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Of the World But Not In It: Barriers to Community Access and Education for
Persons with Environmental Sensitivities

Pamela Reed Gibson

James Madison University

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Address correspondence to Pamela Gibson, James Madison University, Department of
Psychology, MSC 7704, Harrisonburg, VA 22801. e-mail: gibsonpr@jmu.edu; phone: 540-
568-6195; fax: 540-568-3322.

Abstract

In this paper I explore community access - primarily the lack thereof - for persons with disabling environmental sensitivities. Respondents with chemical and electrical sensitivities described their level of access to common community resources that most persons take for granted, including communities of worship, grocery stores, health food stores, community meetings, public libraries, the homes of extended family members and friends, offices of dentists and medical doctors, public parks, and classes at their local universities. Most had tentative access at best. In addition, participants listed the disability barriers that most restricted them from public participation. Results are described using both quantitative and qualitative data and the problem is analyzed within the context of industrial capitalism's influence upon institutions.

Of the World But Not In It: Barriers to Community Access and Education for Persons with Environmental Sensitivities

The emerging disability of environmental sensitivity (ES) involves negative symptoms from exposure to chemicals in ambient air and/or electromagnetic fields. Chemical sensitivity (often referred to as multiple chemical sensitivity or MCS) has prompted more research than electromagnetic hypersensitivity (EHS) and afflicts between 4% and 33% of the U.S. population, depending upon the level of severity of the definition used (Meggs, Dunn, Bloch, Goodman, & Davidoff). Caress and Steinemann (2003) found that 12.6% of respondents in a U.S. urban household population study reported being "unusually sensitive to everyday chemicals like those in household cleaning products, perfume, detergents, insect spray and things like that" (p. 1491). And the problem appears to be prevalent in other industrialized countries (Wilson, 1995), including Denmark, Sweden, Norway, Finland, Germany, Holland, Belgium, the United Kingdom, and Greece (Ashford, Heinzow, Lutjen, et al. 1995). For example, in Denmark, 27% of a random household sample reported multiple symptoms from chemical exposure; for 19% it impacted personal behavior and 3.3% social or occupational behavior (Berg, Linnegarg, Dirksen, & Elberling, 2008). In Sweden, 33% of adults reported some odor intolerance with 19% having "affective and behavioral consequences," meaning that they were very bothered by the odors and had made life changes to avoid them (Johansson, Brämerson, Millqvist, Nordin, & Bende, 2005). Teenagers in the same country reported problems at a lesser incidence (15.6%) with 3.7% reporting associated affective and behavioral effects (Andersson, Johansson, Millqvist, Nordin, & Bende, 2008). Hausteiner, Bornschein, Hansen, Zilker, & Förstl

(2005) found in Germany that 32% of their representative sample of Germans said that chemicals caused their health complaints (although only 19% endorsed that their "body reacted immediately"). Approximately 3% of the U.S. population reports electrical hypersensitivity (Levallois, Neutra, Lee, & Hristova, 2002). Carlsson et al. (2005) found that in Sweden 13.5% reported "some" annoyance and 1.9% reported "much" annoyance from video display terminals or fluorescent lighting.

Studies using volunteer samples are highly skewed toward women, who comprise approximately 70 to 80% of respondents. Household population studies find smaller gender gaps, yet still find larger percentages of women than men reporting chemical sensitivity (Andersson et al, 2008; Caress & Steinemann, 2003; Hausteiner, et al., 2005). Meggs et al. (1996) found that 24 percent of men and 39 percent of women in a U.S. household population study reported chemical sensitivity. With large numbers of women reporting the problem, the condition is subject to all of the gender biases in definition, perception, treatment, and policymaking that have plagued the history of women's health (Geller & Harris, 1994; Laurence & Weinhouse, 1994; Nechas & Foley, 1994; Showalter, 1985; Tavris, 1992). One particular way that women are misperceived is that they are seen as being overemotional and wanting of attention, resulting in the overdiagnosis of histrionic personality, a new name for Freud's old hysteria (Hamilton, Rothbart, & Dawes, 1985; Loring & Powell, 1988). Consequently, their physical complaints are not taken as seriously as men's, as Freud saw women as manifesting their neuroses in their bodies through "somatic compliance" (Freud, 1963).

Persons with chemical sensitivity cite a large number of chemicals as being problematic to their health. Gibson and Rice (2009) found that 254 persons with self-reported chemical sensitivity rated pesticides, formaldehyde, fresh paint, new carpets, diesel exhaust, perfumes and air fresheners as the most problematic of 29 chemicals offered on a checklist. A Japanese study of 106 MCS patients showed some overlap in that the five highest rated incitants were insecticide, paint/paint thinner, cleaning products, fragrance, nail polish/hair spray, and tobacco smoke (Hojo, Ishikawa, Kumano, Miyata, & Sakabe, in press). Other highly problematic exposures in Gibson and Rice's study included asphalt, mothballs, nail polish, fabric softener, and cigarette smoke. With neither medical treatment nor accommodation, chemical avoidance remains the only survival mechanism for persons who become ill/disabled from these exposures and reportedly helps over 94% of persons with sensitivities (Gibson, Elms, & Ruding, 2003). But complete avoidance is almost impossible in industrial culture. Hence persons who have a need for very clean environment are stuck unable to participate in modern culture with its ubiquitous chemical exposures.

Overlap between chemical sensitivity and allergy is considerable. Hojo et al. (in press) found that 84% of their outpatients with CS had comorbid allergy. Millqvist, Bende and Löwhagen (1998) proposed that a subset of persons with chemical sensitivity demonstrate sensory hyperreactivity, or asthma-like symptoms that nonetheless do not respond to traditional asthma treatment. Likewise persons with sensory reactivity to perfumes and other chemicals demonstrate allergy-like responses that do not respond to histamine blockers (Elberling et al, 2007) and have greater cough responses to capsaicin than "normals" (Millqvist et al., 1998). Millqvist

et al. believe that the sensitivity operates through an alternate pathway, “It seems likely that the VR1 receptors of the C-fibers of the sensory nerve system are remodulated in the airways of these patients, or that the number of receptors has increased” (p. 1211). Yet only Millquvist’s research group has addressed this possibility.

ES has qualities of both chronic illness and disability, yet enjoys neither medical understanding nor disability status/accommodations in the broad sense. Without generalized medical care, persons struggle with a myriad of symptoms that affect all bodily systems and include particularly “tiredness/lethargy, difficulty concentrating, muscle aches, memory difficulties and long-term fatigue” (Gibson & Rice, 2008, p. 75). They consequently visit a large number of practitioners (Gibson, et al. 2003), and spend considerable funds in attempt to attain help (Gibson, Cheavens, & Warren, 1996). The lack of accommodations makes for difficulties in the work environment, in social situations, in obtaining any social services or medical care, and in accessing public buildings. Life impacts for some include unemployment, financial devastation, social isolation, and even homelessness (Chircop & Keddy, 2003; Gibson et al., 1996; Johnson, 2000; McCormick, 2001; Zwillinger, 1997). Considerable personal anguish and loss of identity can result from the severe life impacts, lack of services, and widespread skepticism toward people with these sensitivities (Gibson, Placek, Lane, Brohimer, & Lovelace, 2005; Lipson, 2004).

Oliver quoted Stone (1985) that “definition by default remains at the core of disability programs” where disabled categories exist and if you don’t fit one, you are considered able to work. Environmental sensitivity is not included even

passively, in any of the 19 “functional limitation categories” (p. 2) adapted by Brodwin, Parker, and DeLa Garza (2003). Therefore persons with MCS receive little in terms of services and accommodations and are left to negotiate the terrain of the industrial culture in isolation. To become established as a disability, a condition or “impairment” must be legitimized by law, medicine, and other mainstream institutions. The legitimization of ES/MCS is in motion, but it is very early in the process.

Marks (1999) said, “the social model [of disability] looks at the way in which the environment is designed with a minority of young, fit and non-disabled people in mind.” Most non-disabled persons in industrial culture, therefore, take public access for granted, while, as Rioux (2002) remarked, “for many disabled people, rights become privileges to be earned” (p. 214). Hence Thomas’ “landscape of social exclusion” for persons with disabilities consists of barriers to education, work, transport, housing, health and welfare, recreation, and other activities.

Much work on disability and exclusion has focused on employment. We know that work for persons with MCS is highly problematic, and persons are unlikely to receive appropriate accommodations or to win a case with the Equal Employment Opportunity Commission (EEOC) (Gibson & Lindberg, 2007; Lipson & Doiron, 2006; Vierstra, Rumrill, Koch, & McMahon). But Abberly (2002) argued that we need to focus on “aspects of citizenship less tied to economic function” as “Disabled people have inhabited a cultural, political, and intellectual world from whose making they have been excluded, and in which they have been relevant only as problems” (p. 134). Because there has been very little discussion of community

integration for those with environmental sensitivities, in this study we examined community access and education outside of work for this population.

Method

Participants

Participants were primarily Caucasian, 82% women and 90% from the U.S. Mean age was 50 and mean personal income was \$32,000. People reported their disability level as mild (12%), moderate (57%), severe (25%) or completely disabled (3%). Respondents saw their disabilities as eventuating from extended low level exposures (27%), one large chemical exposure (9%), a physical illness (1%), or other causes (11%). Others (43%) said that a combination of several factors caused their condition, or did not know the cause (7%). Twenty-four had electrical in addition to chemical sensitivities. Fifty-eight were currently working and 42 were not.

Procedure

As part of a larger study of work accommodation and community access, 100 persons with self-reported multiple chemical sensitivities (88 women and 12 men) recruited through MCS support group newsletters and websites answered questions about their level of community access, including the ability to enter communities of worship, grocery stores, health food stores, community meetings, public libraries, the homes of extended family members and friends, offices of dentists and medical doctors, public parks, and classes at their local universities. Respondents were asked if they could access each of these resources, given room to make comments about each, and then asked to list the barriers that prevent them from having access to two of these community resources: public buildings

and parks. The employment aspects of the larger study are described elsewhere (Gibson & Lindberg, 2007).

Results

Community Access

Even though participants were asked to respond to each of the eleven community access variables dichotomously (yes or no), there were so many qualifying comments that responses were coded as “no access,” “partial access,” or “fairly good access given MCS-related limitations.” Sometimes judgment calls had to be made when coding partial versus fairly good access. Generally being able to stay somewhere for only a “short time” was coded as partial access. However, if someone could stay in the library for an hour, that was considered to be fairly good access. On the other hand, only being able to stay at the home of family or friends for an hour was coded as partial access, as these gatherings usually last for longer time periods.

There is often no complete access in most settings for persons with MCS and virtually all settings asked about had many caveats. For example, in many settings, people could often stay only a short time or had to use air purifiers. Illustrative of the seriousness of persons limitations is that 52% were unable to enroll in a university course; 45% lacked any access to communities of worship, 29% to extended family homes, 24% to the homes of friends, 24% to dental offices, 12% to medical offices; and 13% could never go to public parks. Frequencies for our coding for each of the eleven settings are shown in Table 1.

Participants rarely had full access to the resources that others take for granted. When good access did exist, it was often because of an aware community, which lessened the disability. For example, one woman had a church with a scent-free section. Another lives in Berkeley and citizens are asked to attend public meetings scent free and smokers to smoke outside and away from the building entrances.

However, most access described came with considerable effort. One woman reported driving 650 miles to see an accessible dentist. Another woman, whose access to her extended family members' homes was rated as "good," still explained that, "No scented candles, deodorizers, or scented cleaning products can be used." A woman whose access to community meetings was rated as "partial" said:

I take my personal ionizer and try not to sit by someone with perfume. I also sit at the end of a row near a window or open door if possible. If it gets too bad, I leave early. I don't go to meeting in the LA Basin . . . which would surely make me sick.

Families sometimes refused access outright: "They refuse to refrain from wearing perfumed products and disinfectants, scented candles, etc. they do not see being exposed as a problem ('if you wouldn't think about it, it wouldn't bother you')."

Sometimes a person's access was terminated when delegitimized by someone seen as having authority:

My family said they like the way they live and I'm the one with the problem. Accommodations at first (when I didn't quite know what I had). But consideration stopped when my cousin, a nurse, told them it was panic attack disorder and my thinking is causing my problem.

For some, access was so poor that isolation resulted. One woman lamented, "I have given up friends or they have given up me. I am very isolated and lonely. I find very few people who understand MCS or are willing to make accommodations." In other cases, women lived as shut-ins for periods of time to avoid illness. For example one woman was "unable to go outside during pesticide season except by car and have to park by doors. Unable to go for walks."

Barriers seemed ubiquitous, occurring in multiple venues. One woman explained, "Every doctor's office I go to gets me sick because of cologne, new paint or carpet, or cleaner or air freshener. Even the holistic or alternative docs use candles or incense or scented hand soap, etc."

Delegitimization was commonly used to place the blame on the person with MCS. One woman was told that she feels sick because she is thinking negatively: "If I would just cheer up and just work, I'd be happier – this from the pastor!"

Barriers to Public Spaces

When asked to specify the barriers that prevent their access to public buildings, respondents listed perfumes, cleaning products, air "fresheners," poor ventilation, carpet, renovations/construction including formaldehyde,

restroom deodorizers, paint, smoke, pesticides, mold, and scented personal products other than perfume as their major barriers. All barriers and their frequencies are listed in Table 2. Barriers most often cited as preventing access to public parks included pesticides/herbicides, vehicle exhaust, barbecues, people's scents, cigarette smoke, and air "fresheners"/deodorizers in bathrooms. (See Table 3 for additional barriers in parks.)

Education

Comments regarding education are reported here in more detail because of the seriousness of educational barriers and the lack of attention to this variable in the chemical sensitivity literature. Respondents were asked, "If you wanted to enroll in a course at your local university, would you be able to do so?" Answers were coded/categorized into the following seven categories as follows: Seventy-four of 100 persons answered the question. Of these 74, 3 responses were not codable. Of the remaining 71, 9 had managed (albeit with considerable difficulty) to find a way to partake in some form of in-person education, 7 were able to take coursework only online, 6 were currently struggling with taking a class and negotiating access, 8 had tried and failed, 11 believed that they could take a class with appropriate accommodations (although some of the needed accommodations were extensive), 23 said that they could not take a course, and 7 were unsure. Of those who managed to enroll in or complete a course, one did so by negotiating with the professors; one wore a mask to graduate school; one had completed medical school, but described it as a "nightmare;" one took evening courses when perfumes are likely to have worn off; one completed an MBA by having classrooms moved;

one sat in the back row of a computer classroom to avoid electromagnetic frequencies (EMFs) from computers in the row behind and near the door for ventilation; one asked classmates not to wear perfumes; one sought out off-campus training; and one endured symptoms from problematic perfumes and odors from markers for whiteboards. Those who said that they could attend only with accommodations mentioned the need for fragrance-free classrooms, ventilation (open doors and windows), no pesticides, no markers, and safe cleaning products. Overall, the major specific barriers to educational access cited by all who answered the question included perfumes (n = 25); whiteboard markers (n = 3); the respondents' own cognitive difficulties such as memory, or reading comprehension (n = 5), or fatigue (n = 2); cleaning products (n = 2); carpeting (n = 2); florescent lights (n = 2); and exposures during transportation to the school (n = 2). One respondent each mentioned pesticides, restroom deodorizers, printers and copiers, formaldehyde, building heating systems, mold, the inability to be in class for more than one hour, and buildings in general.

The eight failures cited were due to lack of accommodations. Two persons were denied outright. Others tried to attend but were forced out. For example, one person became ill from cleaning products and whiteboard markers, one collapsed after four weeks of perfume exposure, and one endured breathing and cognitive problems after 5 weeks of school. One respondent had been forced out of a doctoral program, and another had twice enrolled in school only to be unable to complete the academic year. Online courses seemed to offer

some opportunity for some respondents, but two specifically cited missing the interaction with other students as problematic.

Discussion

Persons with disabling sensitivities are denied access to community resources regularly and made ill when forced to access them out of necessity. Because this population is excluded from sight, business goes on as usual, and public venues remain the purview of those whose bodies conform to the modern day mandate of imperviousness to toxics. Respondents in this study cited fragrance in particular as the major barrier to community access and education. As one person put it:

Until scented products are banned from public places such as schools, university, office building, churches, restaurants, theatres, and other public places, then I run the risk of being exposed to the chemicals that I seem to have the most problems with, namely perfumes, colognes, and aftershave.

When all access fails, as it does for many, persons are left to complete isolation: "I have given up friends, or they have given up me. I am very isolated and lonely. I find very few people who understand MCS or are willing to make accommodations." The hidden nature of MCS serves the status quo well in that persons with sensitivities disappear from the public scape, are not seen and normalized in others' eyes, and business is allowed to proceed as usual. Rarely, persons with ES are given fair access by an aware community, lessening the disability. Yet policies such as those in Berkeley where citizens are asked to attend public meetings scent-free and to smoke outside away from entrances are still the exception.

But even these attempts at accommodation do not always succeed. One respondent said: "The University of Minnesota has a fragrance-free policy for its student body. Not necessarily always observed or enforced, but there is an expectation."

The implications for women's education are considerable when such a large portion of respondents is unable to attend any in-person university instruction. Persons with ES have sometimes devastating work problems and the need to re-train may be urgent. Those who acquire ES early in life before securing any advanced education may be cut off from ever attaining the education necessary for skilled employment or middle class standing. Despite a small body of literature documenting the serious life impacts and isolation for those with sensitivities, little has been done to confront the problems.

U.S. environmental policy in recent years makes it all the more unlikely that persons' environmental disability needs will be addressed. Rioux (2002) blames privatization for taking much of the substance of citizenship and rights out of the realm of the state, and giving the market more and more control of its activities. Many "programs" are now private, profit-motive activities. Rioux cites Arora (2001) that social problems are re-framed as individual responsibility (e.g., unemployment becomes an issue of "skills"). Social problems are then addressed through individual adjustment and the rights of citizenship are thus fiction when people are construed as non-citizens or denied "meaningful access" (Rioux, 2002). Similarly with ES, mainstream corporate-driven researchers attempt to individualize the problem despite documentation that the problem is worldwide (e.g., Hausteiner, et al., 2005). The psychosomatic attribution frees industrial

culture from accommodating the problem or heeding any warning that the problem may represent.

Researchers who do take the problem seriously exist but do so alongside those who blame individual psychopathology for the problem and are hence seen as “one side” of an issue. For example, Ishikawa and Miyata (2000) recommended the following in regard to understanding, treating and confronting chemical sensitivity: the training of physicians and counselors; cooperation with public health centers and hospitals; the creation of guidelines to regulate chemicals implicated in MCS such as formaldehyde, toluene, anti-termite agents, and very poisonous volatile organic compounds (VOCs); money for epidemiological research; creation of a database of the MCS literature; animal study models; public relations with media and public; and the delivery of research findings to chemical companies. Almost none of these has been accomplished in industrial countries where MCS is prevalent due to the influence of chemical industries on legislation, education, health care, research funding, and media. There is some cultural relativity to disability, the inability to tolerate chemicals would cease to be as disabling in a more “natural” culture.

The problem seems to be the implications of believing that people’s bodies are truly rejecting industrial toxins. Spencer and Schur (2008) discuss the challenges of responding to chemical sensitivity, “If proven scientifically valid, MCS would significantly impact public health in general and environmental health specifically. MCS could fundamentally alter our understanding of pathophysiology, affecting disease research design and disease prevention measures.” (p. 26). The same authors warn, “A public health community that is unable or unwilling at a minimum to contemplate paradigm-altering possibilities neglects its duty. With such significant implication, neglect would be insensitive” (p. 26).

Similarly, Ternesten–Hasséus, Lowhagen, and Millqvist (2007) assert, after finding that their patients with chemical sensitivity made no significant changes and did not recover from the symptoms over time, that “in spite of the uncertainties in the evaluation of environmental syndromes, physicians have a duty to deal with the symptoms of those affected” (p. 429).

Barnes, Mercer, and Shakespeare (2005) discuss “risk discourse” that pushes people to minimize their health risk through diet, exercise, and other personal behaviors, but ignores the visible and not so visible threats over which citizens have no control, such as vehicle exhaust, pesticide in public places and drift from agriculture, toxics used in medical treatment, and others. A contaminated environment is viewed as neutral, sensitivities are decontextualized, and the problem is transformed into an individual problem. Garland-Thompson (2006) said “. . . both women and the disabled have been imagined as medically abnormal- as the quintessential ‘sick’ ones” (p. 262). Women with MCS are both, hence the biases in regarding and constructing MCS are over-determined in the direction of pathology.

The consequences for those with disabling sensitivities, who are primarily women, are catastrophic in terms of cultural participation. Lack of access to medical care, education, community services, homes of family and friends, libraries, and parks punishes those with disabling sensitivities and excludes them so that the very practices that have rendered them disabled to begin with can continue. The “normal” body that can imbibe toxics is privileged at the expense of those whose bodies are registering important input for industrial culture – that our limit for tolerating poisons in the name of commerce has been reached.

Community, medical, and educational accommodations are crucial in order to allow for financial viability and quality of life in this admittedly large segment of the industrialized population. The two most commonly-cited barriers to public buildings and hence cultural participation in this study were fragrance/perfume and cleaning products. It would be an easy matter to limit fragrance use and employ less toxic cleaners in order to reduce the health risk for one third of the population. Unfortunately, (as we have seen in the case of tobacco) there is often way too long of a lag between knowledge of health risk and preventive measures. But a human rights perspective would dictate that personal care products and cleaning supplies should not be participation barriers to a significant portion of the population needing to access public premises.

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I thank Amanda Lindberg for her help in coding the community variables other than education.

Table 1

Community Access for 100 Persons with MCS

	NO ACCESS	PARTIAL ACCESS	FAIRLY GOOD ACCESS	NO RESPONSE/ NOT SURE
Community of worship	45%	19%	18%	18%
Grocery store	13%	28%	59%	
Health food store	8%	11%	80%	1%
Community meetings	40%	30%	30%	
Public library	19%	33%	46%	2%
Homes of extended family	29%	31%	37%	3%
Homes of friends	24%	43%	31%	2%
Dentist	24%	11%	65%	
Medical doctor	12%	21%	66%	1%
Public parks	13%	34%	51%	2%
University Course	52%	24%	13%	11%

Table 2

Barriers to Access to Public Buildings for 100 persons with MCS

Barrier	Number Listed
Perfumes	57
Cleaning products	40
Tight buildings/poor ventilation	27
Carpet	25
Air "fresheners"	22
Renovations/construction (including formaldehyde)	16
Restroom deodorizers	15
Paint	15
Pesticide	12
Mold	11
Soaps, hairsprays, personal products other than perfume	11
Scented candles, potpourris	6
Plastics	5
Vehicle exhaust	5
Gas fumes entering building	4
Floor wax/polishes	4
Transport to the building	3
Dry cleaned clothing on people	3
Fabric softeners on people's clothing	3
Air conditioning	3
Carpet shampoo	3

Note. Two respondents each listed lawn care products, computers, fluorescent lights, gas and oil heat, and solvents. One participant each listed solvent markers, vinyl flooring, dust, smoke on people, cell phones, anti-corrosive boiler chemicals, offgassing from wet coats, laundry products, ventilation systems, new fabric, and "toxic building materials."

Table 3

Barriers to Access to Public Parks for 100 persons with MCS

Barrier	Number Listed
Pesticides/herbicides	41
Vehicle exhaust	17
Barbeques	8
People's scents	7
Cigarette smoke	6
Air "fresheners"/deodorizers in washrooms	6
Insect repellent	4
Sunscreen/suntan lotion	4
Mold	4
Fireplaces/burning	4
Pressure treated wood	3
Fresh cut grass	3
Fertilizers	3

Note: One respondent each listed wood mulch, fabric softener, new asphalt, construction, transport to the clean wilderness area, trees/dirt/plants, and birds/animals.