# Accommodating Consumers and Staff with Chemical Sensitivities or Environmental Intolerances

## Introduction

People who are chemically sensitive are made sick by exposures to chemicals found in many common products such as pesticides, perfumes, tobacco smoke, new carpets, air ‘fresheners,’ new paint and building materials, and many cleaning and laundry products. Most of these chemicals will make everyone sick at high levels, but for chemically sensitive people exposures to even small amounts of these substances can cause symptoms. —Multiple Chemical Sensitivity Task Force of New Mexico (2000)

People with chemical sensitivities (CS) experience barriers in many of the same arenas as people with other types of disabilities: transportation, technology, housing, health care, employment, recreation. In addition, people with CS are often treated as though they do not have a “real” disability and are told that this is all in their head. People with CS need and can benefit from the peer support, advocacy, and other services that Centers for Independent Living (CILs) have to offer.

Unfortunately, not all CILs understand the needs of these individuals, or they may be overwhelmed by the idea of providing accommodations for a condition that affects different people in different ways. The purpose of this fact sheet is to increase the knowledge of CIL staff about chemical sensitivities as a disabling condition and suggest ways to be more inclusive of this population. Even a basic understanding of these issues combined with a willingness to listen and make accommodations will make a huge difference in the quality of life and independence of people with CS.

## What are chemical sensitivities?

People who have CS or environmental intolerances may experience a wide range of health effects, from mild to severely disabling to fatal in a few cases. Intolerances may be initiated by an acute exposure to pesticides or a chemical spill, for example, or it may be initiated by a prolonged, ongoing, low level exposure(s), such as living or working in a recently remodeled home or building, or to cleaning agents.

Once the condition is initiated, the number and type of substances causing a reaction will increase, while the level of exposure required for a reaction will decrease. Reactions can be triggered by the initiating exposure(s), as well as a seemingly endless list of substances and products. These include fresh paint, carpeting, cleaning agents, air fresheners, deodorizers, disinfectants, solvents, fragrances and fragranced products, as well as electromagnetic frequencies, including electronic devices and frequencies from cell phones, microwaves, fluorescent lighting, Wi-Fi, and smart meters. Reactions are also triggered by over-the-counter and prescription medications, foods, food additives, preservatives, and pesticide residue (Lamielle, 2015).

Once chemical sensitivities or intolerances develop, the only way to avert reactions is to avoid contact with substances that trigger reactions.The longer individuals are exposed, the greater the number of symptoms they are likely to experience, and the more disabled they are likely to become. Individuals must minimize — or preferably eliminate — exposures that trigger reactions to reduce the level of illness and disability. This becomes more difficult as new intolerances develop and the person’s access becomes more limited. One of the major goals in helping people with CS is to reduce environmental exposures in order to limit worsening sensitivities and preserve the amount of tolerance that the person still has (Gibson, 2006). Removal from triggering exposures will likely ease the intensity of the illness over time, though it maynot halt the progressive nature of the disability.

## Why should CILs serve and accommodate people with chemical sensitivities?

* Multiple Chemical Sensitivity/Multiple Chemical Intolerances (MCS/MCI) is a condition that CILs are required to include in their definition of disability because it fits the [ADA definition of disability](https://adata.org/faq/what-definition-disability-under-ada#:~:text=Because%20it%20has%20a%20legal%20definition%2C%20the%20ADA%E2%80%99s,substantially%20limits%20one%20or%20more%20major%20life%20activity.).[[1]](#footnote-1)
* People with CS are feeling more isolated than ever, especially since many primarily use landlines and no other technology.
* It's important for CILs to be informed about the barriers that people with CS face and how CILs can help address those barriers.
* As with all aspects of running a Center for Independent Living, you widen your impact one policy at a time and one procedure at a time, keeping your vision of total inclusion in mind as you move forward.

## How many people have CS and is that number growing?

* A recent nationally representative study (Steinemann, 2018) found that the prevalence of diagnosed CS has increased over 300%, and self-reported CS has increased over 200% in the past decade. Medically diagnosed CS was reported in 12.8% of this cross-sectional sample of 1,137 Americans while 25.9% self-reported CS.
* 34.7% of the overall population have fragrance sensitivity; 81.0% of those with CS have fragrance sensitivity; and 86.2% of those with medically diagnosed MCS also report fragrance sensitivity, or adverse effects from fragranced consumer products, such as air fresheners and cleaning supplies, (Steinemann 2019).
* In earlier studies, data collected from two national surveys (1,057 and 1,058 cases, respectively) revealed that 11.4% report CS and 3.2% report medically diagnosed CS, (Caress & Steinemann, 2009).
* Using the 2020 U.S. Census population of 253,881,932adults ages 18 - 65 means that between 32 million (12.8% medically diagnosed) and 65 million adults (25.9% self-report) in this country have CS.

## What is the impact of CS?

* By the time an individual with CS finds their way to a CIL, they very likely feel beaten up by a medical system that can’t help them; friends, family members, co-workers and employers who don’t believe them; and constant assaults on their well-being by the thousands of chemicals in the environment.
* Many people with CS have lost everything they own, declared bankruptcy, and gone through long stretches of time in which they could not work or participate in anything.
* Their sense of self will likely be severely traumatized. They may be very fearful about approaching yet another agency.
* You may be the only person who will listen, believe, provide support, and brainstorm solutions with them.
* Chemicals can affect any body system, so an individual may experience symptoms that include, but are not limited to:
* Physical (headaches, severe fatigue, chronic viral/bacterial infections, muscle pain, metabolic disorders, skin eruptions, asthma, irritable bowel, hypertension)
* Cognitive (difficulty thinking, confusion, “brain fog,” memory loss, Attention Deficit Disorder (ADD), Attention Deficit Hyperactive Disorder (ADHD))
* Neurological (seizures, nerve pain, peripheral neuropathy, coordination problems)
* Psychological (irritability, depression, panic disorder) (Jones & Lamielle, 2014).

## Implications for CILs

* These physical, cognitive, neurological, and psychological responses have implications for a wide range of accommodations that your center needs to think about and be prepared to offer.
* For example, it may not just be the removal of chemicals that’s necessary; if the person has cognitive reactions, you may need to make services accessible in ways that you now provide to people with head injuries, ADD, or learning disabilities. **The key is to know the individual**.
* As a non-profit organization with a limited budget, you can’t take on all the issues that are related to chemical sensitivities, but you can take on some things, and make a difference.
* Many accommodations are no cost or inexpensive and can be accomplished with common sense.
* The individual with CS is the best judge of what needs to be done.

## Things that your Center can do

* Take the person at their word. If they tell you they react to the plastic in their phone, or to their computer’s electromagnetic field, accept that as true.
* Assist the person to focus on functional issues and needs, rather than on all the things they’re reacting to and all their physical symptoms. Use a structured interview, guided by well thought out forms and checklists. Assist them to identify their needs, barriers, and goals.
* Example items for your checklist:
* What are the limitations the person is experiencing?
* How do these limitations affect the person’s daily activities?
* Which specific activities are problematic?
* What accommodations would assist in reducing or eliminating these problems?
* Which ones are non-negotiable, and which ones could be phased in over time as resources allow?
* Enact a fragrance-free policy at your center. Don’t get caught up in debates about individual rights and putting whatever you want on your body. If you are a Center for Independent Living, you have an obligation to be as accessible as you can be. Advertise your policy liberally. Examples of policy and email tag lines are shown below:
* ABILITY360 Policy Statement: All offices and spaces used by the staff and their visitors shall remain free of fragrances and scented products.
* ABILITY360 employee email signature: “This is a fragrance-free workplace. Thank you for not wearing or using any of the following during your visit: perfume, cologne, body sprays, aftershave, scented lotion, scented hair products, scented deodorant, scented laundry products and/or similar items. Our chemically sensitive co-workers and visitors thank you.”
* Enact an organizational policy that restricts fragrances in the workplace, including personal fragrances, cleaning products, and scented products such as potpourri, air fresheners, incense, and lighted candles.
* Fragrance-free soap and water kills COVID-19 and is the safest, most effective choice to address the virus. When selecting a cleaning product for your workplace, select fragrance-free, safer cleaning agents (<https://www.epa.gov/saferchoice>) and make sure that coworkers tolerate the product(s) without experiencing reactions.
* Minimize the use of disinfectants because most are harmful to people and cause disabling reactions for people with CS. If a disinfectant is deemed necessary, use the least harmful, least toxic, fragrance-free product(s) such as hydrogen peroxide or isopropanol alcohol, only after you verify that these would be safe for those with CS, coworkers, and visitors. Avoid toxic disinfectants. **Do not use** **citrus or pine-based cleaning agents.** Avoid more toxic disinfectants such as quaternary ammonium compounds, sodium hypochlorite (**chlorine bleach**), or phenolic compounds such as **Lysol**.All of these products are hazardous and cause debilitating reactions for people disabled by chemical exposures.
* Be conservative about renovations, using the least toxic paint and building products.
* Provide advance notice of chemical usage such as carpet shampooing, floor waxing, or painting through email or signage.
* Use only Integrated Pest Management practices that will be safe for ALL your staff and visitors. Links to more information on this topic are shown below.
* When possible, have cleaning done when the building is not occupied with maximum ventilation to reduce exposure.
* If consumers are too ill to come to your office, find ways of providing services that are safe, (i.e. via phone, email, regular mail, or Skype/Zoom). If you go to their home, please follow all their requests as to what you should avoid bringing, using, wearing, etc.
* If your CIL provides housing location assistance, when you survey landlords, include questions about planned renovations, use of pesticides, and neighborhood features such as industrial emissions, or whatever is relevant for your area. Safe and accessible housing for a person with CS may mean some type of segregated housing. Although this may be contrary to IL integrated housing philosophy, this may be essential for people with environmental intolerances.
* Provide the option of an employee with CS working at home if their job can be done at a distance. If not feasible, work with the individual to provide a workspace or office with operable windows and hard surface flooring as a job accommodation. If resources allow, create a safe zone within the center that will make their continued employment manageable. Ask employees or consumers with CS for advice on the room design and construction.
* Recognize that an employee with CS may need to rest during the course of a day. Allow rest breaks and provide a cot or other place where they can lie down.
* Educate coworkers to avert stigma and harassment.
* Many modifications necessary to accommodate the environmentally sensitive employee make the workplace healthier for everyone.
* Educate yourself about the key issues that people with CS face so you can provide support and advocacy. The top issues that you will likely encounter include:
* Constant challenges to identity—if new sensitivities develop, the person’s world may continue to shrink. Talking this through with a compassionate peer could be life-saving.
* Safe housing—it’s hard to come by, so everything you can learn will be helpful.
* Brainstorming solutions—if the person is severely fatigued or dealing with cognitive problems, assistance in sorting through the myriad resources and accommodations needed may be very welcome, (Jones & Lamielle, 2014).

## Where can I find resources and more information?

* Support groups, advocacy, websites, resources: <http://www.mcsfriends.org/resources/>
* Survival online guide by Pam Gibson, reports, studies: <https://www.mcsresearch.net/>
* Accommodating and understanding people with chemical, electrical & environmental sensitivities training: <https://www.accessibilityonline.org/ADA-Audio/archives/110387>
* The Chemical Sensitivity Foundation: [http://www.chemicalsensitivityfoundation.org](http://www.chemicalsensitivityfoundation.org/)
* Chemical Injury Information Network - referrals, library, housing, etc.: <http://ciin.org/>
* MCS Housing Information: <http://www.healsoaz.org/housing.htm>
* The Brief Environmental Exposure and Sensitivity Inventory is a screener for chemical intolerances with excellent predictive validity: <https://tiltresearch.org/qeesi-2/>
* National Center for Environmental Health Strategies - education, direct assistance, policy development, and advocacy: <http://www.ncehs.org/>
* U.S. Access Board’s Indoor Environmental Quality Project Report (2006): [www.access-board.gov/research/completed-research/indoor-environmental-quality](http://www.access-board.gov/research/completed-research/indoor-environmental-quality)
* Tips for transitioning to fragrance-free: <https://ncil.org/tips-for-transitioning-to-a-fragrance-free-life/>
* Sample environmental office policy, consumer statement: <https://ncil.org/abil-environmental-policy/>
* Environmental health barriers tool kit from NCIL: <https://ncil.org/ehb/>
* Beyond Pesticides, latest information on the hazards of pesticides and least toxic alternatives: [www.beyondpesticides.org](http://www.beyondpesticides.org/)
* USDA IPM website with resources, grants, partnerships, ecological strategies: <https://nifa.usda.gov/program/integrated-pest-management-program-ipm>
* National Pesticide information Center IPM information and resources: <http://npic.orst.edu/pest/ipm.html>

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1. One of the questions the Administration for Community Living, Office of Independent Living Programs asks in its CIL review process is: “Is the CIL physically accessible for individuals with significant disabilities, for example individuals with mobility disabilities (e.g., signage, doors, bathrooms, parking lots) or individuals with Environmental Illness and Multiple Chemical Sensitivity (e.g., no-fragrance policy or use of “green” cleaners)? See ACL’s Compliance and Outcome Monitoring Protocol (COMP) at <https://acl.gov/programs/il-comp>. [↑](#footnote-ref-1)