act, that she established a prima facie case of discrimination, and that Lincoln did not make reasonable accommodations for her, and that Lincoln did not demonstrate that making reasonable accommodations imposed an unreasonable hardship. (598 A. 2d 594 [PA. Commw. 1991], 596)

The commission’s judgment against Lincoln required the company to provide more effective ventilation of Atkinson’s apartment (ceiling and exhaust fans); to use low-toxicity paints and pesticides; to provide two weeks’ notice prior to painting, pesticide treatment, and lawn care; to use an organic lawn care program within a hundred-foot
radius of her apartment; and to remove offensive floor covering and replace with it an acceptable material. The plaintiff is required by the commission to help pay for these changes.

In *Lebens v. Country Creek Association* (No. 94-940 A [E.D. Va. 1994]), Melinda Lebens filed a suit against her townhouse community association. She had asked the association on several occasions prior to the suit to implement an integrated pesticide management program in lieu of the usual blanket spraying. Rather than arguing its case in court, however, the association settled with Lebens, agreeing to pay a portion of her legal fees and to comply with the following changes: (1) eliminate blanket spraying programs for pests in the entire townhouse complex, including establishing a pesticide-free zone around her living unit; (2) identify and use chemicals that are low-level threats to Lebens along with mechanical and horticultural controls as alternatives to previous procedures; (3) provide seven days’ notice prior to pesticide application and seek her counsel on which chemicals are the least dangerous to apply; (4) provide notice of planned new construction with potential chemical exposures and, again, seek her advice on how to minimize exposures; and (5) keep machinery away from her townhouse. In this example we see evidence of the chemically reactive body represented in corporate decisions about pest control and new building construction.

We do not know what proportion of legal cases involving MCS are decided in favor of the chemically reactive. Our intention is to provide sufficient evidence that the existence of a new body is recognized with some regularity in the deliberations and decisions of courts, commissions, and other legal venues. Joining the claims for a troubled body to disability, workers’ compensation, and fair housing legislation in legal arenas would seem to suggest an alternative model for the public recognition of a disease, one that diminishes the role of medicine in the making of disease. It is as if the medical profession is on the sidelines watching a game between the chemically reactive and their attorney advocates on one side, and employers, landlords, and other responsible parties on the other side.
The marginal role of medicine in representing the environmentally ill body, while an important observation, is not a historical anomaly. Professional medicine has traditionally been reluctant to recognize diseases with environmental and occupational etiologies (Nelkin and Brown 1984; Freund and McGuire 1991). Coal miners and labor rights advocates, for example, knew well ahead of the medical community the devastating consequences of “black lung,” or “miner’s asthma” (Freund and McGuire 1991, 68). What makes MCS unique is the role of laypersons in fashioning rational, medical explanations for their subjective, somatic experiences. If a miner was likely to know a folk song about black lung, a person whose body changes uncontrollably in putatively benign environments is likely to construct an elaborate biomedical account of his misery. Perhaps this is because a lung disease caused by years of exposure to poorly ventilated, underground environments is an expected, if unwanted, occupational hazard, while a disease caused by routine exposures to culturally defined safe places requires thoughtful explanation.

Some occupational hazards, however, are not expected and are the source of considerable controversy. A legal contest involving the legitimacy of EI is currently being waged between the U.S. Veterans Administration and soldiers sent to Kuwait to fight the Iraqis. The action of the Gulf War was an intense, brief military and technological encounter that took place during the first two months of 1991. After limited occupation and little actual combat, U.S. troops returned home. Many men and women who had not come under enemy fire while in Kuwait and Iraq reported shortly upon returning home troublesome changes in their bodies, including aching joints, swelling of extremities, soreness, fatigue, memory loss, rashes, slurred speech, and loss of coordination (from President’s Committee on Gulf War Syndrome 1995, cited in Parks 1996a).

A nationwide survey of 13,700 Gulf War vets conducted in 1993 by the Federal Department of Veterans’ Affairs Persian Gulf Family Support Program found that 71 percent reported physical problems, including fatigue (25 percent), back, neck, and shoulder pain (25 per-
cent), headaches (23 percent), skin rashes (18 percent), leg and arm problems (18 percent), stomach pain (14 percent), and breathing problems (14 percent) (Parks 1993b). Frank Bray, spokesperson for the regional office of Veterans Administration Affairs in Montgomery, Alabama, reports that claims by veterans for compensation almost doubled following the Gulf War, from 2,214 claims for the twelve-month period ending in February 1991 to 4,068 claims for the same twelve-month period in 1992–93 (Parks 1993a). In her oral testimony before the Committee on Veterans’ Affairs, Subcommittee on Oversight and Investigations, on June 3, 1993, Dr. Claudia Miller of the University of Texas Health Science Center at San Antonio identified Gulf veterans as among the category of patients diagnosed as “chemically sensitive.” Their bodies express typical MCS problems, including fatigue, numbness, dizziness, and headaches, associated with exposures to common, everyday chemical products and environments (U.S. House of Representatives Subcommittee on Oversight and Investigations 1993, 88). In the same hearing, Dr. Charles Henshaw, a physician with the American Academy of Environmental Medicine, concurred with Dr. Miller, noting, “The mysterious illness afflicting the Persian Gulf Veterans is multiple chemical sensitivity (91). To date more than twenty thousand Gulf War veterans have reported suffering from one or more of these symptoms (Parks 1996a).

In 1995 President Clinton appointed a citizen committee to review the circumstances and hear evidence regarding injuries caused by chemical exposures during the war. Recently a dozen ailing veterans from across the country represented their chemically damaged bodies to this committee. Nick Kresch, a thirty-year-old navy veteran, recalls his return from the Gulf War in 1991. At first he thought he had the flu, but the debilitating symptoms continued. His symptoms included weight loss (fifty pounds), bleeding from his gums and rectum, pain, and hair loss. “I got worse and worse,” he explains, “and I worked less and less.” After a series of downward events, he “hit bottom.” He now receives full disability from the Veterans Administration and Social Security, but his symptoms persist (Parks 1996a).
Courts, congressional hearings, review boards, and other litigious settings will continue to be an important arena for dramatizing the problem of MCS. Defendants will continue to deny its legitimacy, while plaintiffs and their attorneys will work tenaciously to persuade judges and juries to recognize a new disease. At one, albeit abstract, level, social representation of the chemically reactive body does not depend on whether a particular case is won or lost. The fact that a case occurs at all means the question of MCS is a legitimate issue in civil, tort, or possibly criminal law. It is, perhaps, the nature of the legal profession to concern itself with a wider array of human troubles than the medical profession, which is limited to the problem of curing disease. For whatever reason, it appears the legalization of the chemically reactive body is occurring well ahead of its medicalization. Likewise, the environmentally ill body is being commodified faster than it is being medicalized.

Commodifying the Environmentally Ill Body

Not surprisingly, the very market that produces consumer goods that allegedly cause or trigger MCS is also willing to produce goods targeted for the new needs of the environmentally ill body. Markets create consumers, openly and without apology. A television commercial that tells adults it is okay, if a bit naughty, to eat Kellogg’s Frosted Flakes, is followed immediately by another commercial for Slimfast, a weight-loss product. And the irony is, few of us see the inconsistency of this juxtaposition of messages, encouraging high calorie consumption on the one hand and dieting on the other. We expect more honesty from ourselves and one another than we do from the market.

Ethical or not, however, markets in late capitalist societies are key resources for creating and representing cultural themes (Baudrillard 1975). To create a product is to also create a symbolic image of a consumer. A sixteen-bit True Value drill in a hard plastic case sitting on a hardware store shelf conjures up an image of a particular type of per-
son, while excluding dozens of other types. When we see the drill, we are also likely to see this person, or could do so with little prompting.

The market, as we will see, is a key resource in both creating and representing the chemically reactive body. One carpet manufacturer participates in a program that seeks to “develop ways to reduce emissions by testing samples of carpet. With fresh air ventilation, most carpet emissions are substantially reduced within 72 hours after installation.” In the same advertising statement the manufacturer also includes important health information, information for sensitive individuals, and carpet installation guidelines (Delicate Balance, fall/winter 1994).

One company, Pillows Futons Furnishings, offers a product list of items made with organic cotton. The advertisement, which appears in Environ: A Magazine for Ecological Living and Health (1994, 35), reads as follows:

- No pesticide, herbicide, or defoliant
- No flame retardant
- Fabric washed in filtered water
- All items made in a controlled air environment
- Packaged in cellophane

An ad in the same issue announces the Tenth Annual National Directory of Organic Wholesalers and Suppliers, noting that there are over eight hundred individually indexed commodities for the environmentally sensitive. In addition, a reader can purchase other indexes, which include “Buyers and Sellers of Every Kind of Organic Product, from across the US, Canada and Abroad.” The directory cost $29.95 (33).

Specialty catalogues offer environmentally “safe” products. Nontoxic Environments, Inc. is an annual compendium of “building, household and personal products for the chemically sensitive and the earthwise.” It is printed with soy-based ink on recycled paper. Among the items listed are safe home construction products: “Healthy Home Designs Portfolio: Environmental, Sustainable Architecture Designed for the Twenty-first Century”; “Eco Specs: A Guide to Planning,
Building, and Maintaining a Healthier Home”; Nilfisk GS 10 commercial vacuum with felt microfilter and HEPA exhaust filter; Natural Linoleum; whole-house radiant ceramic heat; and portable, whole-house and auto air purification systems. Additional items include organic cotton pillows, Clearly Natural Soap, reusable menstrual pads, and a handmade face mask and filter in cotton or silk. The catalogue notes, “The products presented here are the safest alternatives we have found.”

The Allergy Store in Sebastopol, California, offers a free sixty-four page catalogue of products proven effective for the sensitive person, which includes cosmetics, vitamins, air purifiers, household products, and much more.

The Living Source, a store in Waco, Texas, offers “products for the chemically sensitive and environmentally aware.” Among the items on sale are ceramic, charcoal, and cotton masks; dental products for the chemically sensitive; deodorants for the chemically impaired; and “Denny Foil,” a nontoxic substitute for tinfoil.

Cybertec, a cleaning franchise that specializes in services and solutions for sick building syndrome and indoor air pollution, advertises through the Internet. Another Internet entrepreneur advertises “new, affordable, disposable, activated carbon air filters—cure sick building syndrome by removing odors, molecular irritants and allergens, leaving indoor air truly clean and attractive.”

If the courts are capturing MCS through what we might call the legalization of disease, the market is also claiming propriety over this nascent disorder. The chemically reactive body is quite obviously a market opportunity. Its peculiar needs are represented in product lines and services. Examine an activated carbon filter mask, a portable auto air purifying and circulation system, or a nontoxic substitute for tinfoil, and it is possible to discern the outlines of the chemically reactive body.

Commodifying the environmentally ill body is proceeding apace with legalizing it, while at the same time medicine continues to resist acknowledging it. This uneven institutional representation of this emergent body illustrates the idea that social learning is often frag-
mented, with one institution learning quicker than others and still others resisting, if not opposing, the lessons. The effects of this broken pattern of institutional learning on the self remain understudied, though we suppose they might create a more pronounced need for individual discretion than in situations where institutions agree.

Popular Culture and a New Body

A final, brief area worth considering is the representation of MCS in popular culture. Considered by some to be postmodern society’s court of final appeal, popular culture is the most pervasive, some will say invasive, of our symbolic worlds. To be represented in popular culture is to exist, no matter how vacuous or empty the issue. The currently popular phrase “NO FEAR,” for example, is found printed on clothing, stuck to cars, and tattooed on bodies, though its exact meaning, message, and origin are debated. As if conversing with or debating those who claim they are not afraid really mattered, the phrase “FEAR THIS” can also be seen on clothing, cars, and bodies. Indeed, T-shirts are available with one phrase on the front side and the other on the back. Insofar as popular culture enjoys the power to create and sustain essentially meaningless phrases, its authority over how we see and respond to our world should not be underestimated.

The popular television series *Northern Exposure* devoted several episodes to a young man who suffered from MCS. He lived in a bubble house, used a respirator when he ventured outside, and was an object of much scrutiny and conversation among his neighbors. Much to the chagrin of the chemically reactive community, however, he recovered from his disability when, of all things, he fell in love. Like the frog who is turned back into a handsome prince by the kiss of a princess, all you need is love to cure a debilitating environmental disease, or so the story goes. On the other hand, if the show’s writers left the man disabled, they would also be required to write about the possibly toxic environments of a pristine Alaskan village, not a very upbeat theme for a feel-good series.

The chemically reactive body is also the subject of the recent movie
Safe. Set in Los Angeles, Safe is the story of a young, affluent housewife who contracts MCS. It all starts when she and her husband buy a new house. Her body begins to respond to the paints, furniture, and new carpets in the house. She almost faints while driving behind a truck emitting carbon fumes from a faulty exhaust system. Her nose bleeds while she is visiting a beauty shop. Her symptoms persist, and her doctor recommends a psychiatric consult. The psychiatrist, a male, attributes her symptoms to stress caused by moving to a new neighborhood and house and counsels her to relax. She starts her own inquiry into her illness and attends a workshop on MCS.

Eventually, she separates from her family and moves into an alternative health community far removed from the city. The movie closes with her standing in the center of her one-room house, cot on the floor, a single lightbulb dangling from a cord attached to the ceiling providing the only light. She stares at an image of herself reflected in a small mirror hanging on the wall and whispers over and over again the New Age refrain, “I like you. I really like you.”

Billed as a “dark comedy,” Safe leaves the moviegoer wondering just what it was that made this woman so sick. Throughout the film she is depicted as unsure of herself, lacking a strong self-identity. The close of the film suggests she will recover from MCS when she begins to like herself. The source of MCS, in other words, is low self-esteem. On the other hand, the movie also makes it clear she is exposed to countless environmental insults. Perhaps the film is simply trying to be honest about this disease: there is a good deal we don’t know about MCS.

Finally, a colleague who knew of our interest in MCS sent us the following poem by Alondra Orre, published in the February 1995 issue of Blazing Tattles, a monthly magazine with a focus on the political economy of environmental issues:

Old MacDonald had a farm,
EI, EI, oh!
And on this farm was Pesticide,
EI, EI, oh!
With a spray, spray here, and a spray, spray there,
Here a spray, there a spray, everywhere a spray, spray
Old MacDonald had a farm,
EI, EI, oh!

The poem continues, replacing pesticide with fertilizer and antibiotics. It ends on the now familiar theme of lay inquiry.

Old MacDonald saw a doc,
EI, EI, oh!
The doc said, “It’s all in your head,”
EI, EI, oh!
But he checked here, and he checked there,
Here he checked, there he checked, everywhere he checked, checked,
Till he found that he had got
EI, EI, oh!

To clarify for the reader, the publisher included the following postscript to the poem: “Publisher’s note: ‘EI’ is an expression used to mean ‘environmental illness’ or ‘multiple chemical sensitivity’ (MCS).”

We do not have systematic data on how or how frequently popular culture represents the chemically reactive body, and anecdotes do not usually make a very convincing story. But we ask the reader to consider this brief foray into popular culture with the other evidence presented thus far to document the range of institutional settings that are recognizing a new body. And even without additional evidence of representation, we should not underestimate the role of popular culture in shaping attitudes, beliefs, and bodies in a culture oriented as much to symbols as to substance.

Conclusion

What changes when society recognizes MCS? Evidence presented in this and the previous chapter suggests the chemically reactive body is becoming a model for rethinking conventional boundaries
between what is routinely considered safe and dangerous. If common understandings of safe and dangerous are important ways in which people acknowledge one another as members of the same society (Durkheim 1965; Douglas 1966), then each time the chemically reactive body is represented in some institutional context a new boundary between benign and perilous is drawn, however momentarily. People are invited to reconsider commonsense ideas about safe and dangerous. A portion of what everybody thought they knew with certainty is now a question.

AIDS, too, is a demand to revisit important life questions that appeared just a few years ago as manageable. Blood and sex—while always volatile cultural and biological issues—were thought to be under adequate control. Now, of course, we are not so sure. But whatever happens with AIDS, blood and sex will always be different from hair sprays and plastic wraps. We expect, or most of us do, that sustained attention is required to control the former, while the latter are, or were, until the emergence of MCS, thought to be comparatively safe. Environmental illness identifies nothing less than modern material culture as the source of debilitating disease. It is a way of explaining sick bodies that goes far beyond blood and sex, pointing its accusing finger away from the discrete person or couple to the world we have built for ourselves. “If a condom over my dick will protect me and my partner from AIDS,” writes a young gay man with MCS, “then nothing less than a condom over all of my body will protect me from the environment.”

The idea of representation invites consideration of how the lay theorizing of the chemically reactive is becoming a model for institutional practice. It allows us to complicate the orthodox perceptions of illness and disease by seeing how important institutional others respond to the definitional work of the chemically reactive not simply as a subjective experience of somatic distress but as a disease. Measures of this acceptance are found on a continuum from local, situated changes in workstation rules; to community and county ordinances; to federal legislation, the courts, and the markets; and to popular culture itself.
The case of MCS encourages us to be skeptical of the modern idea that physicians control the definition of disease while laypersons experience illness. The body of MCS, it appears, is protesting the conventional boundary between lay and expert medical knowledge.

The last five chapters have followed the narrative accounts of people who have constructed local, multidimensional classifications and conceptualizations of their bodies. Two assumptions guided our observations. First, we assumed that bodies exist before culture and in some fashion are always influencing human experiences. Second, we assumed that people are concept-creating and concept-bearing beings who will seek to comprehend and, if called upon, give an account of their bodies. In the case of MCS, we sought to show that knowing the body is necessary to both sociopsychological health and the well-being of the body.

From perceptions that something unusual is happening to their bodies to the development of rudimentary taxonomies of somatic signs and chemical agents, those with MCS are developing conceptual schemes for interpreting and coping with an array of unruly physical symptoms. They explain their rudimentary schemes to physicians, seeking confirmation and help. A few of the lucky ones are listened to by their doctors, and a kind of collaboration ensues between client and expert in a common cause to understand what is happening to the body. The majority of the chemically reactive, however, find their physicians unable, if not unwilling, to consider the validity of their emergent schemes associating physical symptoms with local environments and the chemical agents found in them.

Ignored or abandoned by their physicians, their symptoms persisting or growing worse, the chemically reactive construct their own biomedical accounts of what amounts to a new syndrome, if not a new disease. Separating the language of biomedicine from its institutional base, they transport it into their local worlds and fashion technical, some might say rational, accounts of their somatic troubles. Theoriz-
ing etiologies of disease that locate the source of affliction in subclinical exposures to putatively benign chemicals found in domestic, workplace, commercial, and other modern built environments, the nascent medical knowledge of the chemically reactive shifts attention from the body as a source of disease to the material world we all inhabit. Theorizing pathophysiologies of disease, the chemically reactive construct accounts, some quite elaborate, of the specific effects of chemical environments on a wide array of body systems, including respiratory, limbic, autoimmune, and nervous systems.

Borrowing from Geertz, we referred to these theories of MCS as lay epistemologies. In constructing biomedical accounts of their recalcitrant bodies, those with MCS are doing more than developing a practical approach to a practical problem; they are pointing to the possibility of a new way of knowing. Specifically, they are reclaiming the importance of subjective, human experience as a source of reliable, and rational, knowledge. Knowing, they contend, cannot be untangled from experience. Between the physical body and the environment is an active, conscious self ready to listen to the body as it encounters a world beset with peculiarly modern dangers. Joining the visceral knowledge of the body to the worlds of medical, toxicological, and ecological knowledge, the self fashions a reasonable account of physical distress and disability.

A rational knowledge that begins by paying attention to the language of the body and its relationship to environments might also assume that knowing is individual and local, indeed perhaps varying from body to body. An epistemology whose measure of reliability is biased toward the immediate, situated context challenges the classic assumption that reliable knowledge is universal, applicable to all people and all situations. The bodies of the chemically reactive can be likened to stations along the local train route. While the local stations are linked to one another by a common track, each one is individually named, acknowledging the particularity of place, and the conductor calls each station in turn. The MCS body is unique, separate from the other bodies, and requires explanation based on its particular,
restricted relationships to immediate, tangible environments. On the other hand, it is linked to other bodies by a common thread of debilitating somatic responses to routinely benign places and commercial products.

Once biomedical language is used to explain the body and its strange relationship to environments, the validity of these explanations is more pragmatic and local than numerical and generalizable. A retired dentist who identifies himself as MCS put it this way:

I know my explanation of MCS is correct because it works. It’s as simple as that. I make better decisions with its help than I did without it. Maybe after all the research is in, if later someone locates my disease in my head and not my body and gives me a pill that cures me I’ll believe his explanation. Until then I’m on my own.

Validity here is essentially a question of adaptation. Not “Is my explanation really true?” but “Is it practical and effective? Does my new knowledge of my body and environments help me adjust to, or survive, a world that is turned upside down, where safe has now become dangerous?”

We use the word adapt with caution. After all, if MCS is really a neurotic-somatizing disorder, lay theories of its environmental origin are themselves part of the problem. Perhaps the chemically reactive are constructing biomedical theories that are themselves nothing more than evidence of personality disorders. Luckily, we are not physical or biological scientists, and therefore can recuse ourselves from judging their accounts valid or invalid by the strict canons of science. We can offer a sensible observation on this question, however. If MCS is a neurotic-somatizing disorder, then we are witnessing the first recorded pandemic of people simultaneously expressing their neuroses through a critical assessment of somatic responses to local environments. From the village of Armidale, New South Wales, Australia, to Zurich, Switzerland, to the Black Hills of South Dakota in the United States, men and women, farmers, professionals, the young and the old are reporting their bodies changing in the presence of what are conventionally
understood as safe places. And in the absence of a common organizational affiliation, they are constructing similar accounts of their troubles. It stretches common sense to write off this remarkable confluence of bodies, environments, and narratives as a psychiatric disorder prevalent throughout the world.

Another measure of the “truth” of MCS might be called sociological rather than clinical. Here and in chapter 7 we identified social, political, and cultural venues that are actively representing the chemically reactive body. If truth is a consequence of acting toward the world as if something exists, an increasing number of institutional others are making important adjustments to this new body and its theory of disease.

The final chapter expands our account of MCS to include another medical-environmental movement, popular epidemiology. It closes with several observations on environments, bodies, and rational knowledge.