

Multiple Chemical Sensitivities, Accommodating Consumers and Staff with MCS
August 10, 2011

>> KATHY HATCH: It's about 4 minutes after the hour. It looks like we have a really nice crowd today. This is great. I'm Kathy Hatch, with APRIL. I want to welcome everybody today.

Today's call is hosted by APRIL, that's Association of Programs for Rural Independent Living sponsored by the IL Net. We're happy you could join us. We're looking forward to a lively discussion,

We have an hour and a half, so we'll start with an introduction of the presenters and they will talk about different areas that concern multiple chemical sensitivities, accommodating consumers and staff with MCS.

We would like to change the format a little bit and keep this as conversational as possible. The presenters will start and we will have questions and answers following each. If you have a burning question during the presentation, go ahead and feel free to ask that -- yes?

>> Caller: This is Sherri, Sherri Meyers.

>> Great, thanks for joining us. If you would mute your phone, using star 6. Thank you.

So just a little housekeeping before we start. First, the APRIL website has several print documents and links that are up there that folks can use to follow along in some cases and the rest are resources, things that you can read after today's event. The website is .

We have a new offering today, we are providing CART captioning services that can be accessed via our website. Go to the APRIL website again, and you'll see today's IL conversation on the front page. There's a yellow section, highlighted in yellow, that is a link to the CART. Click on that link and you will go directly to CART on your computer.

Also, you can send us questions via the chat section and I will see them on my screen. Please put your phones on the mute using *6. Because this is a bridge line, it's really sensitive, it will even pick up paper noises. Cell phones and speakers cause a lot of distortion on the line as well. If you are using either, I would appreciate

it if you would try to get to a land line and re-call in and make sure your phone is on mute.

Once we go to the question-answer part, I will try to moderate and repeat questions. If you could be courteous and try not to talk over each other, that would be great. Thank you so much.

Okay, I would like to welcome our presenters today. I'll begin by telling about each one. First, Ann McCampbell, is a physician living in Santa Fe. She is chair of the Multiple Chemical Sensitivities, MCS, Task Force of New Mexico and a founding board member of the Chemical Sensitivity Foundation.

She has lived with and helped others with chemical sensitivities for the past 20 years.

In 2005, she worked with the federal access board to create the Indoor Environmental Quality Report that makes recommendations for constructing and maintaining public buildings to be more accessible for people with chemical and electromagnetic sensitivities.

Dr. McCampbell is the author of a booklet, Multiple Chemical Sensitivity, and works as an environmental health consultant.

Someone is not on mute. I'm not sure who that is. So star 6, if you can. You'll still be able to hear.

Our second person is Mary Lamielle. Mary is a nationally recognized educator, and an advocate of people with chemical sensitivities.

She is executive director of the National Center on Environmental Health Strategies, and for a number of years she's played a key role in policy development on chemical sensitivities and environmental health issues at the federal, state and local levels.

Mary has served on numerous committees and worked on projects with many federal agencies including access board, HUD, the National Council On Disability, the EPA, Centers for Disease Control and National Institute of Environmental Health Sciences.

Mary's received a number of awards, most recently the 2010 U.S. EPA Region 2 Environmental Quality Award and the 2011 New Jersey Governor's Jefferson Award for Public Service. She has been a NCIL member

for about a decade, during which time she's served on the housing subcommittee, until September 29, 2010.

The third speaker is Darrell Jones. Darrell is a program coordinator for the IL net at Independent Living Research Utilization, that's ILRU, and works with a large multidisciplinary training team in the development and delivery of training and technical assistance, centers for independent living and statewide independent living councils.

She was the founding executive director of the Rochester, New York Center for Independent Living Centers in New York.

Darrell has personal experience with multiple chemical sensitivity, fibromyalgia, and chronic fatigue syndrome.

They are here to talk about multiple chemical sensitivities. I would like to turn it over to Ann McCampbell. Ann

>> ANN McCAMPBELL: Hello, thank you. Wonderful that so many have joined us. I'm going to talk about multiple chemical sensitivities as a medical condition and giving some background on it. I'll talk about what is it, who gets it, what causes it, what are the symptoms, how is it diagnosed and how is it treated.

I'm going to use myself as an example through much of this. I am a physician. I trained in internal medicine and worked in the field of women's health until I became disabled with chemical sensitivities in my late 30s.

For the past 20 years, I have not been able to practice clinical medicine but have worked as an advocate and certainly stay immersed in the field.

So multiple chemical sensitivity is a medical condition that is characterized by heightened sensitivity to chemicals and people who have MCS become ill when exposed to a variety of chemicals, many of which are encountered in everyday life.

Some people have only mild chemical sensitivities and others have a more severe form of the illness

commonly, then called multiple chemical sensitivity.

Some use the term chemical sensitivities and multiple chemical sensitivities interchangeably. You may hear chemical intolerances, all kind of meaning the same thing. When I think of the term multiple chemical sensitivity I'm talking about those so ill that they are disabled by anyone's definition.

Sometimes you'll hear it in the plural, chemical sensitivities, sometimes it's singular sensitivity. Those are interchangeable and kind of personal preference.

The substances that frequently cause symptoms in chemically sensitive people include pesticides, perfume, fresh paint, new carpets, many building materials. Solvents, fresh ink. Other scented products, especially fragrance-emitting devices you might find in a rest room, soaps, fabric softener, shampoo, lots of other personal care products.

Then there's combustion products, smoke, vehicle exhaust, industrial fumes and cleaning compounds. Folks usually can react if they breathe them in, but can react if they touch them or by ingesting them. One thing that's important to point out is it's not a smell, even though some of these like a perfume, certainly has a strong smell, it's really about exposures to the chemicals that are in those kind of products.

And even though I think most of us that have chemical sensitivities feel like our sense of smell increases, some people actually lose their sense of smell and even though they don't smell these pollutants in the air, they still get sick from them.

Further evidence of that was when I was very sick and limited to eating a few foods, one was broccoli. I was steaming broccoli and my mother said you must not be allergic to really strong smells because that smells really strong. I said that's correct, I don't react to broccoli so I will be okay.

Many of these substances that we react to could make anyone sick at high concentrations but when people become chemically sensitive they can get sick by exposures to very low amounts. I mean, minute amounts. Sometimes unbelievably low levels.

When I got very sensitive to a pesticide called deltamethrin, an insecticide, it seemed like it took one molecule to make me very ill. While sometimes the way chemically sensitive people react to substances like a pesticide that is a toxic substance, we might have symptoms like people have at a high level, we have them at a lower level, sometimes we have a very different reaction. Somebody might get a headache and cough because they were in an enclosed room and didn't have good enough ventilation painting, we might have a seizure. So there is a lot of individual variability amongst people with chemical sensitivities.

There's a lot of commonality but everybody's sensitivities are unique to them. This was once described by another advocate, sort of like if we wore eyeglasses but each had our own prescription. Let's see. Besides the pesticides, plastics and fragrances, again, fuels, solvents, tars, asphalt could be a problem.

Sometimes people have a body burden of heavy metals that's part of the development and aggravation of MCS.

Once somebody has multiple chemical sensitivity, there are usually some imbalances or dysfunctions in the nervous system, immune system, and hormone system. I believe it's primarily a neurological illness but of course the brain and the rest of the nervous system is talking closely with the immune system, as well as the endocrine system. They all seem to be involved and impaired. And also, lots of chemically sensitive people have impaired detoxification abilities which compounds the problem in that once you do get exposed to the various substances, it's hard to get rid of them, have your body get rid of them. And so people that react to chemicals often will have trouble with foods and drugs which in effect are just other forms of chemicals. So sometimes people's diets are limited to only a few foods.

In my own case, at one time I was down to eating one food and then probably could eat six foods and olive oil for the next 10 years and I have expanded a little bit beyond that.

Drug intolerance is very common. People are not able to take especially standard drugs and may need compounded medications if they can tolerate the medications at all. Then we have other environmental

substances like mold, pollen, animals and dust, typically thought of as more traditional allergies and people with chemical sensitivities can have trouble with all of those substances and in various degrees.

Personally, I am very chemically sensitive, food sensitive and drug sensitive but do not react particularly to mold, pollen, animals or dust.

The kinds of reactions that people have, we'll get into that a little more, definitely, brain reactions or brain fog, sometimes difficulty thinking or speaking.

And more recently, more attention has come to the fact of more people with chemical sensitivity and more people in general are reacting adversely to electromagnetic fields, including what's called radio frequencies of wireless technology, actually in the microwave range. So people can be made sick by exposure to cell phones, towers, computers, microwave ovens, wireless telephones, fluorescent lights and others.

Often not uncommon for people with chemical sensitivities to have chronic fatigue syndrome, or fibromyalgia. Whether these are all kind of manifestations of an underlying process or representing different diseases or one process is unclear. I like to think of them separately. The chemical sensitivity, the highlight of that person's problem is sensitivity to chemicals.

Chronic fatigue is, as it says, a debilitating fatigue.

Fibromyalgia is a pain syndrome where pain is sort of the main problem.

A lot of people with chemical sensitivity have candida and yeast overgrowth and some people have been diagnosed with lyme disease.

Who gets MCS? It's clear from reports around the world that MCS is a global problem. And it's known to occur in people of all ages, races and economic backgrounds. It occurs twice as often in women as in men. Many people develop MCS after moving into a newly built home, recently remodeled office or exposed to pesticides. A significant number of Gulf War veterans, World Trade Center first responders, people that have been cleaning up the gulf oil spill and those exposed to Hurricane Katrina have developed MCS.

It can't be emphasized enough that you don't have to experience a national disaster to develop MCS. Those of us exposed to the every day chemicals of life are at risk. How many people have it? We have a national U.S. prevalent study, 11.2% of the respondents reported a heightened sensitivity to common chemicals such as perfume, fresh paint, pesticides, and other petrochemical-based substances. 2.5% reported they had been medically diagnosed with MCS. These are probably conservative figures, there are other studies showing up to 33% of survey respondents saying they are starting to react to some degree to these common, everyday chemicals.

Let's see. What causes MCS? As I mentioned, a lot of times there is a precipitating event, a pesticide spray, remodeling of a house or office, moving into a new building. Probably the cause is multifactorial, nobody knows for sure right now. Certainly the chemical load seems to be a significant part of it. But there could be other biological, physical and psychological stressors that kind of tip people over the edge.

There is a concept called total load or sometimes called the rain barrel effect, the thinking going that our bodies, and everybody is different, have a capacity to tolerate exposure to chemicals and you can take it and take it and take it and then one day the barrel fills up and the next drop spills over and you become ill. I think that that makes sense. So some people have a pretty clear idea of what happened to them before they become sensitized.

Other folks don't know what made them ill, I'm one of those. I didn't have any particular exposure. Actually, my illness started by gradually having problems with food over about four years where I just had more bloating and stomach upset and then I started actually shaking after I would eat certain food. At that time I thought, well, I have some kind of diet problem or food allergy. I had no idea how big the problem was going to get. But looking back, I pretty much had the average exposures that other people had. But obviously, I had whatever the genetic makeup or background that led me to really become disabled with this.

>> KATHY HATCH: Ann, we have a question.

>> ANN McCAMPBELL: Okay.

>> KATHY HATCH: And we're coming up on the time to go to the next presenter. How do you handle meetings where people are wearing perfumes and aftershave?

>> ANN McCAMPBELL: Me personally or in general?

>> KATHY HATCH: I think she is looking for any kind of help with that.

>> ANN McCAMPBELL: First you ask people not to wear perfume. I have actually done work with the state department of health and I work with them if I'm going to be able to meet in person to find a location that's not a new location, hopefully the window is open, they haven't sprayed with pesticides and in the meeting announcement ask people not to wear perfume or cologne.

Second of all, I wear an industrial respirator that filters out some of that. And if that doesn't work, then I have them set up a speaker phone and I connect by phone.

>> KATHY HATCH: Okay.

>> ANN McCAMPBELL: Going to the symptoms, there's a laundry list of symptoms but a lot of neurological symptoms are typical, headache, fatigue, dizziness, irregular heart beat, abdominal problems. The symptom that makes chemical sensitivity, whatever ill health you experience after exposure to chemical, that it's related to the exposure. Symptoms come and go with exposures, which isn't to say that most people that have full-blown MCS feel crummy all the time, they just feel worse when they're exposed.

The diagnosis, most people will come and tell you the story, you know what, you know, I can't stand my wife's perfume anymore, I'm feeling nauseated when I go places I used to go. It's a clinical diagnosis, it is the history and people experiment. You go back to that place and you get sick. You go home and you feel better. You go again and you get sick. That's really how you know.

There was a definition, of MCS published in 1999 where MCS is defined as a chronic condition involving multiple organ systems, in which low level exposures to multiple chemically unrelated substances cause

symptoms, and these symptoms improve or resolve when a person is no longer exposed. That's pretty straight forward.

Even though there's no test like an HIV test, a blood test where you have it or you don't, of course that's very rare in medicine that you have a test like that, there's certainly physical findings or a physical exam and lab tests frequently that are abnormal that kind of demonstrate that something is wrong physically and people with chemical sensitivities can appear normal but ones that are very ill usually appear very ill. They have a yellowish discoloration of the skin. May be obviously confused, have trouble speaking and communicating. They can be weak, they can be shaky, they may be wheezing or have a rash. The heart rate can be irregular. Various lab tests will often show some abnormalities in the immune system, not everybody has the same abnormalities. Often vitamin, mineral and other nutrient levels may be low. Often their thyroid hormone is off, high or low, usually low, sometimes with an inflammation as well.

And special brain scans like a Pet, for those well enough to take those tests, can show abnormal metabolism or reduced blood flow to the brain consistent with a toxic encephalopathy.

Quickly on treatment, the best thing people can do is stay away from environments, chemicals, foods and drugs and electromagnetic fields that bother them.

The basic environmental medicine approach, there's doctors that treat this and many that don't treat it and don't know anything about it or worse, really don't believe it exists, the basic approach is avoiding exposures, evaluating for nutrients, replacing those that are low, filling up the tank on the one hand, then checking for body burdens of chemicals and toxins and possibly doing a detoxification regime, sauna or chelation, supplementing thyroid, sometimes estrogens, then there's direct desensitization, there is NATE, that has helped some people. You're looking for possible infections and treating those. That's the basic approach.

>> KATHY HATCH: Can we go ahead and move to questions?

>> ANN McCAMPBELL: Yeah.

>> Caller: I was going to ask a question

>> KATHY HATCH: Okay, go ahead.

>> Caller: My name is Sherri Meyers. I'm a retired attorney. I have had chemical sensitivity now for 20 years and it is very difficult for me. I had to give up the practice of law because of chemical sensitivity. I acquired it through exposure to pesticides. The most difficult thing for me being around people, something you haven't hit on, is personal care products. Not just perfume but all of the personal care products that contain perfume in them. People don't think of them as perfume. The most bothersome is scented shampoo, soap, deodorant and their clothes. If their clothes smell like laundry detergent and especially scented laundry detergent, I can't be around them, it makes me sick. I do have a neurological disorder and one of the symptoms is severe tinnitus. When we talk further, I want people to realize when we talk about perfume, I talk about it in a very broad context. And not just perfume. But any chemical or product with fragrances in it is perfume.

>> ANN McCAMPBELL: Appreciate your question. I'm sorry you're in the club which nobody wants to join. I think some of the other speakers will address this in more detail. I couldn't agree with you more. Certainly it's beyond perfume, it's many other things. I want to say in terms of closure, in terms of prognosis, this is a chronic illness, some people get better, they have periods where they're better, some where they're not so good. It's rarely fatal, but deaths have occurred because of as a result of suicide, asthma, severe malnutrition and inability to tolerate treatments for other illnesses like cancer and infections. [silence...]

>> KATHY HATCH: On that happy note -- I think we'll move on to Mary Lamielle, unless we have another question.

>> Caller: I do.

>> KATHY HATCH: Go ahead.

>> Caller: Yes, the first question kind of was similar to mine when someone does show up just really wreaking with perfume at a place where there have been announcements made not to wear a scented product,

I'm thinking of many of the public performances. We have a theater here in town and they say, refrain from wearing perfume. Does the management then have the right -- can they ask people to leave?

>> ANN McCAMPBELL: This is Ann. I think Mary and the next two speakers will cover that in more detail. I would ask that question to them

>> ANN McCAMPBELL: Can you hang on and we'll ask when Mary is finished?

>> Caller: Sure.

>> Caller: This is Doug Towne, have a quick question for the doctor.

>> ANN McCAMPBELL: Okay

>> Caller: You talk about people's body chemistry and heavy metals. Can you expound on that?

>> KATHY HATCH: He is asking whether people's body chemistry and heavy metals, could you talk just a little bit more about that?

>> ANN McCAMPBELL: I was just saying when an environmental doctor usually evaluates a new patient that seems to be chemically sensitive, to see if they had a body burden, they would look at pesticides and solvents and will usually check for heavy metals. Not infrequently, somebody may have lead, cadmium or something like that which is part of the load and part of the treatment would be to lighten the load, with the mercury, you might get the mercury out of your dental fillings or something like that.

>> Caller: I had never heard that referred to before. Thank you.

>> ANN McCAMPBELL: You bet.

>> KATHY HATCH: Mary, would you like to go ahead?

>> MARY LAMIELLE: I'm going to talk from a PowerPoint that's posted on the website. I have a lot of information to impart, and we'll see how much I get through on that.

I am going to start on page 2. I may or may not say pages as I go along.

First, just a quick overview, I'm going to distinguish between indoor air quality and indoor environmental

quality, talk about select federal agency recognition of chemical sensitivity, areas of policy and practices, a bit about access and accommodations and housing and workplace and several of our own organization, that's National Center on Environmental Health Strategies Advocacy Initiatives.

You may not have heard of the TEAM study, by my guess is you know the findings, and that is that indoor environments are 5 to 10 times, or sometimes 100 or a thousand times more toxic than outdoor air for certain chemicals. That's a piece of a foundation of what's happened in the last several decades looking at these types of problems. You have the issue of indoor air quality, which is the gas, molds and particulates that make up indoor air and the term indoor environmental quality, where it's that indoor air quality and to that you're adding electromagnetic issues, noise, vibration, lighting and temperature and so forth.

Early on in this area you had proposed legislation, Indoor Quality Act of 1989. Our organization testified before Congress three times in the late '80's, early '90's. Although it never passed, it helped push this issue to the forefront in terms of looking at indoor air quality and ultimately people who are sick from indoor pollutants.

Page 4. Early federal recognition of this disability includes the Social Security Administration, 1988, HUD recognition in 1992, Department of Education and the justice department and the regulations that were issued in 1991. Page 5. The U.S. Access board has a history in this area, from 1999 where they held a training for their board on fragrances. 2000, they adopted a fragrance-free policy for board meetings, to refrain from perfume, fragrance as well as asking people to refrain from using fragranced products.

In 2000, they created a committee to look at chemical and electrical sensitivity. It's the project that Ann referenced. Resulted in the indoor environmental quality project report which Ann, Susan Molloy and myself and Tony Temple and indoor air experts worked together to write a report that looks at how to design, construct, furnish, operate and maintain public and commercial buildings to make them healthier for everyone but more accessible for people with chemical and electrical sensitivities.

I think it's a real milestone in this area, and something that you might want to take a look at. In 2010 the

access board opened a permanent meeting space for this agency. That is designated as fragrance-free with unscented cleaning products and trying to maintain it as healthy as possible.

Slide 6, it's a copy of a "perfume pollutes" button that we distribute. We think of accessible indoor environments, there are several key factors, one that they be tobacco free, pesticide free, and fragrance free. When we talk about fragrance and fragrant chemicals, they can contain up to 3,000-plus possible chemicals that can be in a fragrance. Many we know are toxic or allergenic. There is no regulation in that area.

One researcher, Ann Steinman, who has been looking into this issue looked at 25 commonly used scented products, found out they emitted an average of 17 chemicals each, nearly a quarter of which were toxic or hazardous and those marketed "green" or "organic" emitted just as many chemicals.

Fragrances are in so many different things including pesticides. Slide 7. Federal action. The CDC has an Indoor Environmental Quality policy, issued in 2009, that restricts use of fragrances and fragranced products of all employees at all their spaces.

It goes on to note that fragrance is not appropriate for a professional work environment and use of some products with fragrance may be detrimental to the health of workers with chemical sensitivity, allergies, asthma and chronic headaches or migraines.

The CDC policy specifically prohibits incense, candles, reed diffusers, fragrance-emitting devices of any kind, wall-mounted devices, potpourri, plug-in or spray air fresheners, urinal or toilet blocks and other fragranced deodorizer products.

The Department of Health and Human Services has a policy based on the CDC policy, however it's less restrictive than the CDC policy. It does not prohibit the use before you come to work and exempts day care and fitness centers associated with HHS, if anyone you're going to protect I think is children and infants, it does adopt the same list of non-permissible personal care products. That's an identical list.

The census bureau has a policy they adopted March 2009. That has not been particularly effective for

people who work there. It's asking people to refrain from strongly scented fragrances and asking them to use low or non-fragranced products. So again, a little bit less restrictive. Although it does prohibit employee use of aerosols and air fresheners.

FEMA has a policy with regard to their blanket purchase orders for medical supplies requiring they be latex and fragrance free.

Slide 10. Our organization has fragrance free proposals right now with the White House Disability Policy Office, GSA, one with FEMA that would restrict use of fragrances by employees but in terms of fragranced products, personal care and cleaning products in emergency management and disaster relief. The copy of the policy is in the list to read that is attached to the website for today.

Fragrance-free policies are increasingly common out there. Schools, health care centers City of Portland recently adopted a policy. Slide 11 has a framework for a basic fragrance-free workplace policy that would certainly modify to fit your needs.

There have been legal settlements in this area, February of last year \$100,000 settlement in Detroit for a woman who was sick from fragrances in the workplace. Again, I think it's an area that hopefully is moving forward.

Talk a bit about housing, I have a number of topics. And in the area of housing I would say it's the one area for people who are chemically sensitive, it's a crisis for near everyone. A lot of folks who are homeless, most of us who are very sick find our daily lives are about survival 24 hours a day or a good part of it and a lack of affordable, non-toxic housing, failure to accommodate existing housing, failure of multifamily integrated housing and extreme problems with harassment, discrimination and retaliation.

When we talked about the HUD recognition of chemical sensitivity, there has been a whole history of recognition in this area, and that's detailed in slide 13, resulting in the HUD legal memorandum. Subsequent, a history of conciliation agreements, consent to create settlements, not enough to address our needs but a history.

In 1992 HUD allocated \$700,000 to Marin homes for independent living for construction of Ecology House. The important work of Susan Molloy, with the intent to try to house people who are chemically sensitive.

The slides talk about typical housing accommodation requests and they're quite a number and detailed. They are requests based on individuals I would have worked with through the years trying to get accommodating housing, replacing gas or propane dryers to electric units, not using common areas, retrofitting windows to make them operable, making sure if constructing ramps or balconies, using tolerated materials.

Extra bedrooms, for us to isolate products or items we have to have but we actually can't tolerate being around. The importance of avoiding remodeling activities that would make us sick, designated non-smoking homes and communities.

Slide 16. Posting signs prohibiting idling, consulting with tenants about safe remodeling material, non-discrimination policies posting. Discouraging use of toxic chemicals, like air fresheners, scented candles. Making sure you provide notification of building events and educating staff.

In the pesticide area, we think healthy environments are clearly pesticide free. The EPA certainly agreed. The term is integrated pest management, basically not making places favorable for insects. No food, clothing, shelter, keeping them away type of thing. One of the important things that's happened recently, there's training in integrated pest management in multi family housing available to any type of multi family housing facility. It acknowledges there are people out there who are disabled with chemical sensitivities and disabled by pesticide exposure and provides protection from structural, as well as lawn care pesticides, acknowledging them as access barrier and identifying people who are chemically sensitive as individuals in that community who would be helpful in educating others. Basically trying to take folks in a multifamily situation and helping them understand it's important to prevent a pest problem. If you have a problem, to address it with least toxic types of product. To read a sentence from one of those slides, "Conventional pesticides should not be used in units occupied by people with chemical sensitivities or in adjacent or neighboring units or in common areas such as

halls, lobbies, laundry rooms, elevators or stairs or along paths of travel for disability access.” An important piece.

We have a lengthy list of recommendations for HUD action to address housing needs of people with chemical electrical sensitivities. They include, the critical need to do a needs assessment of who is out there affected with chemical electrical sensitivities and move forward to getting us accessible housing as well as there's a dire need for people who are very sick to have separate and protected housing from other communities because of reacting so severely to many different low level exposures and need for HUD to fund mandatory education and training in this area. Various of those recommendations have been supported by the National Council On Disability, and the Housing Position Statement supports these two. That includes the work of Susan Molloy, Lynn Stevenson and myself. In the employment area, EEOC has tracked chemicals since 1993. Sadly we have both low numbers of complaints but extremely low levels of resolution in this area. The latest statistic, fiscal year 2010, 74 complaints regarding chemical sensitivity of which 11 were resolved. That's .2% of the charges. And with eight what are called monetary benefits, basically where settlements gave some type of monetary award. Very, very small numbers.

We would strongly recommend that folks have workplace policies to address these types of issues to both meet employee needs but also consumer needs. So clearly a no smoking policy, fragrance free policy, eliminate conventional pesticides, notification policy for events like remodeling, cleaning the floor, prohibiting idling of vehicles, also a policy with regard to electromagnetic issues, at minimum a cell phone policy.

The other piece would be making sure you know what's happening in your state or region in these areas so you can share that with consumers. For example, maybe your state has a certain smoking policy. Over half the states have some type of policy with regard to pesticides and notification. Those things would be very valuable.

I listed in the slides, pages 23 to 25, quite a number of different typical workplace accommodations for people who are chemically sensitive. I want to go through a handful. I think you get the idea - tobacco,

pesticides, fragrance-free cleaning products. The ability to work in a private office or have windows that open. Access to fresh air. Being careful if remodeling, what you bring into a space and so forth.

>> KATHY HATCH: Mary, excuse me. You wanted me to tell you when you had four or five minutes left.

>> MARY LAMIELLE: I would be glad to talk to anyone interested in the accommodation issues and there are a number of handouts. Another piece in terms of understanding the accommodations issues, or understanding how difficult it is, is looking at the kind of harassment and discrimination we face in this area. These are just things that have been reported to me through the years, but are not uncommon – things like intensified use of perfume, perfume poured on people's chairs, use of microphones or microwaves or cell phones in the area of someone who is sensitive.

A cleaner air logo was adopted in California, to indicate buildings or spaces that will be more accessible for people who are chemically sensitive and endorsed by the Access Board.

The final thing I want to talk about is a couple of organizations' advocacy initiatives. One was fragrance-free proposals, which I think are very important. The HUD recommendations. The third item, two others are research recommendations. The other piece is an interagency committee on chemical sensitivity.

And to give you background on this, in 1993, there was an expert panel convened on chemical sensitivities using funding that had gone to part of the Centers for Disease Control. That expert panel recommended using an environmental medical unit, interagency committee on chemical sensitivity, neurosciences workshop and research in conjunction with big exposures, for example in the future, such as 9/11, Katrina, the gulf oil spills.

The only one that happened is the neuroscience workshop. What has happened in the two or three decades has been very piecemeal. It's been issue by issue. Frequently every little piece, every little step forward is a huge battle and we don't seem to have accumulated any common knowledge. Clearly it's federal agencies and so forth.

We have been calling for an interagency committee that would look at what's happened, that would identify gaps in research policies, regulatory policies, disability policies, try to jump start research and try to provide education information.

That interagency proposal has been supported by the Access Board and HUD. It has informal support from a number of other agencies and agency personnel. Right now we have a congressional request with Secretary Sebelius to establish such a committee.

On this topic, as well as anything else that's been in the PowerPoint and handouts, I would be glad to discuss with anyone either now or offline or by phone call. Thank you.

>> KATHY HATCH: Thank you, Mary. Great. I just had a question from someone regarding your speech. I wanted to tell everybody on the phone that a transcript of this will be available on the APRIL website, probably in a couple of days and also that Mary's PowerPoint is on the APRIL website right now. If you want to go and pick that up, you can.

Are there questions?

>> Caller: What is that website again?

>> KATHY HATCH: www.april-rural.org.

>> Caller: A-P-R-I-L?

>> KATHY HATCH: Correct, just like the month

>> Caller: Thank you.

>> DOUG TOWNE: Kathy, it's Doug. I have a quick question if I can.

Mary, good to hear your voice again, we have missed you on the task force.

Are you aware of any demographic work that's been done? I get questions frequently, how large is this population?

>> MARY LAMIELLE: I think the numbers Ann gave you are some that are out there. We have seen

numbers as far as people who are chronically ill and disabled, 2 to 5, up to 6%, and the numbers of people who are moderately affected I would say we see the range of 11.2 to perhaps 15 or 16%. Mildly, up to a third of the population. So that's going backwards.

>> Caller: And does the same hold true for electrical sensitivities?

>> MARY LAMIELLE: The only study that I know of in the states was in California, part of a risk factor surveillance study in the mid '90's and that was 3%. There might be studies from Europe --

>> ANN McCAMPBELL: This is Ann. That's correct, there have been studies in Europe and it's in the same ballpark as the California study.

>> Caller: 3%?

>> ANN McCAMPBELL: Yes.

>> Caller: Thank you.

>> KATHY HATCH: Any other questions?

>> Caller: This is Sherri Meyers again. The problem in the panhandle in Florida is there is not a doctor that treats people with multiple chemical sensitivities. When you go to a medical professional, you have to go for treatment of just a symptom. So people with MCS are really at a great disadvantage in this part of the United States.

>> KATHY HATCH: Is there a question or a comment then?

>> Caller: It's problematic. When your employer wants a medical statement as to why you need accommodation.

>> KATHY HATCH: Okay. Good. Go ahead, Mary.

>> MARY LAMIELLE: Where do you live?

>> Caller: Pensacola.

>> MARY LAMIELLE: This is to my mind the narrowness of the federal government and inability to

grasp what's happening. I'm part of an NCEHS partners group. We have an epidemiologist. She was working in Louisiana initially.

She presented to our group talking about people she had been interviewing. On one hand describing to the people who have chemical sensitivities and I think she suspected she was talking about that population but on the other hand dismissive of them as though we don't really know how these people felt prior to the exposure and so forth.

To my mind this goes back to the fact that there's been so much resistance at the government level for many different reasons of sort of recognizing, understanding and doing head counts and so forth and so on. I think you need to be persistent with what's going on, making sure doctors hear you and so forth.

>> MARY LAMIELLE: I think it's so important to be persistent in noting what your problems are, going to your legislator. Bring it up at every level you can.

This is why I think the time is right, right now, to really push with CDC and with NIEHS for the critical research and I think we're getting close to having that happen. The more voices the better. If we were people who were not sick, we would be out there in public in a way that would make something happen. Sadly, most people are too sick to do this in a sustained manner or in a manner that's visible enough for the people in power to really understand the level of the problem.

>> ANN McCAMPBELL: This is Ann. I would like to say, often you can find at least physicians that do understand chemical sensitivities by going through the American Academy of Environmental Medicine. They're headquartered in Wichita, Kansas, American Academy of Environmental Medicine, online. I searched on Florida and there's about 12 practitioners listed

>> Caller: Probably not in the panhandle of Florida, though. I'll go online. What's the name?

>> ANN McCAMPBELL: American Academy of Environmental Medicine. There's also a phone -- okay. And a website.

>> MARY LAMIELLE: Yes, . I believe that's what they are now.

>> KATHY HATCH: Okay. Thank you. Any other questions?

Let's move to Darrell Jones, with ILRU. Would you like to speak?

>> DARRELL JONES: Hello, everyone. It's really good to be with you today. I'm delighted there is an interest in this topic among centers for independent living, so thank you for being here.

One of the things that is affected for me is my voice. It is particularly spastic today. So if there is something that you don't understand, please ask for clarification.

I wanted to spend some time talking about the impact on an individual's life and exclusion. It's a hard thing for me to say being that this is where I have spent my life for over 30 years. I'm normally uncomfortable talking about myself and my own personal experiences, but in this instance I'm going to do that because I think it will be useful for me to share just a little bit of my own journey, because of the length of time that I have worked in the independent living field.

Although I have worked in independent living since the early days of Title VII it's only been the past 11 years that I have been able to have significant job accommodations that have made my life and continued employment manageable. Although I have had chronic immune dysfunction since I was a child, when I was the director of a center I was not considered a person with a disability. That was so long ago that there were no doctors who knew anything about this illness. And I was told repeatedly that what I was experiencing was psychological. In those days I didn't make any claims among my peers for having a disability.

As a child I had a long string of respiratory illnesses including three hospitalizations for pneumonia. By the time I was 15, I was chronically fatigued and I developed a long list of health conditions including asthma, hypoglycemia, migraine headaches, irritable bowel syndrome, cognitive problems, food sensitivities, body-wide muscle pain, chronic viral and bacterial infections and nerve pain. When I look at that list or rattle it off for anyone, I understand why so many people, including health care practitioners, dismiss this collection of

symptoms as psychological or psychosomatic.

I wanted to give you enough detail about my own experience just to give you one example of the impact that ignorance can have. For many years, doctors did not connect the dots for me because they were not looking at me holistically. Thank goodness there are a growing number of doctors nationwide that get MCS as a real illness even though they are kind of hard to find sometimes and in certain states. There aren't any cures yet, but there are a number of protocols, including avoiding chemicals to the greatest extent possible.

I started making the connection between some of my symptoms and chemical sensitivities when I was in my 30s. I had known for some time that tobacco smoke gave me wicked headaches, so severe that I would have to go to bed for a couple of days. When I entered a freshly painted building or sat in a meeting where people were wearing perfume, not only would I get headaches, I would notice changes in my coordination and I would get dizzy and confused. I would have difficulty tracking the conversation and feel stupid because I couldn't process what was being said.

I remember one time when I had gone to a nursery to buy plants for my garden and I was standing in line waiting to pay for my purchase. I began to have a very strange taste in the back of my throat. It tasted like what fertilizer smells like and I mentioned it to the cashier. She said they were unloading fertilizer in the back of the store at that very moment. And that obviously I was very sensitive and I should get out of the store immediately. That was the first time it began to click for me that there was something real going on with my body related to chemicals.

I had experiences like driving somewhere that I had gone hundreds of times before like home to work and getting lost because something like dyslexia would take over my brain and I would turn the wrong way. I was so frightened in those days because no one seemed to believe me, not doctors, not family members, not friends and even my independent living coworkers would say things to me like, that's psychological. If you would just relax, you would be fine.

I remember many incidents among independent living peers where I told them that I couldn't socialize with them in a smoke-filled bar and asked if the group could go somewhere else. The reply was, no, we're going to hang out here, we'll see you tomorrow. And so I was excluded, and I spent the evening alone.

Even now, in 2011, there are independent living colleagues who say to me, that's psychological and I'm not really going to pay attention to the kinds of accommodations that you're asking for. So, for many years I did not feel accepted by the movement or feel like I was an equal partner.

Now the good news for me is that I have reached a point where I don't care anymore about other people's opinions or judgments. I now choose to have a life that works for me and surround myself with people who take me at my word and honor my boundaries. However, I'm very fortunate that I now have the job accommodation of working at home. Not everyone has that option, so I realize how blessed I am. I have an employer that takes great care to accommodate me and include me. I am treated as a valued and essential part of the team.

What I wanted to illustrate by sharing my story with you is that probably most of the consumers with MCS who would seek services from your center are feeling pretty isolated and beat up by the time they call you.

Many of them may not have found the sense of empowerment that I have in my life. They may feel discriminated against, by the disability rights movement, by the health care community, family, friends and public accommodations. They may be discouraged and overwhelmed believing that they will never again have any quality of life and true friends. They may have lost everything they own which is another experience I went through when I was too ill to work for several years.

I think that there are quite a few things that centers can do to be useful and relevant to people with MCS. And quite a few of these things have been mentioned already and at this point I'm just going to mention 10 things that I think most centers can put at the top of their priority list. Some of this is going to be repetitive but it bears repeating. So take a look at Mary's and Ann's material for broader recommendations.

- 1) The first thing -- this is going to seem obvious but I mention it because of what I have heard from so

many people -- take the person at their word. If they tell you they react to the plastic in their telephone or electromagnetic field from their computer, accept it at face value. As you would with any person with a disability who seeks services from your center, accept their self-reporting of their experiences regardless of how strange and far-fetched it may seem to you.

Be aware that they have probably experienced a great deal of prejudice and judgment about their disability. They may feel quite fearful about approaching yet another organization for services. And they may act defensive. They certainly don't need a discussion about whether their disability is psychological. They need assistance with the day by day management of their life.

2) Second, assist the person to focus on the functional issues and needs, rather than on all the things they are reacting to and all their physical symptoms. As true with any consumer, a structured interview guided by well thought out forms and checklists will help them as well as you to identify needs, goals and barriers.

3) Third. As has been said before, and you're going to hear this probably a lot more times, enact a fragrance-free policy at your center which includes all fragrances. A number of centers around the country have done this and it has worked quite well. Don't waste your time getting caught up in debates about whether people have the right to put whatever they want to on their bodies. If you're a center for independent living you have an obligation to be as accessible as you can.

And yes, you can ask people to leave if you have announced your policy in a public way. One center that has enacted policies that I think has been very successful with this is Arizona Bridge to Independent Living in Phoenix. Not only do they have a fragrance-free policy, they liberally make that policy known so that "accidents are minimized." At the bottom of their E-mails they put the tag line, "ABIL is fragrance-free! Please don't wear scented products to ABIL meetings and events. Thank you!"

4) Fourth. This is another policy that's important for a center to enact, and that's that the least toxic cleaning products will be used at your center. And, be very conservative about renovations and only when

absolutely essential. Use least toxic building and paint products. Remember to place signs at the entrance of your building to warn people so they don't unknowingly expose themselves to things that will harm them. Of course don't spray pesticides. There are some natural remedies for pests that are quite effective. Do some investigation, find out what is available to you and do what you can to find alternative solutions.

5) Fifth, if you are a larger center that has the space to create a safe room, do so using consumers with MCS as advisors on the design and construction of that room. It will provide a space to meet safely with staff or hold peer group meetings.

6) Six, if they are too ill to come to your office, find ways of providing services that ARE safe for the individual. Work with them over the phone. Through E-mail, or regular mail or through Skype if they request it. If a home visit is necessary, ask the person what steps you should take to make yourself as chemical-free as possible and honor their request. If you can't honor the request, don't make the visit of course.

7) Seven. If your center provides housing location assistance, this disability population needs to be thought about differently than you would think about most other populations. When you survey landlords, include questions about recent renovations, use of toxic cleaning products, neighborhood features such as prevalent fireplace smoke, or whatever else might be relevant for your area. Acknowledge,(and here is a center policy matter), that safe and accessible housing for a person with MCS may mean segregated housing of some kind. And I know that that feels like it flies in the face of the integrated housing philosophy of independent living, but for many people with MCS segregated housing is the accessible approach that works for them.

8) Eight. Provide the option of an employee with MCS working at home if their job can be done at a distance. If that's not feasible, see if you can work with the individual to create a safe zone within the center, if that will make their continued employment manageable. It might involve stripping out carpeting, removing furniture with fabric and formaldehyde, purchasing an air purifier, forbidding the use of aerosol sprays or making other changes, but it's important to take a look at that. Recognize that an employee with MCS may need

to take time to rest during the course of the day and provide a cot or other place where they can lie down.

9) Nine. Keep in mind that if the employee's job involves visiting buildings outside of the center, those need to be taken into consideration. Of course, as it is with any disability, it is the essential function of the job that you must look at when determining if a person is right for the position they have applied for.

10) Tenth, and final, and this one really comes from my heart because of the personal struggle I have had, keep in mind that an employee with MCS may push themselves far beyond what their bodies can endure because they're afraid of losing employment. It is important to have frank discussions with them about how things are working for them.

In conclusion, I want to say that because I've been a director of a center for independent living, I understand how thinly stretched your budgets and staff are. I understand the range of disabilities, age groups and racial and cultural concerns that you have to develop expertise in and the range of life issues that you have to address. So in making recommendations for things you can do, I'm mindful of everything that you're trying to juggle.

My suggestion is that, as you would with any enhancements you want to make to your center, create a vision of where you want to go and move toward it one step at a time. It will begin to manifest step by step, policy by policy, procedure by procedure. And at some point your center will be much more inclusive and responsive to people with MCS.

And again, thank you guys for being here today. This has been wonderful. Thank you.

Kathy?

>> KATHY HATCH: Okay. Thank you, Darrell. That was great. Those ten steps are wonderful. They are going to be very helpful to people, I know.

Does anyone have a question at this point for Darrell or for anyone? Had a couple of people on chat. I think I have answered their questions for them I hope.

>> Caller: Can I ask a question?

>> KATHY HATCH: You may, absolutely.

>> Caller: So --

>> KATHY HATCH: Who are you asking?

>> Caller: Darrell or -- what was the name of the woman that just spoke?

>> KATHY HATCH: Darrell was the last one.

>> Caller: Okay. Sorry. What would you suggest for combating smells in offices if there are methane smells or body odor smells. If you can't -- I mean, naturally, people can't use chemicals or candles or things. Are there air purification systems that don't tend to bother people with MCS?

>> KATHY HATCH: What kinds of products that you would use that do not affect people with MCS?

>> Caller: Yeah or systems or something.

>> KATHY HATCH: Are there systems?

>> DARRELL JONES: I think you might want to look at things that affect the air circulation.

>> MARY LAMIELLE: It sounds like you're almost suggesting that someone is not going to wear deodorant because they have scented products.

>> Caller: Sometimes offices have smells from being in the bathroom and that stuff.

>> MARY LAMIELLE: If you are using air fresheners, candles, that sort of thing, whether you're aware or not, you're making your indoor space more toxic and contaminated and unhealthy for everyone. The first thing to look for is ability to ventilate, use windows or put in a window that would be operable.

>> Caller: What if windows aren't an option?

>> MARY LAMIELLE: Windows would be the first piece. Exhaust fans, making sure that rest room areas, cooking areas, are exhausted to the outside.

The third would be the ventilation system. There are minimum recommended ventilation standards so you

want to perhaps hire an indoor air expert to make sure you're meeting the standard. You can enhance your ventilation. The more fresh air you bring in, the better the space is going to be.

The next piece might be to look to filtering systems such as charcoal filters. They will help filter chemicals out of a space. If you have people there with any level of sensitivity, you want to consult them to make sure you buy products that meet their needs, are not detrimental to their health, but that would be the next level.

Now I'll turn it over to Ann.

>> ANN McCAMPBELL: I would say you pretty much covered it. In terms of body odor, it's not that nobody should be bathing. We're not discouraging, we're encouraging personal hygiene, but discouraging fragrances.

>> Caller: I have something, this is Sherri Meyers again.

>> KATHY HATCH: Okay.

>> Caller: Hello?

>> KATHY HATCH: Go ahead, Sherri

>> Caller: If you go to the United States Access Board website and Google in multiple chemical sensitivity, you will find an 80-page document that they have on there that deals with indoor air quality. And it's really good.

>> MARY LAMIELLE: That's the report that Ann -- this is Mary -- Ann and I talked about. We worked on that project. It was a several year project and a very good foundation for all the topics we talked about today.

>> KATHY HATCH: Is that one of the documents that you put on --

>> MARY LAMIELLE: The address is on one of my slides, I think it's slide 4. I can tell you in a minute. It's slide 5. Actually, the web address is , as in indoor environmental quality.

>> KATHY HATCH: Okay. Other questions? Comments?

>> Caller: You were talking about ventilation systems.

>> KATHY HATCH: Go ahead.

>> Caller: Is there one or is there a type of ventilation that is better or better than others?

>> KATHY HATCH: Is there one or a type of ventilation that is better than others?

>> ANN McCAMPBELL: This is Ann. I think natural ventilation is the preference. If windows will open, and can be opened, that's the best. I don't know in terms of one brand or one type of manufacturer like an HVAC system.

To re-emphasize what Mary said, there's cleaning them, making sure the regular filters have been changed properly. It's kind of surprising and somewhat appalling, sometimes these things never get any maintenance. And then the other aspect of just running it a lot, moving a lot of air, going beyond legal, whatever the standards are. Moving the air a lot.

The other piece would be to open it up and bring in outside air, as much outside air as possible. Another thing we ran into when writing that report is finding out there's sometimes a habit of people trying to save money and they turn the HVAC system off at night when nobody is there and turn it on when people get there. It might take an hour before the air is really cleared. I think more than one type HVAC system over another, use what is there to maximize air exchanges and fresh air.

>> KATHY HATCH: I would say, too, make sure your vents are clean, the runs, you know, for the HVAC system and the filters, make sure to change them as often as possible, as often as they recommend.

>> Caller: I have a question. Crystal from the center for independent living in California. My question is, what guidelines would you suggest as far as for shampoos and deodorants and all those things to create the most accessible space for those with chemical sensitivities, especially for independent living centers?

>> KATHY HATCH: the question is, what guidelines would you suggest as far as shampoos, deodorants and other personal products?

>> Caller: To make sure that that doesn't affect someone with chemical sensitivity, to make it most

accessible?

>> MARY LAMIELLE: This is Mary. You begin with the unscented products, keeping in mind that some unscented products have masking chemicals that can be a problem for folks.

You might secondly create your own list of recommended products that you know folks who work there tolerate.

I think the next piece is if you have consumers who use your facility or employees who are particularly sensitive to products, if they have difficulties with individual items that you're considering, make sure they stay off the list or they're particularly noted that you don't want people to be using them.

>> KATHY HATCH: Kind of make your own list.

>> MARY LAMIELLE: Yeah, I think so.

>> DARRELL JONES: I was going to underscore that's an extremely important point. Just talking to individuals is really the first place to start.

>> KATHY HATCH: Great. Okay, well --

>> Caller: I have a question.

>> KATHY HATCH: Go ahead.

>> Caller: Do you have a list or a suggestion as to what we can use for cleaning products in the office? Rest room, break room, small kitchen area, just the general office itself.

>> KATHY HATCH: The question is, are there cleaning products that you can recommend for different areas.

>> MARY LAMIELLE: This is Mary. The first thing to keep in mind is things you want to stay away from, don't want to use. These days with talk from everybody about "green" products and knowing that green is not necessarily healthy, you do not want to use citrus or pine based products because they are particularly problematic.

The second thing, you want to stay away from chlorine based, phenol based, alcohol probably to some degree. You have a list of don't use these, these are specifically addressed in the Access Board report that Kathy gave you the web address for earlier.

Then the next level what you want to do is to see, you really want to look at products that might be possibilities.

I'm going to give you an example. I got a call from the New York City library and several folks were having difficulties with the cleaning products being used. They literally got the names of samples of cleaning products and checked with the people who worked at the facility, and basically decided based on acceptability to the people who worked in that space in choosing a product.

So you want to start with don't use these things that are particularly toxic and rule in items that might be acceptable based on individual needs and preferences.

>> Caller: Okay. You said they would be on the website?

>> MARY LAMIELLE: It tells you items you definitely don't want to use.

>> Caller: Which one?

>> MARY LAMIELLE: .

>> Caller: How do you resolve conflicts between sometimes very strong fragrances associated with medicated shampoos and multiple chemical sensitivities?

>> ANN McCAMPBELL: It does come up, this is Ann. Competing disabilities. Something that they need to use that. I don't think there's any simple answer other than to try to bring people together and come up with a compromise or something that will work. And needing to respect and honor each person's needs. Do the best you can to be creative.

>> KATHY HATCH: Okay.

>> MARY LAMIELLE: This is Mary. Less frequently that is the situation, although I have faced it. It's

people insisting to use personal products because of personal preference.

>> Caller: Are you familiar with the U.S. Department of Interior Green Janitorial Program?

>> MARY LAMIELLE: No.

>> ANN McCAMPBELL: This is Ann. I've heard of it.

>> KATHY HATCH: One yes, one no. Let Ann speak.

>> ANN McCAMPBELL: I'm aware that they have that. But I don't remember the details right now.

>> Caller: Well, it's very good. Fragrance free is required in all of our national parks and all of their contractors they purchase from have to meet certain standards. I mean, but again, you have to take into consideration, there are so-called green products that I can't be around either so you really have to take into consideration the individuals.

>> MARY LAMIELLE: Absolutely.

>> Caller: There are a lot of things out there that weren't available even five years ago.

>> ANN McCAMPBELL: This is Ann. I wanted to throw in about the cleaning products. One thing, the city of Santa Monica in California had some of the best purchasing specifications now for over a decade. If somebody really has, if you're a state agency or something looking to develop specifications I usually refer people to Santa Monica. They use different vendors.

A small, independent living place could do well with a little dish soap, all-purpose, unscented low toxic soap, baking soda for a little bit of grit, maybe vinegar for windows although be aware some chemically sensitive people couldn't tolerate that and minimize the number of products. You don't need something to clean a chair and a desk and a bathroom and -- you know, you kind of have one soap and then a lot of stuff comes up about sanitizing and disinfecting. Actually, hydrogen peroxide will do the job and is usually fairly well tolerated or more tolerated than bleach or -- you never want to use a Lysol product, that would be a recommendation if you have chemically sensitive people around.

>> DARRELL JONES: This is Darrell. One of the problems some encounter because they rent space where there are other tenants, there are common bathrooms, there needs to be a fair amount of advocacy with the landlord to deal with the kinds of deodorizers and cleansers. Some of these automatic dispenser things can be lethal. Not only in the restroom itself but they get through the ventilation system and leak into offices.

>> KATHY HATCH: It is 4:37, we are a little over. Are there other questions? If there are, we can keep going for a bit. If not, we'll begin to close up. This has been a wonderful conversation, guys. No more? Well, then --

>> Caller: I want to say one last thing. Centers for independent living have federal contracts and those have non-discrimination clauses in them and failure to provide safe facilities for consumers and those with multiple chemical sensitivity could be a violation of their federal contracts.

>> Caller: This is Sandy in California. Thank you very much for what you have done and particularly having it on a website where people can get to it.

>> KATHY HATCH: You're very welcome.

Okay, closing then, I just want to thank you all for being here today. Again, I would like to invite you to visit the website where you will find the documents discussed today and an archived copy and a transcript of the presentation. Give it a day or so and it will be up there. Just go to [www.ilnet.org](#) and look for IL Conversations.

And if you have any questions about today's discussion, you can reach me, that's Kathy Hatch, at kathatch@charter.net.

Thanks everybody. And this IL conversation is presented by the IL Net which is operated by the Independent Living Research Utilization Program at TIRR Memorial Herman in partnership with NCIL and APRIL. Support for the presentation was provided by the U.S. Department of Education, Rehabilitation Services Administration. No official endorsement of the Department of Education should be inferred.

Thanks everybody for joining us, I really appreciate it. Goodbye. Take care.