

# **Chemical Sensitivity at the Federal Level**

## **A Reality Check: Where We've Been, Where We Are, Where We Need To Go**

*Presented by*

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CHEMICAL SENSITIVITY AT THE FEDERAL LEVEL: A REALITY CHECK  
WHERE WE'VE BEEN, WHERE WE ARE, WHERE WE NEED TO GO

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**Objectives:**

1. Describe federal action on multiple chemical sensitivity (MCS) over the last decade.
2. List successful policy statements and specific legislative and regulatory action on MCS.
3. Discuss obstacles to continued educational, research, and policy efforts.
4. Discuss efforts to preserve accomplishments and to develop a comprehensive agenda to advance additional issues relevant to patients, physicians, the public, and others.

There has been significant federal action on multiple chemical sensitivity (MCS) over the last ten years. As director of the National Center for Environmental Health Strategies (NCEHS), I have been directly involved in and frequently a catalyst for such action. Yet, as we approach the end of this decade, we are finding that progress has slowed down in some areas. We are also finding some of our landmark achievements subject to challenge from industry and segments of the medical community, among others. It's an appropriate time to review our past successes and to develop an action plan that will ensure future progress.

The accomplishments over the last ten years are many and substantial. They include the Social Security Administration recognition of MCS in the agency's Program Operations Manual in February 1988, the evolving HUD policies and landmark legal memorandum issued on April 14, 1992, and the inclusion of MCS in the Americans with Disabilities Act.

Meanwhile the first Congressional testimony on MCS was presented by the National Center for Environmental Health Strategies in support of the Indoor Air Quality Act in May of 1989. A recommendation for a report to Congress on MCS was subsequently included in the legislation. In September 1992, NCEHS worked to secure the first directed Congressional funds for research on MCS. The funding went to the Agency for Toxic Substances and Disease Registry (ATSDR). ATSDR subsequently convened an expert panel on MCS, funded a Neuroscience workshop held in Baltimore, Maryland, and funded, in part, efforts by the California Department of Health Services. It also funded the Interagency Workgroup Document, A Draft Report on Multiple Chemical Sensitivity (MCS). The review period for the document closed October 30, 1998.

During this same period I was invited to be part of numerous government invitation-only committees, Congressional Advisory Boards, national policy programs, legislative efforts, research planning committees, and research workshops on MCS as well as related topics of indoor air quality, pesticides, and disability policy. This included the U.S.

Environmental Protection Agency (EPA) Lawn Care Pesticides Advisory Committee, appointment to the President's Committee on Employment of People with Disabilities, the 1996 Disability Policy Summit sponsored by the National Council on Disability, EPA Human Health Policy Committee, and others. I have also presented workshops and lectures for many federal agencies including the U.S. Department of Housing and Urban Development (HUD), regional and national offices, Department of Agriculture, and the Department of Justice.

Even before I was able to participate in the dialogue in person, a trio of officials from the U.S. EPA Office of Pesticide Programs, including the Director, visited me to discuss the effects of pesticide exposures on those with MCS.

Having a seat at the table, being a player, is essential to moving our agenda forward in any meaningful way. Direct participation, however, does not guarantee success or inclusion, nor does it even ensure respect for our disability. Nevertheless, participation is power. It clearly makes it difficult to ignore MCS.

Our greatest successes have been with agencies that deal directly with populations facing discrimination and disability. With HUD, for example, action at the federal level was possible because those disabled by MCS sought agency assistance in their homes, in their communities. The agency and its regional offices got involved with real people. These officials became aware of the hardships faced by those with environmental disabilities. They listened to those in need, and learned about the disability and its impact on health and survival.

This level of success has not been repeated in agencies such as the EPA, for example, where policy derives from the top down, and where many aspects of the government program depend on the non-existence of MCS. The concept of multiple chemical sensitivity challenges the very standards that define the agency. If it's true that people are susceptible and vulnerable to low level chemical exposures, some of the agency's core health assumptions are wrong. This is not to say, of course, that agencies such as the EPA and others have not responded to MCS, or that individuals or divisions within these agencies have not been helpful. They certainly have been. However, it does not appear that there is a significant commitment on the part of such an agency to answer the hypothesis: are people sick from low level chemical exposures.

In the last several years attacks on MCS patients and on their physicians propelled by the economic interests of industry and segments of the medical community have intensified. This climate has side-tracked regulatory, policy, and research efforts that might have otherwise addressed or clarified many of our issues. The longer we remain in such a tenuous position, the greater danger we face in seeing our progress erode or disappear. The challenges from vested interest in industry and segments of the medical community have hounded our success throughout this decade. Shortly after HUD announced its initial policy on MCS in October 1991, the American College of Occupational Medicine

(ACOM), currently known as the American College of Occupational and Environmental Medicine (ACOEM), challenged the agency's authority to make such a determination. Similarly, coverage of MCS by the President's Committee on Employment of People with Disabilities in their publication *WorkLife* led to protests from the corporate medical community. In these instances agency personnel were entirely committed to their decisions and held their ground.

It is important to keep in mind that the more susceptible we are to challenge, the more difficult it can be for our allies to defend us. It can make agency support for and inclusion of MCS more difficult in part because an agency such as HUD or an independent agency such as the President's Committee on Employment of People with Disabilities may be forced to take on industry attacks on their larger agenda items, such as the Americans with Disabilities Act (ADA), as well as on our inclusion in that law in particular.

This Anti-MCS mindset defeated us in February 1998 when we worked to get report language in the proposed Reauthorization of the Vocational Rehabilitation Act to identify considerations specific to those with MCS. The legislative aide involved in this decision was familiar with persons disabled by MCS as people who have been taking advantage of the ADA. Despite support from other disability organizations, the proposed language was rejected.

In some ways we are still dealing with repercussions from the ABC 20/20 segment on MCS with John Stossel. The segment successfully undermined support for MCS among some individuals in government and the professional community. We found that many contacts who were formerly fence-sitters, but willing to work with MCS patients and MCS issues, were suddenly less tolerant of patient needs and more willing to challenge the disability. In the future, we might need to be more cautious when putting our hand into the hornet's nest. Patients are too vulnerable to face such significant fallout, and it can be difficult to defend against such well-orchestrated attacks.

We are in a tenuous period. It is important to preserve our victories, to educate and cultivate professionals, government personnel, policymakers, legislators and the public, and to find or create opportunities to advance our agenda. It is important to explore more effective means to catalyze action when opportunities present themselves. Most importantly, we need to develop a platform that will examine the myriad of issues relevant to patients and their physicians, including medical services, healthcare, insurance, housing, employment, education, research, and the like. Such a strategic plan would review where we have been, where we are, and where we need to go, and provide a map for the journey.

# FEDERAL RECOGNITION OF MCS

- **Social Security Administration**

February 1988 Transmittal Letter, Program  
Operations Manual

- **Department of Housing and Urban Development**

October 26, 1990 - Policy Statement  
Recognition of the disability;  
Reasonable accommodations for those disabled under Fair  
Housing Act and Rehabilitation Act of 1973

April 14, 1992 - Legal Memorandum  
Recognition of MCS/EI as a physical disability entitling  
reasonable accommodation on a case by case basis  
Excludes allergies  
Extends coverage to those recognized as disabled by Social  
Security Administration  
Lists other federal agencies that recognize MCS

- **Department of Education**

Recognition and relevant legal cases referenced in the HUD  
Legal Memorandum

- **Civil Rights Division, U.S. Department of Justice**

Americans with Disabilities Act Guidelines, July 26, 1991  
Those severely affected by MCS “will satisfy the requirements  
to be considered disabled under the regulation.” **Federal  
Register**, Vol. 56, No. 144, pp. 35549, 35699:

# HUD RECOGNITION OF MCS

## • Department of Housing and Urban Development

October 26, 1990 - Policy Statement  
Recognition of the disability;  
Reasonable accommodations for those disabled  
under Fair Housing Act and Rehabilitation Act of 1973

June 6, 1991 - Draft Technical Guidance Memorandum 91-3  
Discusses HUB recognition of MCS as a handicap and provides  
examples of accommodations which are considered reasonable

April 14, 1992 - Legal Memorandum  
Recognition of MCS/EI as a physical disability entitling  
reasonable accommodation on a case by case basis  
Excludes allergies  
Extends coverage to those recognized as disabled by Social  
Security Administration Lists other federal agencies that  
recognize MCS

## **NCD Recommends Action on MCS**

**Mary Lamielle, director of the National Center for Environmental Health Strategies (NCEHS), was one of several hundred disability leaders invited to a disability policy summit sponsored by the National Council on Disability (NCD) in Dallas, Texas in April 1996.**

**Those NCEHS recommendations which were incorporated into the NCD report Achieving Independence emphasize the nature of this disability and the serious needs of this underserved and frequently misunderstood population.**

**The following passages are recommendations from the NCD report:**

### **INTRODUCTION:**

**Some disabilities are less acknowledged and less understood than others. For example, people with multiple chemical sensitivities have a particularly difficult time securing recognition for their disability. Most people do not understand the chemical and environmental barriers that preclude such persons' access to the most basic and essential areas of life, such as housing and education. (p. 10)**

### **HOUSING**

#### **Construction Practices:**

**5. The Congress and the President should develop initiatives to promote the universal and accessible design of housing, including:**

- e) Increasing the number of two-and three-bedroom units available to people with disabilities in order to support families that include members with disabilities and to accommodate individual needs such as equipment storage, attendants' rooms, home offices, and space to isolate toxic products within dwellings (for people with multiple chemical sensitivities).**

#### **Research and Data Collection:**

**6. Congress and the administration should develop initiatives to expand research and data collection about housing for people with disabilities that involve the input and participation of the disability community. Research results and data collected as a result of these initiatives should be routinely disseminated through a variety of accessible communication mediums. Topics for research and data collection should include:**

- b) ways to expand the effective design of housing for people with multiple chemical sensitivities (pp. 123-124)**

## **HEALTH INSURANCE AND HEALTH CARE**

### **Public Health:**

**10. Congress should establish a focal point of leadership within the Federal Government to define, implement and coordinate a public health agenda for individuals with disabilities.**

**...The promotion of clean air and use of nontoxic substances (such as industrial cleaners) in public places is of particular concern to people with multiple chemical sensitivities and should be addressed within the public health agenda. (pp. 93-94)**

## **Appendix A**

### **Recommendations for the National Council on Disability**

#### **Multiple Chemical Sensitivities:**

- 23. NCD should catalyze action on multiple chemical sensitivities in the appropriate federal agencies to expand and enhance the rights of those with these disabilities.**
- 24. NCD should engage in and urge Congressional authorization and funding for a comprehensive education, research and policy development agenda to address multiple chemical sensitivities and related disabilities. (p. 159)**

## **Appendix B**

### **Emerging Issues**

#### **Multiple Chemical Sensitivities**

**Discussion led by Mary Lamielle**

**Decision makers are generally unaware of the disability called multiple chemical sensitivities and lack information about the chemical and environmental barriers that preclude access and accommodations for people with this disability. Most people with this disability find it difficult to achieve a reasonable quality of life because, owing to environmental exposures. They are frequently denied access and accommodations in the most basic and essential areas of their lives, including housing, employment, and education, and in their efforts to secure basic goods and services. The nature of these barriers and their impact on this population must be integrated into any policy response to this disability. (p. 161)**

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