

Scientific Study

Disability and Social Stigma

“Invisible disabilities bring with them social stigma.”

An estimated 15 – 20% of the population suffers from one or more disabilities. A few of these disabilities are ‘visible disabilities’. A visible disability is one that apparent to a casual observer, such as the use of a wheelchair.

However, invisible disabilities are much more common than visible disabilities. Invisible disabilities are those which cannot be seen and understood by a casual observer. People with invisible disabilities look normal to others. Invisible disabilities include diabetes, asthma, heart conditions, fibromyalgia, fatigue, or back problems.

Invisible disabilities bring with them social stigma. According too Juliene G. Lipson of the University of California School of Nursing, “Hidden disabilities impose such difficulties as social and work restrictions; having to explain or defend one’s condition to others; having others doubt, blame, or trivialize one’s symptoms; and being misunderstood or having one’s behavior misinterpreted.

Lipson says that people’s perceptions of an individual with a hidden disability have three complica-

tions:

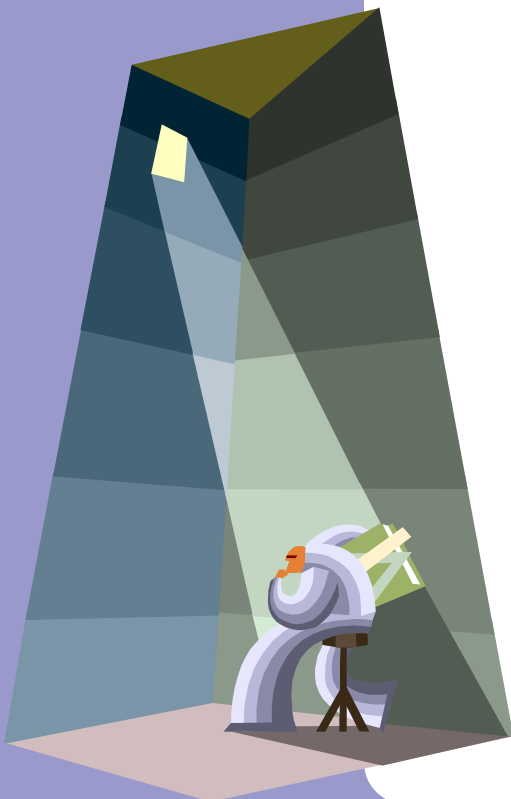
Sensory Invisibility - It is not manifested in differences that others can see, hear, or smell. Therefore it is not picked up on and may not be believed to be real.

Cognitive Invisibility – An observer’s mind set or bias alters their perception and blocks understanding and believing that the disabled person has a problem.

Absence – Other people do not see the disabled person when he or she is not feeling well enough to be out. Therefore, the disability may be viewed as an exaggeration or as non-existent.

Multiple chemical sensitivity (MCS) is an invisible disability in which negative health effects are experienced from exposures to common chemicals found in fragrances, perfumes, cleansers, personal care products, building materials, and others. The health effects range from minor headaches to pain, brain fog, fatigue, and breathing difficulties. Seizures and loss of speech result in more severe cases.

People with MCS, like others with indivisible and stigmatized disabilities face considerable social, attitudinal, and logistical barriers. Lipson describes the challenges that people with MCS face in terms of cultural and economic impact.



“The corporate profit motive also reinforces the stigma attached to MCS.”



Cultural – As opposed to group or community well-being, Americans place a strong emphasis on individual “rights” to wear what they want and do what they want. There is a general lack of concern for how the things we do affects others. “When someone with MCS mentions a problem with someone else’s fragrant body product,” Lipson says, “quite often that person will say or think “You can’t be serious!” instead of examining what he or she is wearing.

It is difficult for most to understand the extent to which we all share the air, particularly the concept that fragrance, cleaning chemicals, and pesticides remains in the area long after they are used or the person wearing it has left. Those who try to be accommodating rarely realize that the fragrance residue on their clothing or their deodorant could be a problem. The predominant dogma in America, supported by the fragrance industry’s profitable advertising campaigns, is that nice smells are better than bad smells or no smells.

Economic – Lipson says, “The corporate profit motive also reinforces the stigma attached to MCS.” The fragrance and chemical industry have made valiant efforts to deligitimized MCS because they stand to lose trillions of dollars. Industry has also interfered with the development of a case definition for MCS, which has interfered with funding for research on MCS.

MCS impacts several areas of life according to Lipson:

Family and friends frequently do

not understand the seriousness of their loved one’s MCS condition. Becoming ill from air freshener or perfume, for example, sounds strange enough to be ignored as the fabrication of a hypochondriac. In some cases, these seemingly strange comments and requests from those with MCS generate hostile behavior. Being shunned by family and friends is not uncommon, nor is being called weird or crazy. Some patients will try to tolerate exposures just to be with family, but this comes with the price of rapidly deteriorating health.

Work and school associates often fail to take the MCS condition seriously and fail to comprehend the extent of the sensitivity due to an otherwise normal appearance. Asking for accommodations,” according to Lipson, “may be met with hostility, scapegoating, or harassment.” Hostility from associates is common, as is assaults, such as intentional spraying of copious amounts of perfume. Since they can’t see the disability and wrap their brain around why it would impact performance, bosses and teachers are shocked when a person with MCS does not meet their expectations or fails to produce a high volume of work. Lipson sites limitations in activities or problems with access, general low energy, or an upsurge in symptoms following a large exposure as impacting factors. Because employers and teachers cannot understand and see these factors, they often turn to blaming the person with MCS for being irresponsible or lazy, even though they are working to the best of their ability. Being fired, rather than accommodated, is not uncommon.

“There are various ways to fight back and regain some normalcy in life.”

Physicians who treat MCS are frequently stigmatized themselves. There is a concerted industry effort to remove the licenses of physicians who research and treat MCS. Since, pharmaceuticals often make the MCS patient worse, physicians who are not informed about MCS may take a stance that the patient is malingering or has a non-medical condition. Many MCS patients leave mainstream medicine because it has proven ineffective and frustrating.

Moving Forward – Despite the many challenges of MCS, social stigma can be the most devastating. There are various ways to fight back and regain some normalcy in life, such as:

- Joining an online forum or other peer group for support and socializing.
- Becoming an activist and fighting for the cause.
- Educating others about MCS and their own chances of getting it.

- Lobbying for access rights through the Americans with Disabilities Act.
- Engaging in report and petition writing.
- Getting involved in legislation for greater fragrance and chemical controls.
- Reaching out to others and sharing with others who have MCS.
- Finding alternate ways to enjoy meaningful things and activities.
- Cherishing the good moments and using pacing for the rest.
- Keeping expectations realistic.
- Seeking help when it’s needed.
- Addressing problems actively with a resolution in mind.
- Finding ways to unwind and deal with anger.

Reference

Lipson, JG. Multiple Chemical Sensitivities: Stigma and Social Experiences. *Med Anthropol Q.* 2004 Jun;18 (2):200-13.

