

Pioneering Access for those with Environmental Sensitivities: An Interview with Susan Molloy

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Introduction

Chemical and electrical sensitivities are “invisible” disabilities often ignored by industrial culture and its institutions, including mainstream service providers. Persons with chemical sensitivities (often called “multiple chemical sensitivity” or MCS) experience a wide range of negative disabling reactions to common chemicals such as fragrances, pesticides, paints, cleaners, and exhaust fumes. These reactions can affect any bodily system, and common symptoms include tiredness/lethargy, difficulty concentrating, muscle aches, memory difficulties and long-term fatigue (Gibson & Rice, 2009). Those with electrical hypersensitivity experience symptoms from exposure to a variety of sources of electromagnetic fields and radiation, including electrical appliances, florescent lights, computers, and cell phones and their towers.

More is known regarding chemical sensitivity than electrical hypersensitivity at this time. For example, it is believed that people with chemical sensitivities first sensitize to one chemical, which then causes symptoms upon subsequent exposures. The sensitivity then tends to spread to other similar, and subsequently dissimilar chemicals, until the person is faced with a need to avoid a large number of common settings (Gibson, 2002). Because of the incapacitating health effects of exposures, people with disabling sensitivities thus lack access to crucial resources including housing, employment, medical care, education, rehabilitation programs, and even homeless and domestic violence shelters. Consequently numerous stressors, including health emergencies and personal violence, may go unacknowledged in this population.

Prevalence studies suggest that chemical sensitivity is a worldwide and not uncommon disability. For example, Caress and Steinemann (2003) found in a U.S. household population study that 12.6% of respondents reported being sensitive to chemicals. In the Netherlands, 27% of 6,000 people reported experiencing multiple symptoms from common chemicals and 19% had made life adjustments to compensate (Berg, Linnegarg, Dirksen, & Elberling, 2008). Likewise, 15.6% of Swedish teenagers reported being “bothered by strong odors” and 3.6% had made life changes as a result (Andersson, Johansson, Millqvist, Nordin, & Bende, 2008). And in Germany, 32% of persons report that chemicals

cause them symptoms (Hausteiner, Bornchein, Hansen, Zilker, & Förstl, 2005). Chemical sensitivity seems to cross lines of race, gender, and age, with severe life impacts for substantial numbers of people. For example, job loss due to chemical sensitivity resulted in 1.8% of Caress and Steinemann's U.S. sample.

Susan Molloy has been advocating for persons with environmental sensitivities since 1983. Part of her attention has focused on gaining recognition of this problem by the Centers for Independent Living (CILs), nonprofit corporations that have been established in the U.S. and other countries to provide accommodations and services for persons with disabilities. The centers exist in the United States, United Kingdom, Australia, Canada, and Japan, and have been heralded as grass roots agencies run by and for people with disabilities. CILs vary in size and budget, but all are mandated to provide information and referral, independent living skills training, advocacy, and peer counseling to consumers with disabilities.

Members of the James Madison University MCS Research Team (Lauren G. Sledd, Sahisna Suwal, & Pamela Reed Gibson) were interested in Molloy's efforts to gain access to CILs for persons with sensitivities and crafted questions to explore these efforts. Lauren Sledd put the questions to Molloy to highlight the history of her pioneering advocacy. Susan's own survival challenges are examples of the difficulties faced by persons with environmental sensitivities.

Sledd: When did you decide to go to the Centers for Independent Living and advocate for persons with chemical and electrical sensitivity disabilities, and what was your first experience with an Independent Living Center?

Molloy: I'd never heard of an ILC, nor had I heard of the disability that within one day, in summer 1981, took over my life. After getting hit hard with chemical and electrical sensitivities, the barriers to my participation in society were blatantly, immediately apparent. I couldn't go into offices or stores, or travel in a car or on the bus. When I walked down the street, I felt a huge weight that seemed to come from the overhead power lines. I lived in downtown San Francisco and something painful kept coming at me from Sutro Tower. Within weeks, I was wearing the same lavender cotton blouse and beige pants day after day even as they became filthy. It hurt too much to touch freshly laundered clothes.

None of this made sense to me and there was no one to talk with about it. I was going through a wrenching process, being morphed into a sick, disabled, homeless person. It was nearly impossible to rest anywhere. I had to be ready to get out...fast...from any place I lived or stayed in case something bad floated in on the air. I slept on a friend's back porch. I stayed with family. I stayed any place I could find where it seemed like I might not get hurt by whatever it was that

floated in the air.

My possessions – household furnishings and clothes, my cat, nearly everything was soon given away or traded to friends, or appropriated if not outright stolen by strangers. I had never heard of “Environmental Illness,” the chemical and electrical sensitivities, when I got hit.

Sledd: So did you not know at this point why everything hurt?

Molloy: The first night that I got sick with anaphylaxis, two friends took me to the emergency room. The E.R. doc used Atropine, Benadryl, and epinephrine to get me through the night. He said, next morning, that I was having an allergic reaction that had nearly killed me, and might have more. Several people in my family had serious sensitivities and allergies, but I’d always thought they were pathetic and effete. I assured him that I didn’t have allergies.

Following repeated horrifying reactions to food, electricity, mold, and chemical exposures over the next several weeks, the possibility of some sort of allergy began to seem worth exploring, or at least nothing else did. It seemed a reasonable step to check out this theory at a hospital. University of California Medical Center was a few blocks from the apartment where I was staying, so I made an appointment.

Sledd: How was it at the hospital?

Molloy: Then as now, medical facilities presented a number of threats. Diesel ambulances idle at the E.R. door, cleaning and maintenance chemicals, insecticide, fluorescent lights, carbonless copy paper forms, new synthetic carpet and furniture, and unshielded electrical devices present barriers throughout. In those days, patients and families smoked in hospital hallways, doorways, restrooms, and waiting rooms. It felt risky to entrust myself to anyone who’d make me fight through all the problems the hospital presented, but what were the options? So I did it. The conventional allergists and conventional tests – eventually at least they pointed toward some changes I could make in my diet. There was no help for the other reactions though.

Sledd: Yeah, I bet.

Molloy: Within the following weeks I became increasingly sensitized and threatened by every exposure, so figured I’d approach the Social Security system for help. I knew that sometimes a person who was very ill could apply for a monthly check in order to survive a calamity until back on their feet again and back at work. With no more idea about it than that, I called the Social Security

office in San Francisco and said I was having a bad health problem, I didn't know what to call it, and it didn't seem to be getting any better. I asked to talk with someone who could help me plan what to do.

The clerk explained that I'd have to visit the office and sit in the waiting room like everybody else. I explained that there seemed not to be a way I could leave the house without risking anaphylaxis again. Besides I'd seen the location of the Social Security office before, and there were always men smoking along the sidewalks around the doors.

As it turned out, I was unable to apply for two more years because I wasn't able to go to their office, and they refused to consider provisions such as interviewing me by telephone, coming outdoors to meet me, doing a home visit, or making any other provision. That seemed shortsighted and arbitrary to me, but I didn't yet see things in a civil or legal rights context.

The next year, I moved north to the country around Arcata, where I'd grown up. The air was better and the electrical exposures weren't so bad. I was glad to be near my family, no matter how they interpreted what had gone wrong for me.

One day I was walking along the pier by the bay, and noticed a little office with big windows facing the street. On the door there was a sign saying "Humboldt Access Project." People with disabilities were rolling around, walking around inside that office. I tapped on the glass and said I needed help. The director, Ben Harville, came to open the door, holding a lit a cigarette. He had no idea that he could kill me with that thing. I stayed outside, backing away. I gave Ben a description of the kinds of places I needed to go and what happened when I tried. I told him things had become like this only recently after years of having been a relatively "normal" person. I wanted him to tell me if what was going on with me had anything to do with access, if his agency helped people get access. He gave me some literature about the Independent Living principles, pamphlets and things, and invited me to come back, to the extent that it was possible, whenever I wanted to.

I did go back. I felt less stigmatized there than other places, even though I couldn't go inside. Over time, I learned the language and something about disability law and etiquette, and how the ILCs choose what projects to do with funding they receive from the federal government. It had come to seem like a good thing to me, to work for inclusion within the IL movement. I liked the ILC people, and they used some concepts I thought might help to protect people like me. I learned a lot out on their sidewalk over the next few months.

Sledd: The first place you went to — you were going to for help? And they didn't

understand?

Molloy: They didn't. Later, we realized that there were plenty of people disabled like me but they didn't get out a lot.

Sledd: At that point what did you learn about others with MCS?

Molloy: By 1982-1983 I'd learned there were other people whose lives had been changed abruptly in some of the ways in which mine had, and they were described as having "Environmental Illness." We called it "EI." I realized that we'd landed on the map when someone sent me a Sunday, October 30, 1983 L.A. Times article entitled "Victims of Rare Illness Allergic to Everything" by staff writer Lee Dye.

The article featured Phyllis Saifer, M.D. and patients in her Berkeley practice, and they were chemically sensitive. Clearly, I wasn't the only person with such an illness. Dozens of people in California alone had the same thing I did. A friend found a support group for me and I did get to go to two meetings, of the Environmental Illness Association, at the old ballroom at San Francisco's French Hospital. The support group included people living with variations of what had happened to me. They reported searching everywhere to find clothes that didn't make them sick, some way to wash them, the pain of bathing in tap water, difficulties finding food when they couldn't enter stores and the grocers refused to go outside.

These people had become helpless, frightened the same as I was. They too faced what amounted to daily assaults. They faced effective eviction, from wherever they'd found to stay, when their neighbor would spray for ants, someone would walk by smoking a cigarette, the landlord would dry clean the draperies. People were out on the street with what they could carry of their now contaminated possessions. Several people were sleeping in their vehicles. One was a businessman still struggling to work in the financial district. He couldn't change his clothes and he slept in his station wagon, out near the ocean. His career was crashing, and he'd never see insurance or Workers Comp because his illness was too mysterious to explain. There was a Palo Alto woman who'd become horribly sensitized, was living in the yard of her own house, and was losing her marriage. Her husband had simply had it. Even the people who were well to do couldn't buy their way out of this. There was no cure, no remedy, no help, and no recourse through the legal system. Clearly, what was happening to us was more than an illness.

It wasn't until later, when I was exposed to Humboldt Access Center, that I began to see civil rights as a concept that might help us defend ourselves, defend each other.

It was my nervous system that took the hit from environmental exposures. My gait was affected due to movement disorders (dystonia and clenching), triggered by specific, common chemical and electrical exposures. By a few years later, I needed a wheelchair to leave home. My speech was sometimes unintelligible. I pinned notes to my clothes in case I had to get help. Over time, it all resulted in my learning a little about mobility impairment, speech and learning disorders, lost focus and concentration, and resentment at being dependent.

Sledd: Right — so is that when you became more politically active?

Molloy: From that first ILC, Humboldt Access Project, that I visited through the window I got literature. The article I read over and over was “Guide to Section 504” by Peter Coppelman, from the Summer 1977 issue of “The Independent, A New Voice for People with Disabilities” published by Berkeley’s Center for Independent Living. (Yes, I still have a copy.) It said Section 504 of the U.S. Rehabilitation Act states that people with disabilities can have the expectation that public facilities and programs would be accessible. People with other disabilities had fought to achieve at least this expectation of access. But why did it seem as though we weren’t given even the chance to try? It felt like maybe we’d missed the last boat, and those on board weren’t looking back. Could we catch up, and be part of this effort?

What drove the Disability Rights movement was newfound self respect, fierce loyalty to people even less able to cope with the system, and a “no prisoners” attitude. EI people were way behind, still unsuccessful at bringing our access issues out into the open, but I could see no option, but for us to get to work and do it. I decided to volunteer for the board of Humboldt Access Project in Eureka. I envisioned an educational exchange where I’d learn the “nuts and bolts” of ILC management and the board and staff would learn about EI.

It was a near total failure. I got so sick at the board meetings that my contributions had no value. I’d sit outside on the porch, horribly ill, and one night I even blacked out. I got sicker and sicker trying to participate in the board meetings. I couldn’t hold my own with the other people. I couldn’t understand that my participation was useless to them and dangerous for me. Then the agency got a new director, Dr. Devva Kasnitz. She listened and she paid attention. I told her I thought there might be dozens of people in California alone with this kind of a disability, variations of Environmental Illness, and they were going completely unserved by the IL Centers or any other social service agencies. Devva told me to do an intake on everyone I could locate, and find out whether they were able to get benefits and whether they could go to public places.

Devva was sophisticated about the politics and finances of disability agencies, and I did what she said. Within six weeks I'd done intakes on well over 100 people in California who were not just ill, aggravated, or inconvenienced by Environmental Illness, but who were truly disabled. When I contacted one person with this illness, they'd know a couple of friends who had it too. Many had no phones, so I'd go try to find them. I met a lot of people. As a result of the brutal stigma of the times, there was developing an underground network of people with this condition. To some degree, it remains that way.

Devva had helped me begin the process of turning this sickness into a disability. I learned to push on behalf of people who were in worse shape than I was. Humboldt Access Project's facility was still deadly sickening. At one point, a new carpet was glued down and other people on the staff became sick too, even though they didn't identify as Environmentally Ill. We wondered whether people with other disabilities might be impacted by chemical exposures, but in different ways. We started keeping notes on avoidable errors in construction, remodeling, and maintenance that were jeopardizing people in the two-dozen ILCs up and down the state of California.

My employment at the Humboldt Access Project lasted only 5 months, but it gave me a start at the education I wanted. With backing from one of the community outreach programs at Humboldt State University, I started a newsletter for people with environmental illness called "The Reactor." I wanted it to be a primer on disability rights – a way we could "catch up" with people who had other disabilities and were accomplishing groundbreaking work. I liked the name "Reactor." Individuals who'd become so sensitized that they reacted to absolutely everything were referred to in those days as "universal reactors." Besides I enjoyed the dynamic, explosive sound of it.

That year, I got married and moved back to the S. F. Bay Area. My personal stamina had improved to the point where on occasion, I could have productive, if careful, contact with people. I found myself a new ILC home at San Francisco's Independent Living Resource Center. They helped organize outreach work to all the ILCs I could get to in California. I got sick if I stayed inside any of them for more than a couple minutes, but we all learned a lot.

I found in the course of interviewing people with EI around the state that they had no more idea what an ILC was than I'd had. However, they too were denied access to services, disability benefits, housing, and any protection under the law. It seemed like I needed a better technical background to work with the ILCs, and other social service agencies, and the EI people's families. An Urban Studies professor, Dr. Debra LeVeen at San Francisco State U., helped me design a Masters program, through the Department of Public Administration, through

which I could study Disability Policy. During the following years, I found my way to Washington, D. C. agencies and elsewhere for conferences and presentations, seeking allies with whom EI people could work.

In 1992, after five grueling years of graduate school, I moved to the high desert of Northeast Arizona. By that time, various support groups in the U.S. and abroad were publishing good newsletters, and the online discussion and advocacy groups had come into their own. It was no longer essential to work so hard on “The Reactor,” so I stepped down as editor in 1994. Once moved and adjusted, I represented the NE rural part of Arizona on the Statewide Independent Living Council for three and a half years. I still participate on the Housing Subcommittee of National Council on Independent Living, and on the Indoor Environmental Quality workgroup convened by the U.S. Access Board to chart our course. Great, challenging experiences, all over my head, all wear me out.

I’ve worked part-time, usually from home, for New Horizons Independent Living Center based in Prescott Valley, from its inception in 1994. I’m often asked why I’m so unafraid of losing my monthly Social Security Disability pittance, since I always report on the books the work for New Horizons or any other agencies that give me a chance. It isn’t that I’m brazen or have a “make my day” stance toward the Social Security Administration. It’s that although I’ve worked as much and as hard as I’m capable of with the ILCs for years, they’ve never paid me (or any other employees for that matter) enough to jeopardize my \$253 per month. Honest, we don’t go into this field for the big bucks, no matter how it looks from the outside.

Sledd: So you just mentioned some of your successful attempts and failures in advocating – are there any more that you didn’t already mention that stick out in your mind?

Molloy: I’ve participated in 25 years of Independent Living Center efforts that mostly didn’t work, and a few that turned out OK. There’s just enough positive reinforcement to keep me trying. There are some very dead ends to pursue and sometimes it seems like I’ve gone after most of them. Then I find out no, there are more. The concept of “Disability Rights” presents a moving target. There is no manual.

Sledd: Do you have any specific projects that you’ve organized yourself that you can talk about?

Molloy: I work hardest advocating for affordable accessible housing for people who have chemical and electrical sensitivities – particularly those who are also mobility impaired, a huge percentage of our population. There is substantial crossover among people with various orthopedic and brain injuries and those of us

with chemical and electrical sensitivities.

Sledd: So you worked on that a lot?

Molloy: Accessible housing is where I spend the most effort and work the hardest, and have had the most failures. A couple of projects have gone all right. I'd never have believed how slowly the progress has come or I'd never have tried.

Sledd: If everything worked out the way that you wanted it to, what would be your major overall accomplishment?

Molloy: Had you asked 20 years ago, I'd have said I wanted us integrated into the greater independent living and disability rights movement. At this point I have to modify that goal. I don't see that we'll survive if we strive to integrate at the expense of our safety. It is too threatening to be integrated with people who disrespect our requirements. Our quality of life issues are huge. We can be incapacitated by common everyday exposures. A seemingly small risk for our non-EI colleagues presents a huge assault, with disparate impact to us. We have to maintain the option of being separate, then as equal as possible.

Sledd: So you would say that that is a major goal for you?

Molloy: We need separate areas that are safely accessible to us in public facilities and in housing.

Sledd: Well I definitely think that you're right, as you can't get everybody to comply — it is almost impossible.

Molloy: I see us needing one good accessible room and path of travel — entryway, hallway, restroom, water fountain, public phone — per hospital, social services agency, educational facility, all those entities that now make life and death decisions about us regarding, for example, surgery or child custody, without the benefit of meeting us. For the people too sensitized to safely approach any facility whatsoever, or who can't ride in a car or a bus to get to a public facility, telephone or fragrance-free home appointments can be preferable to no appointment at all.

Essential for us would be hospitals, clinics, medical centers, a courtroom, and areas of refuge for use during emergencies. Anyone with the illness has had outdoor appointments with medical or social services staff during which a bus pulls up, vehicles idle, people walk by smoking or wearing fragrance, someone paints or applies cleaning and maintenance products — exposures that make us too sick for the appointment to have been worth the effort. Plus, in an outdoor

appointment, our current option, there's no confidentiality. Anybody hears about our personal medical issues, whether we qualify for food stamps, how our kids are behaving in school, or whatever. It's degrading. Think about having your next annual exam in the hospital parking lot.

Sledd: You wouldn't think it would be that hard to make the most basic resources accessible, especially given the prevalence. I've noticed when we've been researching that it's way more common than one might think.

Molloy: Might it not be construed as fraud, possibly criminal negligence, on the part of tax-supported entities to deny services to people on the basis of our having a certain disability, certain access requirements? To this day, even the ILCs themselves hold us to a higher standard than people with other disabilities. We have to be medical experts with attractive personalities to explain our functional impairment to ILC gatekeepers. This is not OK. We need the civil right to access, not individual favors.

Sledd: What has been the most rewarding part overall for you in your many years of advocating for MCS/ES??

Molloy: Advocates with other disabilities are now somewhat less likely to leave us out on the sidewalk and forget about us. That used to be the norm. That's what happened during the work on regulations to implement the A.D.A., and we still live with the repercussions. Those days are not over, but there are fewer of them.

Sledd: So you think being involved in everything, right in the middle of it, has made you appreciate the small progress more so than if you were not involved?

Molloy: We've been turned away at critical junctures, and it is likely to happen again. Some of the people in leadership positions have found it too hard to stand by us, fearing that we are too much a political liability. However, knowing some of the history helps me keep working on our projects without wanting to fall on my sword.

Sledd: So how do you now view the tactics that you have taken?

Molloy: We'd be in much better shape had we not stalled around waiting for approval and acceptance from other groups within the disability rights movement. I have to take responsibility for aspects of this error. My faith in the value of cross-disability work, and my hope that we'd become integrated, were substantially overblown. I am more useful and down to earth now. I chase fewer illusions but my aim is better.

Sledd: So what are you looking forward to doing in the future?

Molloy: We've just finished four safer-than-average wheelchair accessible rental houses in our neighborhood, for people with moderate chemical and electrical sensitivities. What an honor, to have gotten a chance to help get those up and running. Dream come true? There will be housing, plenty of housing for people with any and all disabilities, built and maintained using safe materials, all over the country.

Also, we might be able to create an ILC here in the mountains during the next couple years. We would start it as a satellite of an existing center, then later, stand on our own.

Sledd: That's a respectable goal. And, from what I have learned, I definitely agree that housing is a crucial issue.

Molloy: It's primary. As of now, we don't have a right to stay in even marginally accessible apartments, because convention and the law support neighbors who smoke, light incense, use dryer sheets, spray their rose bushes, idle their motors, or otherwise effectively drive us out.

We'll keep working toward accessible affordable safe housing for people with sensitivities. I wish housing were less toxic for everyone, disabled or not, but I don't waste time arguing about it any more. I'm busy.

Sledd: People shouldn't be living in cars or be homeless just because they're disabled.

Molloy: No one should have to live isolated in a car while exhausted, in excruciating pain, threatened by every whiff of smoke, every power line, every stranger.

Sledd: And you live in a home right now?

Molloy: I live in a small, sturdy, safe (for me) house in a neighborhood where most of the people have chemical and electrical sensitivities. Each of us had become dysfunctional in the various urban environments where we'd built our lives so we risked all and moved out to the high desert in Northeast Arizona. Some of us can visit each other, help with chores, and go outdoors almost whenever we want to without oxygen tanks. It's segregated, it's isolated — everything the rest of the independent living movement is fighting to get away from. But what other model exists that can work, at least during this generation,

while the larger culture hasn't yet begun to get used to us?

Research Team Note: Services and accommodations for persons with disabling environmental sensitivities remain uneven and problematic in most service venues.

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