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Services Requested and Received by Consumers with Chemical Sensitivities at the
Centers for Independent Living

Pamela Reed Gibson

Sahisna Suwal

Lauren G. Sledd

James Madison University

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Contact: Pam Gibson, Ph.D., James Madison University, Department of Psychology, MSC 7704, Harrisonburg, VA 22807. email: gibsonpr@jmu.edu

Abstract

This paper presents results from surveys of 41 persons with environmental sensitivities (ES) who requested help from Centers for Independent Living (CIL), primarily in the U.S. The most common requests were for help with safe housing, employment services, and application for SSDI. Consumers with ES encountered multiple problems not only with receiving services, but also simply with “getting in the door,” as many centers were not equipped to understand or serve persons with chemical or electromagnetic sensitivities. We present suggestions from respondents for improved access and service for this population and for training of CIL advocates.

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Environmental sensitivities (ES) involve experiencing adverse reactions to chemicals in ambient air and/or to electromagnetic fields that result in disabling symptoms. Reactions or symptoms can range from mild to life-threatening, can affect any bodily system, and vary from person to person. Gibson and Rice (2008) found the most problematic symptoms reported in 254 persons with self-reported chemical sensitivity (CS) to be tiredness/lethargy, difficulty concentrating, muscle aches, memory difficulties and long-term fatigue. Persons can react to a vast number of triggers, some of the most common being pesticides, formaldehyde, fresh paint, new carpets, diesel exhaust, perfumes and air fresheners (Gibson & Rice, 2009). Chemical sensitivity has been studied more extensively than electrical hypersensitivity (EHS) and seems to affect approximately 13% of the U.S. population (Caress & Steinemann, 2003). Persons report that their chemical sensitivities have been initiated by one large chemical exposure, ongoing lower level exposures (such as in a “sick building”), or by a combination of variables (Gibson, Cheavens, & Warren. 1996; Gibson & Lindberg, 2007).

Life impacts of environmental sensitivities often include difficulties with work, public access, social support, medical care, and housing (Gibson et al., 1996; Johnson, 2000; McCormick, 2000; Zwillinger, 1997). In fact, Gibson and Rice (2009) found that persons with multiple chemical sensitivities (MCS) reported more sickness-related dysfunction on the Sickness Impact Profile than most other populations with disabling chronic illness in the published literature.

Often people with environmental sensitivities do not know that their symptoms are caused by environmental exposures. Gibson et al. (1996) found that it took people with chemical sensitivities a mean of seven years to identify the cause of their symptoms. Once diagnosed, either by a physician or by oneself, a person may seek medical care, visiting a large number of physicians and spending a considerable

amount of money in an attempt to improve, only to find that many offered treatments are ineffective. Gibson, Elms, & Ruding (2003) researched 101 treatments (n = 917) with MCS and found that a chemical-free living space and chemical avoidance were the most highly rated therapies among participants.

Given that chemical avoidance is the most effective way of coping with chemical sensitivity, chemical free environments both at home and in the workplace are crucial to those with ES. Finding ways to accommodate this need should be a priority for anyone working with this population, including medical practitioners and advocates. Yet workplace accommodations and safe housing may be the two most difficult challenges for people with ES. Sadly, the ubiquity of chemical exposure and the prevailing lack of understanding and cooperation in the workplace coincide for some to result in unemployment and homelessness.

Over half of those who believed their chemical sensitivity to be caused by one large chemical exposure stated that it occurred in their workplace (Gibson et al., 1996). Fifty-two percent of Gibson & Lindberg's (2007) persons with ES (n = 100) were either working without accommodations or had been driven out of their work due to supervisors' failure to remove workplace barriers. Employers and co-workers did not take their condition seriously and had little knowledge regarding chemical or electromagnetic sensitivities. The lack of workplace education about chemical sensitivities led to harassment and negative attitudes towards this specific population. Unemployment was usually accompanied by financial, social, and psychological losses. Gibson & Lindberg (2007) suggest that providing appropriate work accommodations could improve workplace retention and quality of life for people with disabling sensitivities.

Some persons with MCS have attempted to acquire services from Vocational Rehabilitation Services (VRS). Gibson (2006) found that only 53 of 100 respondents in an MCS employment study were even familiar with VRS and 25 of those had applied to VRS for help. Nine of the twelve persons who physically went to the centers got some

help, but only five received any help with employment. Six encountered scented advocates/staff. Nonetheless customers did receive items such as appropriately altered home computers (n = 3), home office equipment (n = 3), air filters (n = 2), and other items such as work clothing or dietary supplements. Problematic for applicants was the fact that VR required psychological evaluations for eight customers and evaluators not only do not generally make safe accommodations, but also are often uneducated regarding sensitivities and thus engender psychological attributions.

Centers for Independent Living (CILs) are 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 (UK), Australia, Canada, and Japan. Mike Oliver (1990) praised the Independent Living Movement for being a new social movement aiming to solve “problems defined by disabled people themselves” (p. 120).

Gibson (2006) inquired about services from CILs and found that the 100 respondents were even less familiar with the CILs than the VRs. Only 33 knew of the Centers, 15 asked for help, and 7 received any services. Though a few customers received exemplary services, many were turned away, seen as psychosomatic, or given only minimal help. Twelve customers found their way to a center, but only 3 reported that the center was accessible and 6 that the staff were familiar with MCS. Seven people reported that their CIL provided the services they requested and 4 believed the response they got was “reasonable” (Gibson, 2006). No one received viable help with housing. Requests for oxygen and transport assistance with a fragrance-free driver were refused, and one person was told that she had a mental illness.

It is important for service providers to know the significance of environmental sensitivities in order to help and to accommodate persons who experience them. There are many facilities across the United States and Canada that help those with disabilities, but help is often unavailable for unfamiliar disabilities like chemical and electrical sensitivity. We undertook this project in order to look further at help received from CILs

for customers with environmental sensitivities and to better understand the services and accommodations that respondents would like to see provided in these agencies.

Method

Participants

Participants were 41 persons who reported asking a Center for Independent Living for help with their chemical sensitivity. Forty participants were female and 39 Caucasian. Ages ranged from 30 to 86 with a mean of 52. Respondents' education included some high school (n = 1), high school degrees (n = 5), associate's degrees (n=5), technical certificates (n = 5), bachelor's degrees (n = 20), master's degrees (n=3), and doctoral degrees (n = 2). Thirty-five of the 41 participants were unemployed, and all 35 noted that having MCS was a factor in their unemployment. Fourteen persons had applied for worker's compensation and 32 for Social Security Disability Insurance (SSDI).

Procedure

Participants were gathered from January 2008 to April 2008 through placing notices in newsletters and on our MCS research team website requesting "persons with chemical sensitivity that have requested help from a Center for Independent Living (CIL)." Those who were eligible were invited to request either a hard copy of the survey or to anonymously complete the survey on WebSurveyor. Hard copy surveys were separated from any identifying information and stored separately.

Respondents first responded to demographic questions. We then asked participants to rate their level of severity of their sensitivities on an instrument published in 1987 in the *Human Ecologist* ("EI disability classification," 1987). For details of the rating scale, see Table 1. Six rated their level of severity as being moderate, 24 as severe, and 10 as totally disabled.

Other closed and open-ended questions asked whether respondents had ever applied for Worker's Compensation or Social Security Disability Insurance, whether they

found the CILs to be accessible to them, whether their advocate was scented, whether they had asked for and/or received any accommodations for the initial visit, and what services were requested and/or provided. In addition respondents were asked to describe the best aid they could receive for their sensitivities, and to suggest content for inclusion in an educational program designed for advocates employed by the CILs.

Results

Of the 68 participants that completed this survey, 41 had applied to Centers for Independent Living for services (38 in the U.S., 2 in Canada, and 1 in Australia). Only 17 said that they had received any services. When asked if CILs were accessible or safe to them, 25 of the 41 applicants said “no.”

Fifteen respondents believed the staff member who worked with them was “not at all familiar with MCS,” 20 said that their advocate was only “somewhat familiar,” and 4 said “very familiar.” Thirteen customers faced scented advocates, making the meeting problematic for their health. Out of the 19 participants who requested accommodations for the visit to their CILs, 11 said their requests were not met.

A respondent who *was* accommodated for the initial visit described,

The counselor would not wear fragrant products on the days she met me. She would wear clothes not freshly laundered. We met in a concrete walled room or in an older office. I'm not sure if they did use safe cleaners.

Yet most were not accommodated. One respondent said, “They didn't accommodate me, they made fun of my disability saying it was a mental illness.” Another was told that there were many disabilities and that they were “only focusing on a few.” Yet another, who also reported poor treatment said,

I asked for disability accommodations and got made fun of because it was ‘just an allergy’ and why didn't I take a pill? I asked for scent and smoke free area plus scent/smoke residue-free worker. Didn't get those.

Table 2 lists all requested accommodations for initial visits. Table 3 lists accommodations actually provided for on initial visits.

Services requested from CILs by participants included help finding safe housing (n = 15), support groups (n = 6), employment services (n = 6), assistance in filing for SSDI (n = 6), and help filing for SSDI or SSI (n = 6). Table 4 lists all services requested from the CILs.

Nine respondents stated that they did not receive the services they requested from the CILs. Two participants received vague information through email. Two received some form of transportation, one was welcomed to a support group, and one received fair housing information. Table 5 lists all services provided to respondents as described in an open-ended question.

To be certain that we did not miss services rendered we also asked about services received in a closed-ended checklist. Table 6 lists services received as recorded on the checklist.

When asked if they thought that their treatment from the CILs was reasonable given their disability, 14 said “yes” and 25 said “no.” One respondent reported, “They tried, but they had not been educated, and did not have procedures in place to allow them to help me, basically.” Another was critical as well,

My needs ignored. They told me than unless I was in a wheel chair (mobility impaired) or blind (sight impaired) they would not do much to help me (think out of date housing list). They knew nothing about MCS, and did not want me or my doctors to educate CIL. Primarily they wanted to work with military men in wheelchairs.

Respondents felt generally that the CILs could and should better respond to their disabilities. As one participant put it:

I feel the CIL should not only have appropriately cleaned-up personnel doing home visits, but should become knowledgeable about MCS/EMF housing issues, and should actively advocate for accessible housing in the region. While the local CIL includes MCS/EMF issues on a superficial token basis, there is no one there who is appropriately trained to advocate for clients with these diseases.

Another agreed, "Given that MCS is a fairly common disability, and a disability with little institutional support, I would hope that the staff would be better informed about MCS and MCS resources."

When asked if there was anything else about their experience that they would like us to know, respondents expressed disappointment and anger as in the following three comments:

The persons behind the desk reacted with indifference to my request. Their attitude could not have been more indifferent, dismissive, 'not our problem' clearly was the attitude: 'get lost.'

I was disappointed in that their personal assistants did not have training in working with the clinically sensitive.

I usually have been more knowledgeable about MCS and available resources than ILC staff. I have never had the impression that anyone there was going to research something for me, provide financial assistance, assess my situation, provide physical labor, or think through a problem that was novel to them (the counselor I saw was available for emotional, not practical, problems.)

Participants listed the most beneficial help they could receive from the CILs in coping with chemical sensitivity. Seventeen participants believed that help with safe housing would be the most beneficial. Six wanted group and counseling activities to be

available. Other responses included work accommodations, trained assistance with chores and shopping, acknowledgement that MCS exists, fragrance free settings, legislative actions, provision of information on MCS, financial and emotional support, and medical care. Table 7 lists all responses.

When asked for suggested content for an educational program regarding sensitivities for CILs, participants suggested the following: Seven participants wanted to include information on managing and accommodating life with MCS, including physical, emotional, and mental support. Six wanted to educate the public regarding symptoms and prevalence of MCS. Five wanted the staff to be educated about MCS and toxicology, and for advocates to adjust their thinking about MCS. Other respondents wanted advocates to treat the consumers with respect, be knowledgeable of alternative/safe products, help make public facilities chemical-free, and provide books on MCS from those who actually have it. Table 8 lists all content suggested by respondents. One respondent addressed the issue of being asked to help train CIL advocates despite feeling too ill to do so:

I love what they have done for me before. In fact I don't know how I would have made it without them. Somehow it appears that the CIL has changed policy recently and they don't seem to offer what I need. I have been asked to train their staff on MCS safety, which I am willing to do, but I am too ill to do that . . . leading me to question how professional it is to request that I do work for them when I need help as a client. On the other hand, if I don't train them, who will?

Discussion

Although there were some helpful exceptions, for the most part, results were similar to Gibson's 2006 study in that many persons with ES received poor treatment from Centers for Independent Living. The majority of respondents found CILs to be ill equipped to accommodate their needs or to provide them with services. In addition, persons reported feeling insulted and humiliated by the exclusion and by the

suggestion that their sensitivities were mental illnesses. The request for accommodations began with the initial meeting for 19 persons, the most common request being to meet with a scent and smoke-free advocate. For 10 people, even this was not granted. The majority of customers requesting services found the agencies to be inaccessible.

The most common help requested parallels the need for a safe CIL space in that 15 persons needed help with safe housing. Of these 15 customers, one received a referral to Fair Housing, one received help securing a HUD housing voucher, and one was given an outdated list of Section 8 housing. This is particularly problematic given that 17 customers listed safe housing as the most beneficial type of help that they could receive to cope with their sensitivities.

The disability movement has been accused of addressing only a limited range of disabled constituents even with ES notwithstanding; Phil Lee (2002) alleges that many groups such as older people, severely disabled people, and people with learning disabilities are left out. In addition, certain impairments, such as mobility may have enjoyed more focus than other conditions (Marks, 1999). Chemical and electrical barriers are poorly understood and have not been integrated into a general understanding of disability (Gibson, 2009). Advocates may be unfamiliar with chemical and electrical sensitivities, and may view these invisible conditions as low priorities competing for scarce resources (e.g., as with the participant who was told that there were so many disabilities and they were only focusing on “a few”), or even as a non-legitimate category of disability (e.g., the woman who was told that the CIL did not deal with people who were “mentally ill”).

Though CILs were created to be orchestrated by and for persons with disabilities, advocates' understanding of disability reflects that of capitalist industrial society where chemicals are not generally seen as agents of disability or injury. Disability status in current U.S. culture is mediated by the medical profession, which has not integrated

environmental sensitivity as a category of disability. Consequently, people disabled by chemicals are not recognized as disabled even in the eyes of other disabled people who work as advocates at CILs. Though CILs were created by and are staffed by persons with disabilities, those with environmental sensitivities are not included as persons with disabilities in the mental schemas of those who organize and offer these services.

Doiron (2007) has discussed the general failure of service agencies to address the problem of environmental sensitivities:

Because of social service agencies' lack of knowledge about environmental health issues and toxic environments, people with ES/MCS are not always able to obtain services from them. This lack is even more imperative given the current trends of recognizing environmental issues. It is important to plan ways to educate the leadership in social service agencies so the staff can become informed of such less recognized health issues such as ES/MCS. (p. 141)

Doiron indicts the three paradigms of individualism, neo-liberalism and the biomedical model in providing the context in which denying services to persons with chemical sensitivities is commonplace and acceptable.

In addition, the patriarchal nature of our health care system may disadvantage women with poorly understood and/or invisible conditions. The preponderance of women with environmental sensitivities makes them vulnerable to any gender bias in systems' responses to this population. For example, there is considerable suggestion that the rehabilitation field favors men. Bounds, Schopp, Johnstone, Unger, & Goldman (2003) cite a number of studies that found women to have poorer vocational outcomes than men. In their own study, even with similar demographics and severity, women with TBI were given less Maintenance service (financial support for necessities while enrolled in DVR programs). Only one woman of 23 was successfully employed at closure. A higher portion of men became employed and women's cases were more likely to be

closed before services were even begun (VR said that the cases were terminated per client request). Warren, Cavanaugh, & Giesen (2004) cite a number of studies that found women and older persons more likely to have homemaker closure, which, although not seen as optimal in that it is not competitive employment in an integrative setting, is still allowed as a noncompetitive outcome by the Rehabilitation Act. In their own study of blind VR clients, gender was a significant predictor of VR outcome, women being more likely to be closed as homemakers.

Bounds et al. (2003) think that stereotypes may play a role in how clients are perceived and/or view themselves in that men are expected to be earners, while women may have options to stay home. In the Bounds et al. study VR counselors were the informants and the authors acknowledge that consumers may have reported differently (i.e., that cases were closed per clients' request). Crisp (2002) found in an Australian sample, that when interviewed about their situation, the stories of 35 persons with a variety of disabilities embodied dominant gender stereotypes. Crisp urged rehab professionals to examine their own biases and realize that clients' values and strivings are culturally situated.

There is no reason to believe that CILs will operate in any more enlightened fashion than the VRs. In fact, Gibson's (2006) respondents were treated considerably better by VRs than by CILs. Though it may seem counterintuitive given that CILs are situated as being run "by and for" persons with disabilities, persons with ES are not currently constructed by many service providers/advocates as persons with disabilities. Persons with ES may require more flexible and previously undelivered services (e.g., fragrance-free advocates), than better-understood disabilities, thus challenging existing protocols. In addition, the medical notion of disability may operate, even in the minds of advocates with disabilities, for persons with delegitimized conditions. Given the prevalent lack of understanding regarding toxics and health, and that conditions such as ES challenge common beliefs about the safety of common chemicals, there may be a tendency to categorize these conditions as psychosomatic. This tendency may

remove the motivation for advocates and others who interact with this population to attempt to grasp the intricacies of how sensitivities develop and operate in people's lives.

In addition, the gender distribution of chemical sensitivity (primarily women) may be influential in engendering some of the dismissive attitudes and behaviors toward this population. Given that the CIL applicants in the present study were almost all women, many gender biases could have been operating. The issue of medical uncertainty was very likely an issue for many of the participants given the lack of understanding of toxicants in general and of environmentally related injuries in specific. Women with environmental sensitivities thus represent a group poorly understood for at least two reasons, making them vulnerable to biased and ineffective interventions.

Ahlgren and Hammarström (2000) found that men were more likely to be able to demand and get services not usually rendered by VR (such as university study), but that these services were denied to women. While men *demanded* help; women instead *hoped* for and *asked* for it. When customers disagreed with VR's offers, men were more often heard and supported (most doctors were men). Women reported that decisions were instead made *for* them. Women finally stopped "hoping" and left VR, looking for other solutions. The authors believe that the medical uncertainty of unspecified/ambiguous diagnosis for women targeted the women as "difficult clients" and fostered distrust in the relationships which then "followed them into the vocational rehabilitation" (p. 93). Ahlgren and Hammarström conclude, "When doctors as well as social security officers and clients act the way they usually do, men are favored in the system" (p. 94).

The results of the present study raise questions about how persons with environmental sensitivities are to be included in disability services when agencies have limited resources and little understanding of the problem, industrial culture at large has not conceptualized illness from technology as a crisis worthy of attention, and

women have not been treated equally in regard to work and rehabilitation. In addition, how will agencies with varying means and staff resources include an emerging disability that requires new knowledge and special unique physical accommodations in order for persons to access services? Currently it appears that service acquisition for environmental sensitivities at these agencies relies on the applicant having the luck of finding that somewhat rare advocate who understands these issues.

Participants in this study have offered suggestions for program content that could be used to educate advocates at CILs regarding environmental sensitivities. Most suggestions revolve around familiarizing advocates with how to manage and accommodate sensitivities on physical, emotional, and mental levels. A program should address symptoms, prevalence, resources, and the need to treat persons with respect. That ES is a substantive disability that yet varies from person to person and for which access is very difficult should also be included. Although a booklet published by ILRU, the educational arm of the independent living movement, was sent to all CILs in 2002 addressing these issues (Gibson, 2002), it is questionable whether advocates have read or utilized the booklet or its advice. Further efforts should be made to ready CIL advocates for consumers with environmental sensitivities. Our recommendation is that each center encourages one advocate to receive training in and to specialize in this disability and create one accessible physical area where customers with ES can meet this advocate. This would begin the process of inclusion for this population within an agency developed specifically to serve persons with disabilities. Agencies must keep services congruent with the public need and industrial culture is creating the need to understand and respond to environmentally induced impairment.

This study has several limitations, including a relatively small number of participants, unknown external validity, and retrospective survey response. Further study is needed to determine if these results are indicative of the larger picture

Services requested

regarding customers with sensitivities and their treatment by CILs.

References

- Ahlgren, C., & Hammarström, A. (2000). Back to work? Gendered experiences of rehabilitation. *Scandinavian Journal of Public Health, 28*, 88-94.
- Bounds, T.A., Schopp, L., Johnstone, B., Unger, C., & Goldman, H. (2003). Gender differences in a sample of vocational rehabilitation clients with TBI. *NeuroRehabilitation, 18*, 189-196.
- Caress, S., & Steinemann, A. (2003). A review of a two-phase population study of multiple chemical sensitivities. *Environmental Health Perspectives, 111*, 1490-1497.
- Crisp, R. (2002). Gender differences in the perceptions of psychosocial experiences reported by persons with disabilities. *Australian Occupational Therapy Journal, 49*, 188-199.
- Doiron, N. (2007). People with environmental sensitivities: Life, identity, and services. Doctoral Thesis in Social Work, University of Toronto.
- E.I. Disability Classification. (1987). *The Human Ecologist, 35*, 13.
- Gibson, P.R. (2009). Chemical and electromagnetic exposures as disability barriers: Environmental sensitivity. *Disability & Society, 24*(2), 187-199.
- Gibson, P.R. (2006). *Multiple chemical sensitivity: A survival guide, 2nd Edition*. Churchville, VA: Earthrive Books.
- Gibson, P.R. (2002). *Understanding and accommodating multiple chemical sensitivity in independent living*. A 57-page guide published by IL NET, a cooperative National Training and Technical Assistance Project of the Independent Living Research Utilization (ILRU) Program and the National Council on Independent Living. Available at <http://www.ilru.org>

- Gibson, P.R., Cheavens, J., & Warren, M. L. (1996). Multiple chemical sensitivity/environmental illness and life disruption. *Women & Therapy, 19*, 63-79
- Gibson, P.R., Elms, A.N.M., & Ruding, L. A. (2003). Perceived treatment efficacy for conventional and alternative therapies reported by persons with multiple chemical sensitivity. *Environmental Health Perspectives, 111*, 1498-1504.
- Gibson, P.R. & Lindberg, A. (2007). Work accommodation for people with multiple chemical sensitivity. *Disability & Society, 22(7)*, in press.
- Gibson, P.R. & Rice, V.M. (2009). Sickness related dysfunction in persons with self-reported multiple chemical sensitivity at four levels of severity. *Journal of Clinical Nursing, 18*, 72-81.
- Johnson, A. (2000). *Casualties of progress: Personal histories from the chemically sensitive*. Brunswick, ME: MCS Information Exchange.
- Lee, P. (2002). Shooting for the moon. In C. Barnes, M. Oliver, & Barton (Eds.). *Disability studies today* (pp. 139-161). Malden, MA: Blackwell
- Marks, D. (1999). *Disability: Controversial debates and psychosocial perspectives*. NY: Routledge.
- McCormick, G. (2001). *Living with multiple chemical sensitivity; Narratives of coping*. Jefferson, NC: McFarland.
- Oliver, M. (1990). *The politics of disablement*. NY: St. Martin's Press.
- Warren, P.R., Cavanaugh, B.S., & Giesen, J.M. (2004). *Journal of Rehabilitation, 70(4)*, 16-21.
- Zwillinger, R. (1997). *The Dispossessed: Living With Multiple Chemical Sensitivities*. Paulden, AZ: The Dispossessed Project.

Table 1

Categorical Guidelines for Levels of Disability

Level	Description
Mild	Able to work. Frequently has many symptoms, some of vague nature. May find petrochemicals and other environmental exposure such as auto exhaust, cigarette smoke and cleaning materials to be unpleasant or produce uncomfortable feelings, but able to work effectively.
Moderate	Able to work at home or with controlled environment at work place. May have to use gas mask or charcoal mask and air purifier filter system. Exposure to inciting agents causes acute symptoms, which may alter functional capacity (severe headache, muscle pain, poor concentration, memory loss, etc.). May have to change job or work conditions if environmental pollution is severe enough.
Severe	Unable to work effectively, even with environmental control, using avoidance, masks or filters. On some days, may be able to work 30 to 60 minute shifts several times a day if in a very controlled environment. Reacts to chemicals such as insecticide, phenols, chlorine, formaldehyde, perfume, petrochemicals, etc. Has severe mental and physical symptoms which may or may not clear. Public exposures such as church, post office, movie, or shopping are not tolerated. Visitors to home much clean up significantly. Can usually care for self in a home situation. May be able to drive if automobile made free of inciting agents, sealed and has charcoal air filters. Has difficulty with other family members of guests in home who bring in aggravating exposures on clothing, printed material, hair, etc. Adversely reacts to many medications. May have to move if existing home has uncontrollable outdoor pollution, is new and has not outgassed, or has other significant problems of mold, flooring, or other incitants. Requires a clean room, carpet-free, cleared of inciting agents, special heating and air filtering. Must wear natural fiber clothing specially laundered.
Disabled	Requires assistance to function in rigidly controlled home environment. Reactive symptoms have spread to virtually all environmental agents including chemicals, foods, pollens and molds. Has mental and physical symptoms that are incapacitating, although frequently not structurally described. Total and very restrictive environmental control required in home and vehicle. Cannot tolerate family or help who have outside exposures with even small contamination of clothing or hair with odors. Visitors usually are too toxic to be tolerated indoors. Usually requires several moves to different areas of the country to find tolerable climate, which is also chemical free. May require unusual and extensive measures to make a tolerable clean refuge area to sleep in. Has difficulties with virtually everything in environment (universal reactor).

Note. From 'E.I. Disability Classification', 1987, *The Human Ecologist*, No. 35, P. 13. Material relating to food sensitivities was deleted.

Table 2

Initial Requests for Accommodations by Chemically Sensitive Customers

Service requested	# requested	% requested
Scent/smoke free worker	10	24.3%
To meet outdoors	5	12.2%
Requested scent/smoke free area	4	9.8%
Telephoned the CIL	2	4.9%
To come to individual's home	2	4.9%
"Disability accommodations"	1	2.4%
Asked about pest control, cleaning, etc.	1	2.4%
To be contacted prior to visit to discuss accommodations	1	2.4%

Table 3

Initial Accommodations Provided to 41 Chemically Sensitive Customers

Service provided	# provided	% provided
Met outdoors	5	12.2%
Met with unscented worker	3	7.3%
Talked to individual by phone	2	4.9%
Moved individual to another room	1	2.4%
Visited person in their own home	1	2.4%
Attempted to be unscented	1	2.4%
Put individual on a list	1	2.4%

Table 4

Types of Help Requested by 41 Customers with Chemical Sensitivity

Help requested	# requested	% requested
Safe housing	15	36.6%
Employment services	6	14.6%
Help filing for SSD or SSI	6	14.6%
Personal care assistant	3	7.3%
Accommodations from landlord or condo	3	7.3%
Support group	3	7.3%
Section 8 housing	2	4.9%
Work accommodations	2	4.9%
Safe place to wash clothes	2	4.9%
Information/resources	2	4.9%
Installation of air conditioner	2	4.9%
Transportation	2	4.9%
Safe computer	2	4.9%
Legal referrals	2	4.9%
Someone to screen housing	1	2.4%
Help with community accommodation	1	2.4%
Finding an IHSS provider	1	2.4%
Library remodel	1	2.4%
Respect	1	2.4%
Assistance with finding medical care	1	2.4%
Loan referrals	1	2.4%
Housekeeping	1	2.4%
Peer counseling training	1	2.4%

Table 5

Types of Help Provided to 41 Customers with Chemical Sensitivity

Help provided	# provided	% provided
No help	9	21.9%
Information by e-mail	2	4.9%
Tried to set up an IHSS provider for an MCS support group	1	2.4%
Helpful information about disability job services and social security	1	2.4%
Installed AC unit	1	2.4%
Welcomed individual to a support group	1	2.4%
Personal care assistance services (but scented)	1	2.4%
Transportation to medical appointments	1	2.4%
Incontinence washable pads	1	2.4%
Mobility aids	1	2.4%
Filing complaints with equal rights	1	2.4%
Referral to fair housing	1	2.4%
Referral to employment attorney	1	2.4%
Referral to EHN of California	1	2.4%
Help securing HUD housing voucher, talk-therapy, counseling, advocacy, and purchased air purifier	1	2.4%
Staff member worked with me on a town access committee	1	2.4%
Helped get hospital accommodations for surgery	1	2.4%
Got outdated list of Section 8 housing	1	2.4%
A few months of phone counseling	1	2.4%
Internet search suggested	1	2.4%
Told they don't help people with mental illness	1	2.4%

Table 6

Responses to Checklist of Types of Help Received by 41 Customers with Chemical Sensitivity

Service received	# received	% received
Help finding counseling and/or a support group	6	14.6%
Help making their home safer	5	12.2%
Help with transportation to community/medical services	3	7.3%
Help applying for disability benefits	2	4.9%
Help financing medical care	1	2.4%
Help finding low-income housing	1	2.4%
Help setting up self-employment	0	0%
Help applying for worker's compensation	0	0%

Table 7

The Most Needed Types of Help Listed by 41 Customers with Chemical Sensitivity

Most beneficial help needed	# suggested	% suggested
Safe housing	17	41.5%
Counseling/support activities and meetings	6	14.6%
Trained assistance with cooking, cleaning, laundry, grocery, etc.	4	9.8%
Work accommodations	4	9.8%
Recognition that MCS exists	4	9.8%
Advocacy and case management services	4	9.8%
Legislative actions	3	7.3%
Medical care (safe and affordable)	3	7.3%
Fragrance free community access	3	7.3%
Outlawing toxic induced products	2	4.9%
Provision of information regarding sensitivities	2	4.9%
Transportation	1	2.4%
Access to safe food and water	1	2.4%
Opportunities to work at home	1	2.4%
Money and emotional support	1	2.4%
Referral to disability rights attorney	1	2.4%
Organic cotton mattress	1	2.4%
Funds for supplements, detox treatment, filters	1	2.4%
Funds for safe equipment (computers, printers, etc)	1	2.4%
Replace air filters	1	2.4%
Dietary/herbal education for symptom control	1	2.4%

Table 8

The Most Important Content that 41 Chemically Sensitive Customers Would Like to See Included in an Educational Program Targeted to CIL Advocates

Suggested content for education programs	# suggested	% suggested
Information re: managing and accommodating life with MCS	7	17.1%
Public education about symptoms and prevalence of MCS	6	14.6%
Staff education/class in toxicology	5	12.2%
Adjustment in thinking	5	12.2%
Knowledge about safe products	4	9.8%
Use of books on MCS from those who have it	2	4.9%
The need for a public facility to be chemical-free	2	4.9%
To ask the individual with MCS directly what s/he needs	2	4.9%
Background biological elements of MCS	2	4.9%
The need for advocacy	2	4.9%
How to improving the home/find housing	2	4.9%
Finding and getting accommodated at Jobs	1	2.4%
Community service	1	2.4%
To not use the term MCS	1	2.4%
To be supportive and encouraging	1	2.4%
Reading of Pam Gibson's book on MCS	1	2.4%
Make the staff wear chemical free clothing	1	2.4%
Counseling	1	2.4%
Be willing to work by phone	1	2.4%
Understand the brain involvement with MCS	1	2.4%
Medical profession needs to think outside their box	1	2.4%
Know the limiting aspects of welfare and disability	1	2.4%