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

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Abstract

Here we present results from 41 persons with environmental sensitivities (ES) who requested help from Centers for Independent Living (CIL). 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 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 negative 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, 2008). 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 (2008) found that persons with 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 visit a large number of physicians seeking care and spending a considerable amount of money, only to find that many offered treatments are ineffective. Gibson, Elms, & Ruding (2003) researched 101 treatments for 917 persons 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 prevalent lack of understanding and cooperation in the workplace coincide for some to result in unemployment and homelessness.

Gibson et al. (1996) found that over half of those who believed their chemical sensitivity to be caused by one large chemical exposure stated that it occurred in their workplace. Fifty-two percent of Gibson & Lindberg's (2007) 100 persons with ES 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.

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) asked persons with environmental sensitivities about services from CILs and found that of 100 respondents only 33 knew of the centers, 15 asked for help, and 7 received any services. Though a few persons received exemplary services, many were turned away, seen as psychosomatic, or given only minimal help. Twelve persons 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 to know the significance of environmental sensitivities in order to help and to accommodate persons who experience it. 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. Further research on help received from CILs will help us to better understand the services and accommodations that should be provided to those with these sensitivities.

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). Six rated their level of severity as being moderate, 24 as severe, and 10 as totally disabled. 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.

Measures

Respondents were asked to respond to demographic questions, including the level of severity of their sensitivities using a four-anchor scale including mild, moderate, severe, and totally disabled. The criteria used to assess each severity level are shown in table 1. 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 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. Only 17 said that they had received any services. When asked if CILs were accessible or safe to them, 25 participants 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 persons 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 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. In Table 3 we list the accommodations actually provided for initial visits.

Services requested from CILs by participants included help finding safe housing (n = 11), support groups (n = 6), work accommodations (n = 4), assistance in filing for SSDI (n = 4), and help finding safer home appliances, including installation of a safe air conditioning system and a washing machine (n = 2). 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 that 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 invisible 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, persons 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. Fifteen participants believed that help with safe housing would be the most beneficial. Six wanted group and counseling activities to be available. Other responses included 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, persons in this study 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 persons 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 people, 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 seventeen persons listed safe housing as the most beneficial type of help that they could receive to cope with their sensitivities.

Though CILs were created to be orchestrated by and for persons with disabilities, advocates' understanding of disabilities 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.

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)”

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, 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 specialize in this disability and create one accessible physical area where persons 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.

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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.

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Table 2

First Meeting Accommodations Requested from CILs by 41 Persons with Chemical Sensitivity

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

First Meeting Accommodations Provided by CILs to 41 Persons with Chemical Sensitivity

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 from CILs by 41 Persons 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 by CILs to

help provided	# provided	% provided
No help	9	21.9%
Information by e-mail	2	4.9%
Told they don't help people with mental illness	1	2.4%
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%
Internet search suggested	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%

Table 6

Responses to Checklist of Types of Help Received from CILs by 41 Persons 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 serv	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 Persons 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 shopping, 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 of the illness	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 the 41 Persons with Chemical Sensitivity Would Like to See Included in an Educational Program Targeted to CIL Advocates

Important content for education programs	# suggested	% suggested
Managing and accommodating life with MCS	7	17.1%
Educate the public about symptoms and prevalence of	6	14.6%
Staff needs education/class in toxicology	5	12.2%
Adjustment in thinking	5	12.2%
Knowledge about which products are safe/providing alternatives	4	9.8%
Treat the consumers with respect	3	7.3%
MCS is real and varied	3	7.3%
Medical management	2	4.9%
Books on MCS from those who have it	2	4.9%
Public facility chemical-free	2	4.9%
Ask the individual with MCS directly what they need	2	4.9%
Background biological elements of MCS	2	4.9%
Advocacy	2	4.9%
Improving home/housing	2	4.9%
Jobs	1	2.4%
Community service	1	2.4%
To not use the term MCS	1	2.4%
Being 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%
Willing to work by phone	1	2.4%
Brain involvement and difficulties	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%