

**Community Rebuttal to the Government's  
Response to the Social Development Committee  
Inquiry into Multiple Chemical Sensitivity (MCS)**

**OPENING COMMENTS**

The Government's Response to the Social Development Committee Inquiry into Multiple Chemical Sensitivity is unacceptable to people living with MCS and the community-based groups that support them. The Response is inflammatory and escalates the existing conflict between the people affected by MCS and the authorities that obstinately refuse to address the problem. The Department of Health claims that it has "assumed a lead-agency role" that incorporates the response of other departments. Rather than showing leadership it is clear that sceptical elements within government are seeking to undermine the good work of the Social Development Committee and the decades of effort by people living with MCS in trying to bring this serious and growing public health crisis to the attention of authorities.

The Response has referred to the term MCS as a "misnomer, as it is not proven that chemicals are the sole causal factor". The tiresome debate surrounding the nomenclature of MCS has been used by sceptics and the chemical industry to obfuscate the facts and prevent action on MCS. The main objection to the term MCS arises from the fact that, since the discovery of allergy related antibodies in the 1960s, conventional immunologists have used the term "sensitivity" to describe immune system mediated allergy-type reactions and the alternative term "intolerance" to describe non-immune system mediated sensitivity reactions. According to this conventional understanding, MCS must not be described as "sensitivity" because there is little evidence that the condition is mediated by the immune system. This dogmatic objection to the term MCS has not resulted in any benefit to those people who actually live with the condition. Moreover, MCS sceptics must realise that they do not hold a monopoly over the evolution of medical nomenclature. The term MCS is in common use in medical literature and objections to the term are immaterial when considering the actual signs and symptoms of the illness and the available evidence of their association with chemical exposures.

The Response has focussed on the "lack of consensus on causation and diagnosis" surrounding MCS. Those who are ideologically opposed to the recognition of MCS will likely never be satisfied with any understanding of MCS until a diagnostic marker becomes available for the condition and the physiological mechanisms behind MCS are fully elucidated. That the sceptics should demand such a level of proof before beginning to address the problem is entirely unreasonable given the very poor state of research and medical interest in MCS. It may be many decades before a single diagnostic marker becomes available, if at all. However, despite this so called "lack of consensus" people with MCS and the clinicians and researchers who support them have made great progress in the medical and scientific understanding of the disorder. Unfortunately, this work has been almost entirely ignored or treated with antipathy by the mainstream. This problem of academic bias and its resulting discrimination against people with MCS must be addressed if the questions of causation and diagnostic consensus are to be resolved.

Objections to the recognition of MCS are generally based on ignorance and utilitarian economic principles rather than good medical science, where meticulous clinical assessment of the patient is fundamental to first-class medical practice. Often these objections come from academics and scientists who have no experience whatsoever in the clinical management of the patient with MCS. The fact that the Department of Health has no existing protocols with regard to the diagnosis and management of MCS is a clear example of how government bureaucracy has abjectly failed to engage with the issue.

MCS can very easily be diagnosed on clinical presentation using internationally accepted criteria. Medical practitioners in South Australia are already applying this diagnosis and the Social Development Committee heard evidence from the Department of Health that nearly 1% of South Australians have been medically diagnosed with MCS. The Committee concluded that "up to 6 percent of the population may have MCS, with between 10-25 percent experiencing sensitivity to chemicals".

If people with MCS were not pointing to a chemical causation for their disease it is unlikely that the level of controversy surrounding their diagnosis would exist. To quote Bartha et al in "MCS: A 1999 Consensus", published in *Archives of Environmental Health*, Vol 54:

*The millions of civilians and tens of thousands of Gulf War veterans who suffer from chemical sensitivity should not be kept waiting any longer for a standardized diagnosis while medical research continues to investigate the etiology of their signs and symptoms.*

The Response has correctly stated that the Social Development Committee "appears to have moved to a view that chemicals are the cause of MCS". However, the Department of Health has advised that "it is not proven that chemicals are the sole causation of MCS". The Social Development Committee is composed of sensible, intelligent people who undertook an unbiased review of the medical and scientific data on MCS and received an unprecedented number of national and international submissions, including many from people with MCS and the community groups that support them. Given the wealth of evidence that MCS is associated with chemical exposures it is not surprising that the Committee should have formed the view that chemicals are the main cause of MCS. In its negative response to the Committee's findings the subtext from the Department of Health is that MCS is a psychological condition, a kind of mass psychosis affecting up to 6% or more of the population. In fact, there is very little evidence for a psychogenic aetiology in MCS and this view is most likely to be based on academic bias and commercial conflicts of interest. To quote Caress and Steinemann in "A Review of a Two Phase Population Study of Multiple Chemical Sensitivities," published September 2003, Vol 111, No 12 of *Environmental Health Perspectives*:

*"A significant percentage (27.5%) [of people with MCS] reported that their hypersensitivity was initiated by exposure to pesticides, whereas an equal percentage(27.5%) attributed it to solvents. Only 1.4% had a history of prior emotional problems, but 37.7% developed these problems after the physical symptoms emerged. This suggests that MCS has a **physiologic and not a psychologic etiology.**"*

The covert promulgation by the Department of Health of the unscientific view that MCS is a psychological entity requiring no organised response from governments threatens the maintenance of public health and endorses the continuing discrimination against people with MCS.

The Department of Health has stated that it "believes that it is extremely difficult for SDC or others to identify priority areas of action while the central issue of causation remains unsolved. Notwithstanding, it is evident that MCS leads to morbidity in some people and may represent a significant cost to society".

The debate surrounding MCS is comparable to other contemporary environmental crises, such as global warming. Despite clear evidence of the role of human activity in climate change, sceptics continue to cast doubt on these data and have inhibited governments from taking clear action to address the problem. Often these sceptics have links to those industries that are major producers of greenhouse gasses. The same situation is true of MCS, with chemical industry representatives and scientists with links to the chemical industry attempting to deny and distort evidence of the association between chemical exposures and MCS. Unfortunately, there are MCS sceptics within government who have historical links to the chemical industry, either directly or indirectly through chemical regulatory mechanisms, and whose prior training and existing mind-set makes them incapable of supporting reforms in chemical use in order to protect public health and human rights. What is required from government and the Department of Health is a far more precautionary approach with respect to the use of toxic chemicals and a willingness to creatively review current toxicological paradigms in order to include MCS.

The Social Development Committee heard medical evidence that the incidence of MCS is increasing in the community. The cost of MCS to society is already large with one Canadian study, which found 2% of Canada's population seriously disabled with MCS, estimating the cost of environmental illness in that

country to be around \$13 billion dollars annually when lost productivity is included. As more people become affected by MCS the cost to society will increase. Also, as evidence of the link between MCS and chemical exposures increases, so will there be increasing demands from people with MCS for just compensation for their chemical injury. The angry public rallies seen recently with respect to asbestos related diseases are an example of what the future holds for MCS. However, in the case of MCS, public anger is likely to be directed against governments, rather than individual companies, for allowing the widespread use of toxic chemicals under regulatory mechanisms that have clearly failed to protect public health.

There is now a significant body of epidemiological and clinical data spanning more than fifty years to show that toxic chemical exposures are capable of initiating MCS and that the most effective treatment for MCS is the avoidance of chemicals, foods and medications that trigger symptoms. The Department of Health's efforts to deny the link between chemical exposures and the reality of the experience of people with MCS is an attempted negation of their basic human rights.

Unfortunately, it is not entirely surprising that government institutions with responsibility for public health appear incapable of responding appropriately to the emergence of MCS. To quote Pamela Reed Gibson, PhD, Associate Professor of Psychology at James Madison University, in her booklet "Understanding and Accommodating People with Multiple Chemical Sensitivity in Independent Living", published by the Independent Living Research Unit, with funding assistance from the US Department of Education:

*MCS is an illness that is caused by industrialism, it is an indictment of industrial culture because it directly points to chemicals as a cause of disability, and it is totally incongruent with industrial culture. We are a culture that does "risk assessment" of each of our chemicals allowing a certain number of people to get sick or die from exposure to each chemical. While the EPA continues to compile lists of cancer causing agents, the field of health psychology continues to look for the "cancer personality" that supposedly renders some persons more psychologically prone to the development of cancer. We are experts at ignoring the obvious. While babies on the U.S. - Mexico border are born without brains, our industries continue to dump wastes into the air and water of that geographic region. Our institutions are created out of the same industrial paradigm that allows this contamination, and are therefore not only not positioned to respond in any constructive way, but are in many cases set up to deny and distort the reality of chemical-induced disability. This cultural set-up makes for personal struggles in a number of venues.*

The Government's Response to the Social Development Committee Inquiry into MCS has been to fully support less than a handful of the most conservative recommendations (numbers 3,4,6, and 9.1), while giving only in-principle support to six (numbers 1,2,5,7,8, and 10), and rejecting two crucial recommendation that would assist people with MCS to equitably access health care services (numbers 9.2 and 11).

There are numerous unacceptable inconsistencies in the Response, notably those surrounding equitable access to services and public spaces for people with MCS. People living with MCS and the community groups that support them therefore call on the government to give its full and unqualified support to all the Social Development Committee's recommendations and to implement them within a reasonable time frame.

## RECOMMENDATIONS

- 1. That the Department of Health (DH) monitors the prevalence of MCS in SA and compiles comparative data on the incidence of MCS to enable trend analysis.**

## Supported in principle

The Department of Health has stated that: “the Department has already gathered data from over 4,000 individuals and determined that MCS has a prevalence of about 1 per cent in SA. Whether further surveys can be done will depend on priorities for resources within the Department for surveillance activities.”

National and international epidemiological data have shown that up to 6% or more of the population may have moderate to severe MCS, with up to one third of the population reporting some form of chemical sensitivity. Experienced MCS researchers are warning that those people in the larger chemically sensitive group may be at risk of developing more severe and permanent symptoms of MCS. This situation must be monitored closely in the public interest.

The Social Development Committee heard medical evidence that the incidence of MCS is increasing in the community. MCS researchers generally agree that, with the current situation regarding chemical use, it is inevitable that cases of MCS will increase. In order to monitor this expected increase the Department of Health must demonstrate a responsible interest in this matter and be provided with sufficient resources. Any impediments to a full understanding of the incidence of MCS due to variations in survey questions and medical knowledge can be adequately resolved through careful attention to the problem. The government’s response to MCS must be based on accurate population data and the accumulation of that data should be given priority.

***This recommendation should be fully supported by Government.***

## **2. That DH:**

- 2.1 coordinate and consult with relevant professional bodies, organisations and community groups in the production of an Information Sheet outlining the current position of MCS, including working definitions and symptoms commonly associated with the condition;**
- 2.2 coordinate the dissemination of information on MCS to a wide range of organisations and groups including medical practitioners, local Councils, and the general public, through appropriate information distribution channels.**

## Supported in principle

The Department of Health’s objection to providing unqualified support for this recommendation is based on its demand that there be full consensus regarding the diagnosis and causes of MCS. Until this is achieved the Department appears to intend to remain silent on the issue. Given the long history of denial of MCS and the well resourced efforts of the chemical industry to prevent recognition of MCS, it is extremely unlikely that such consensus will be achieved in the near future.

What is required from the Department of Health here is strong leadership in promoting the MCS debate and responsible information dissemination to the public, not vacillation and silence. Waiting for complete consensus before proceeding with any public education campaign is unacceptable.

This official mind-set of denial and inaction on emerging public health issues has been seen far too often. For many years the tobacco industry successfully denied evidence of links between smoking and cancer and the public is still waiting for adequate controls on smoking in public areas. Asbestos manufacturers knew as early as the 1940s that asbestos was linked to lung disease but it has only been in recent years that adequate controls on asbestos were introduced, and only then because of the actions of those people affected by asbestos related diseases.

The Department of Health should be reminded that there is still no complete medical consensus that HIV is the cause of AIDS and we have seen the results of the “waiting for consensus” strategy in recent years in Africa, where governments have denied their people access to life saving antiviral medications on the basis that HIV might not be the cause of AIDS.

The public has a right to be accurately informed of the MCS debate so that people can make their own choices as to whether they wish to be exposed to chemicals associated with MCS. Medical education on MCS is also urgently needed as people with MCS need access to informed medical services, instead of being shunted from one ignorant practitioner to another during their prolonged medical odyssey. A broad education campaign on MCS is vital if this is to occur.

***This recommendation should be fully supported by Government.***

- 3. That DH convene an MCS Reference Group including representatives of relevant Government departments and agencies including PIRSA and the EPA, professional bodies and organisations, community groups, and Councils nominated by the Local Government Association, to maintain ongoing communication and provide up-to-date information on developments in the MCS debate.**

Supported

The MCS Reference Group should be convened as soon as possible within the first six months of 2006 and its Terms of Reference clearly outlined. It is vital that membership of the group includes people who actually live with MCS and that the group operate under MCS disability access principles.

Although the establishment of an MCS Reference Group is a progressive step forward, simply continuing to discuss MCS is not sufficient to address the problem.

- 4. That the PIRSA Chemical Trespass Coordinator continue to provide assistance to people with MCS in addressing instances of chemical trespass as they arise.**

Supported

While support for the continuance of PIRSA’s Chemical Trespass scheme is welcome, this recommendation does not go nearly far enough to protect the public from chemical exposures associated with initiating and exacerbating MCS, notably pesticides. Current arrangements with respect to incidents of chemical trespass are principally reactive and do little to pro-actively prevent the serious problem of involuntary chemical exposures. What is actually needed here is pesticide legislation requiring mandatory prior notification of pesticide applications to a register of people with MCS, or others who wish to be informed of possible health risks caused by other people’s use of chemicals. Penalties must apply for failing to notify.

An example of how current pesticide standards and associated legislation have failed to protect people with MCS was reported to the SA Task Force on MCS around Christmas 2005. A mother and her young child, both of whom suffer with severe MCS, were made extremely ill and forced out of their home due to their neighbour’s failure to notify commercial pesticide use, as previously agreed. All attempts by the mother to secure state assistance for emergency MCS accessible accommodation failed. The mother and child spent their Christmas alone, on an isolated property, with no amenities, in a tent ripped by gale force winds, as they could not return to their pesticide contaminated home without experiencing severe sensitivity reactions. This situation is blatant and immoral human rights abuse.

***Government must introduce prior notice pesticide legislation.***

5. **That the MCS Reference Group convened by DH work to develop best practice guidelines to enable local Councils to establish No-Spray Registers that identify MCS sufferers, and those with chemical sensitivities generally in local communities. This would include identifying current best practice models of No-Spray Registers among Councils to inform the reference group's best practice guidelines.**

Supported in principle

The Department of Health has pointed to the fact that some Councils have already established No-Spray Registers and intends to build on existing experience to expand such programs.

The Government should be aware that any existing arrangements with Councils for No-Spray Registers are not based on any acknowledgement of the health problems associated with herbicides but merely offer residents the opportunity to be responsible for the maintenance of the footpath weeds directly outside their property in exchange for an agreement not to spray herbicide in that area. These no-spray agreements are frequently breached by Council contractors, who have no training in MCS and who are educated to believe that herbicides are safe for everyone when used as directed.

People with severe MCS have reported serious and potentially life threatening herbicide sensitivity reactions when Councils spray herbicide up to one kilometre or more from their homes. These people are often being forced to relocate during and shortly after their Council's herbicide activities. People with MCS also report severe herbicide sensitivity reactions from using public areas that have been treated with herbicide up to five days prior. At present there is no recognition of the breach of basic human rights this situation represents. If Councils are benefiting economically from their use of what they claim is relatively inexpensive herbicide, then the rights of people with MCS to enjoy the amenity of their own homes and to safely access public areas must be recognised in order that they can be protected and adequately compensated for any losses.

No-spray arrangements with local Councils must take the above factors into account. Furthermore, the need to routinely spray herbicides in residential areas must be questioned. The Social Development Committee found evidence that the herbicides used by Councils are associated with MCS. The Committee described these herbicides as "particularly pernicious" for people with MCS and recommended No-Spray Registers. However, if these chemicals are so noxious to a minority of the population to require no-spray registers, why are they being routinely sprayed in our streets and parks?

The wider community is increasingly intolerant of chemical herbicide use in public areas. On Dec 2, 2005, a public health protest rally was held outside Local Government House calling on the Local Government Association and all local Councils to end the routine use of herbicide in residential areas. This event marks the beginning of a continuing community campaign for more responsible herbicide use by local government.

***This recommendation should be fully supported by Government, together with ending the routine use of herbicide in residential areas.***

6. **That PIRSA:**

- 6.1 **encourage all relevant bodies across SA to adopt and implement best practice guidelines for administering chemicals;**
- 6.2 **advise local Councils through the LGA, on best practice in the use of chemicals and in working with local communities to implement best practice measures, particularly in relation to No-Spray Registers;**

**6.3 ensures that all Councils clearly understand their legal obligations with regard to chemical use, as outlined under Control of Use legislation.**

Supported

While support for this recommendation is welcome, it must be acknowledged by government that existing standards in chemical regulation have failed to adequately protect public health or the basic human rights of the minority with MCS. In most cases Councils are already using best-practice guidelines for herbicides, with their contractors' use of herbicide being overseen by the Department of Health.

Continuing reliance on failed best practice guidelines is an integral part of the MCS problem. A new paradigm of chemical regulation which recognises chemical sensitivity as the serious public health problem it has become and which reduces overall human exposure to toxic chemicals is urgently required. Governments at all levels must be actively involved in these necessary chemical reforms.

**7. That the DH collaborates with the Department for Families and Communities (DFC) and other appropriate agencies and organisations, with the view to exploring practical measures that could assist in addressing disability access issues experienced by MCS sufferers, in relation to public facilities and services in the community.**

Supported in principle

While giving in-principle support to this recommendation the Department of Health then attempts to back-pedal with claims that "the lack of consensus on chemical causation means that improving access to public facilities for MCS sufferers may not be as simple as reducing chemical exposures voluntarily or legislatively". While acknowledging that "institutions would need to be made aware that some MCS sufferers do have specific needs" the Department then seeks to deny people with MCS disability status and the need for a broad MCS disability access strategy across its services.

It is not acceptable that the Department of Health attempt to stall social action on MCS solely on the basis of official uncertainty regarding the exact causes of the condition. There are now numerous clinical studies which have concluded that avoiding chemical exposures is the most effective treatment for MCS. Some people with severe MCS may have extreme intolerances to very low levels of exposure which makes accommodating their needs difficult. However, people with MCS generally agree that any reduction in chemical exposures is of benefit. Products identified as commonly triggering symptoms of MCS include, cleaners, pesticides, tobacco smoke, fragrances, new building materials, volatile solvents and petrochemicals. Offering people with MCS reasonable access to services by limiting and controlling those products associated with MCS is not impossible. What is required from authorities is a committed determination to undertake this task.

The Response states that the Department of Families and Communities "is keen to address the disability access issues faced by people with disabilities in relation to public facilities and services in the community. However, MCS does not fall within the scope of disability for this purpose since DFC currently regards MCS as a chronic medical condition, as opposed to a disability." Clearly the Department of Families and Communities is actively discriminating against people with MCS by attempting to deny them disability status.

In its opening General Comments the Department of Health acknowledges that "it is evident that MCS leads to morbidity in some people and may represent a significant cost to society". It is, therefore, difficult to understand how the Department of Families and Communities justifies its position that a "chronic medical condition" leading to "morbidity" does not result in disability. This attempt by the Department of Families and Communities to exclude people disabled with MCS from access to its services is reprehensible and based on economic rather than medical considerations. With respect to recognising MCS as a disability the 1996

New Mexico, USA, Senate Inquiry into MCS, which was undertaken by the Governor's Committee on Concerns of the Handicapped, made the following comments:

*One concern raised to the Committee was that it would be a costly and improper expansion of benefits to imply any legitimacy to the concerns of persons experiencing MCS especially to accept it as a "disability". We find this argument a distraction and based on an assumption with which we take great exception. Accommodating persons with disabilities is not a great expense and is well justified by the advantage both to the person with a disability and the accommodator in that a fuller spectrum of society is served. Even if one is considered to have a "disability" there is no automatic right to any benefit: the disability must prevent work to obtain social security benefits, it must affect mobility to get a parking placard, and it must "substantially limit a major life activity" to be entitled to accommodation. Further the accommodation must be reasonable and not considered a personal service. These determinations are made on a case by case basis and it is the functional limitation, not the title given the condition, that determines medical necessity, a precondition to any medical benefits.*

Below is an incomplete list of South Australian organizations that have agreed to adopt specific MCS disability access strategies to date, either as general policy or for specific events and circumstances.

- Adelaide City Council
- AIDS Council of South Australia
- Art Gallery of South Australia
- Australian Democrats
- Australian Greens
- Barossa Meats
- Bear Men of Adelaide
- Catholic Church of the Holy Name
- Department of Health
- Department of Primary Industries and Resources
- Disability Action
- Disability Advocacy and Complaints Service of SA
- Disability and Rehabilitation Professionals' Association
- Disability Information Resource Centre
- Feast Festival
- Health Consumers Alliance
- Local Government House
- ME/Chronic Fatigue Syndrome Society of SA
- Onkaparinga City Council
- People Living with HIV/AIDS
- Pilgrim Uniting Church
- Pocketwomen
- Royal Adelaide Hospital
- South Australian Task Force on MCS
- South Australian Tourism Commission
- South Australian Housing Trust

These strategies generally focus on fragrances, pesticides, cleaning products, building and maintenance products, tobacco smoke, vehicle exhaust, maintaining indoor air quality and prior notification and signage where toxic products are in use.

There are now numerous models of MCS disability access policy available. One good example is from the Job Accommodation Network (JAN), a service funded by the Office of Disability Employment Policy of the

US Department of Labor. JAN's publication "Worksite Accommodation Ideas for Individuals Who Experience Limitations Due to Chemical Sensitivity or Environmental Illness (EI)" can be accessed at <http://www.jan.wvu.edu/media/MCS.html>.

The Department of Families and Communities claims that "People affected by MCS would not appear to benefit from the wide range of disability services which are currently offered by DFC. These being respite services, independent living training, accommodation services, therapy services, home care and family support services, etc. Indeed, in addressing disability access issues as stated in this Recommendation, the expertise of DFC is, in the main, addressing issues arising from people's physical, cognitive, neurological and sensory impairments and relate mainly to making modifications to physical environment through the fitting of rails, ramps, hearing loops, easy-read signs, etc. These are not the same access issues which are faced by MCS sufferers."

For obvious utilitarian and commercial reasons the chemical industry has been keen to ensure that MCS is not recognized as a disability. Unfortunately, governments have too often been complicit in this aim. The Department of Families and Communities should be aware that the Human Rights and Equal Opportunity Commission and the Equal Opportunity Commission recognise medically diagnosed MCS as a disability under the state and commonwealth legislation. If refusing to recognize chemical sensitivity as a legitimate disability is truly the current position of DFC, it would be interesting to see this position challenged in the courts.

It is very hard to see how people disabled with MCS might not benefit from the range of disability services offered by DFC, provided appropriate MCS disability access accommodations were also made available. This attempt to exclude MCS as a disability by DFC is another clear example of the institutionalised discrimination facing people with MCS. The Department must develop a more constructive position that includes the disability needs of people with MCS. The Minister for Disabilities must clarify DFC's position on the status of MCS as a disability. Non-acceptance of MCS as a disability is not acceptable to people living with MCS and a growing proportion of the wider community, including the disability sector.

***This recommendation should be given full and unqualified support by Government.***

- 8. That the Minister for Health place MCS on the Australian Health Minister's Advisory Council agenda to ensure that a co-ordinated national approach is taken to addressing emerging issues, including the need for:**
  - 8.1 A national review and evaluation of the medical literature in relation to the status of MCS, with a view to :**
    - 8.1.1 guiding further research into the cause, management, impact on fertility, and prevalence of the condition; and**
    - 8.1.2 contributing to the formulation of an ongoing national research agenda.**
  - 8.2 A Federal Government commitment to funding a national research agenda on MCS;**
  - 8.3 A national position statement on MCS.**

Supported in principle

Without a clear commitment from government to develop an MCS research agenda together with a constructive position on MCS this issue will continue to flounder, with the response to the problem being developed primarily within the community.

Pamela Reed Gibson's comments in "Understanding and Accommodating People with MCS in Independent Living" are enlightening in this instance:

*It is expected that many more people will develop MCS in coming years due to environmental contamination. Many of the people in my study have had MCS for decades (the average time was 15 years). Therefore, if MCS is environmentally caused, many people suffered their initial sensitizing exposure many years ago. How many more people are developing MCS now as a result of increasing air, water and food contamination? And events such as the World Trade Center destruction set up large portions of the population to develop environmentally induced illnesses that may or may not develop into MCS. It is crucial that our institutions recognize and respond to the plight of these people in order to be positioned to help the increasing numbers who will request help. However, I do not expect that this recognition will begin in the hierarchical/professional institutions such as universities and medical centers, but rather in grassroots types of settings where people have ongoing contact with people with the problem. The MCS support groups have begun the fight for recognition of this disability. Centers for independent living are perhaps the next level where this work can continue with your help.*

South Australian communities are already responding to MCS without the support of government agencies. This situation will result in growing political pressures if governments continue to ignore the MCS problem.

The Office of Chemical Safety has indicated that its review of MCS, which is scheduled to be completed before the end of March, 2006, will seek to move beyond the entrenched position of official denial evident in the current MCS debate towards a more pragmatic approach. OCS expects to work collaboratively with the state Department of Health in bringing MCS to the attention of the Australian Health Minister's Advisory Council.

***This recommendation should be fully supported by Government.***

**9. That the DH:**

**9.1 urgently resumes its review of existing MCS hospital protocols with the view to introducing guidelines to provide greater access to chemically sensitive patients requiring medical services. To assist with this task, the DH is encouraged to continue to investigate and monitor intrastate and interstate protocols and procedures such as the Royal Brisbane Hospital draft MCS protocols, and other relevant overseas protocols on MCS;**

**Supported**

The Department of Health has agreed to convene a Working Group "to develop consistent protocols and procedures for dealing with MCS sufferers in hospitals." The challenges in achieving MCS hospital protocols should not be underestimated, particularly when faced with the intransigence of the medical establishment with respect to understanding and recognising MCS. Again, the comments of the New Mexico Senate Inquiry into MCS from the Governor's Committee on Concerns of the Handicapped are informative:

*One principle not well accepted in the medical community but highly regarded by the Committee is to respect the wishes of the individual to the extent possible. Persons with physical disabilities are usually the best judge of what they want and need. We do not need a bureaucrat or social worker to tell us "what is best for us" even though many programs still use this service model.*

It is vital that people who actually live with MCS be included in the membership of the hospital protocols Working Group and that community organisations supporting people with MCS and medical clinicians experienced in the care of patients with MCS be closely consulted in the development of any MCS hospital

protocols. The expressed needs of people with MCS must be central to the protocol, which must not be hindered by medical claims of “lack of consensus”.

The Minister for Health is called on to provide accurate timelines with respect to the formation of the MCS hospital protocols Working Group.

**9.2 convene a working group of representatives from relevant Government departments and agencies, health service providers, and community organisations, to consider developing appropriate protocols and procedures that enable greater access to health care services for people with MCS.**

Not supported at this time

In rejecting this recommendation the Department of Health has stated that it “is already supporting moves to establish Working Groups and review teams under Recommendations 3 and 9.1.”, which relate to the establishment of an MCS Reference Group “to maintain ongoing communication and provide up-to-date information on developments in the MCS debate” and the development of MCS hospital protocols “to provide greater access to chemically sensitive patients requiring medical services.”

It is highly inconsistent that the Department of Health should support measures to assist people with MCS to access hospitals, yet has refused to consider developing similar protocols in other areas of health care. People with MCS often avoid hospital based services due to the fact that they are highly chemically polluted environments. Frequently the most appropriate health care services for people with MCS are those that are provided at home or in the community. Without MCS protocols these services are difficult and sometimes impossible to access. To refuse people with MCS with proper assistance with access to non-hospital based health care is to endorse the continuing institutionalised discrimination against people with MCS. As a matter of social justice and equity, MCS disability access protocols must be developed for community-based health care services. Even relatively simple strategies such as fragrance controls would be of significant benefit.

The Minister for Health must explain why the Department of Health is seeking to exclude people with MCS from equitable access to health care services that are not hospital based.

***This recommendation should be fully supported by Government.***

**10. That the relevant State Government Ministers:**

- 10.1 lobby the Federal Government to conduct ongoing research with a national focus on effective alternative measures for weed control, including identifying herbicides with lower toxicity than those currently in common use;**
- 10.2 ensure that local Councils are informed of the findings of Federal Government research on alternative measures for weed control.**
- 10.3 lobby the Federal Government to consider undertaking a review of the adequacy of the current chemical regulatory structure and assessment processes in addressing issues raised by people with MCS with regard to chemical use, including the adequacy of health and safety labelling information on chemicals associated with MCS.**

Supported in principle

The Department of Health has stated that: “It should be noted that chemicals other than herbicides are causally related to MCS by MCS sufferers.” In making this statement the Department appears to dismiss as

mere hearsay amongst people with MCS the numerous studies across North America and Europe that have consistently pointed to a range of chemicals initiating MCS. The subtext from the Department here is that MCS is some kind of Pavlov's dog reaction, with people with MCS "training" each other to react adversely to chemicals through a conditioned response. This position is absurd and has no basis in fact.

With respect to the causes of MCS, the Social Development Committee found research based evidence that "herbicides, such a Glyphosate, pesticides, solvents and sterilisers, have been associated with the condition" and described the herbicides used by local Councils as "particularly pernicious" for people with MCS.

Local Councils have responsibilities under the Public and Environmental Health Act, Sect 17, which states:

*PUBLIC AND ENVIRONMENTAL HEALTH ACT, 1987 – Sect 17*

*Control of Offensive Activities*

*17 (1) If an activity-*

- (a) gives rise to a risk to health, or*
- (b) results in the emission of offensive material or odours, the authority may, by notice in writing to the person responsible for the activity, require that person to desist from the activity or to observe requirements stipulated in the notice in relation to the carrying on of the activity.*
- (2) A person who, without reasonable excuse, fails to comply with a notice under subsection (1) is guilty of an offence. Penalty: Division 5 fine. Expiation fee: Division 6 fee.*

In Canada, where MCS is widely recognised, local government bans on both the public and private use of pesticides and herbicides have been supported by the Canadian Supreme Court under similar legislation to the Public and Environmental Health Act. However, the Local Government Association has advised that, with respect to the use of herbicides, it intends to ignore the MCS problem and "continue to ensure compliance with State and Federal requirements". This position is totally unacceptable to people with MCS. The continued use of herbicides in residential areas by local Councils in Australia cannot be justified by referring to failed standards in chemical regulation. The practice of routinely spraying herbicides widely across residential areas is not safe for a significant percentage of the population and must be discontinued. It is only a matter of time before people with MCS start taking legal action against local Councils for compensation for damages under common law.

There is no reason why local governments in Australia cannot immediately enact pesticide reforms similar to those seen in a growing number of international jurisdictions. Although Councils and others might benefit from formal research into alternative weed controls, people with MCS and those who might be at risk need immediate protection from the herbicides used by local Councils. Safer and relatively cost effective alternatives to chemical herbicides are already available, including the use of steam. What is absent here is the political motivation to address the problem. The Government must strongly support community initiatives to end the routine use of herbicides in residential areas by local Councils.

With respect to any review of the current chemical regulatory structure, in the face of the failure of this system to protect people with MCS and those at risk, local and state governments cannot abrogate their public health responsibilities. Any national review of chemical regulation must be accompanied by the development of MCS prevention, disability access and health care strategies that respect the right of people with MCS to safely access services and public spaces.

The Office of Chemical Safety has advised that the Environment Protection and Heritage Council's initiative for improved management of chemicals in Australia is still in development. However, people with MCS have not been consulted at any stage of this initiative and it is unlikely that their needs will be included in the outcome. This situation will not be tolerated by people with MCS whose health and safety must be seen as central to any regulatory reforms.

**This recommendation should be fully supported by Government.**

**11.1 that the State Government's Minister for Disability lobby the Federal Government to consider providing some Federal assistance for essential aides and items to assist people with severe disabilities arising from MCS symptoms in managing their condition.**

Not supported at this time

The Department of Families and Communities' position of denial of MCS as a recognised disability is outlined in its response to Recommendation 7. In refusing to support Recommendation 11.1, the Department denies people with MCS equitable access to health care services and the use of equipment that is vital to their health and welfare. Again we see DFC endorsing the continued discrimination against people with MCS and it would be interesting to see the Department's position challenged in the courts.

**11.2 That the DH consult with existing service providers such as the Southern Chronic Illness Links Network, with regard to extending its existing support services for people with chronic illnesses to support people with MCS across South Australia.**

Not supported

In rejecting this final recommendation the Department of Health made the following statement: "As MCS is not recognised as a defined medical condition in Australia, DH is unable to extend its stretched resources to assist MCS patients at the loss of assistance to sufferers of recognised diseases."

This statement is an example of why people with MCS and their supporters are regularly protesting on the steps of Parliament House and elsewhere. The Department of Health's position on MCS is reminiscent of that surrounding chronic fatigue syndrome, prior to its formal recognition, where people severely disabled and often bedridden with CFS were cruelly denied assistance to access basic aids such as wheel chairs on the basis of their diagnosis. Clearly the Department has learnt nothing from this past experience.

The Department's final comments on the validity of MCS are highly offensive and discriminatory and do nothing to progress the debate or address the problem. The Minister for Health must apologise for these comments and ensure that people with MCS are provided with equitable access to services.

**This recommendation should be fully supported by Government.**

## CONCLUSION

The official MCS debate is most often couched in medico-scientific terms. In fact, although a more complete scientific understanding of MCS is vital, the MCS dilemma is fundamentally a human rights issue. The emergence of MCS can be compared to that of HIV/AIDS, particularly during the early years of the epidemic. In his presentation to the Consumer Health Forum's Continuing Consumer Representative Training workshop, Peter Canavan, the National Treatments Portfolio Convenor of the National Association of People Living with HIV/AIDS, made the following comments on consumer participation:

*I want to start with a particular notion which sometimes gets called "centrality of HIV people", but which really just means HIV positive people being seen as crucial to the decisions which will affect our health and our lives: in policy, in research, and in the doctor's surgery.*

*Early in the epidemic, people with HIV coined the phrase “talk to us, not about us”. There had been a lot of “talking about”. In the media, people talked about us as either dying, “innocent victims”, or potential threats and dangers to public health and morality. At scientific conferences, people talked about us as a puzzling set of diseases and infections, but also as a kind of career move – solve “positive people”, and you might get the Nobel prize.’*

*After a while, positive people, sick of being talked about, decided to intervene with an unambiguous message; these are our lives, our bodies, and our choices. So talk to us as if we matter. We are the reason you are here. In many ways, this approach has been the enduring hallmark of our response as HIV positive advocates. That it should be we, the people living with HIV and AIDS, who, where possible, represent ourselves to government, in clinical research, or around any other table where significant decisions affecting our lives and health are likely to be taken”.*

People with MCS have been marginalised, excluded and treated with indifference for too long by governments, by chemical regulators, by healthcare services. If authorities wish to understand and solve the phenomenon of MCS they must begin speaking directly with the people who are most closely affected by the problem; that is people who actually live with MCS. For decades people with MCS have been bullied and forced by governments, under an oppressive system of chemical regulation, to endure sickening and disabling chemical exposures in order just to live. This situation will no longer be tolerated and governments must now understand that the inclusion of people with MCS must become central to any decision making process that affects their welfare, health and lives.

Accordingly, people with MCS call on the South Australian Government to give its full and unqualified support to all of the recommendations of the Social Development Committee Inquiry into MCS.