

ALLERGY, SENSITIVITY & ENVIRONMENTAL HEALTH ASSOCIATION Qld Inc

Website: www.asehaqld.org.au

**A volunteer community organisation providing support for
people with allergy, food and chemical sensitivity
A participating organisation of National Toxics Network**

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**SUBMISSION TO THE DRAFT DISABILITY (ACCESS TO PREMISES – BUILDINGS)
STANDARDS**

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1. INTRODUCTION

Disability (Access to Premises – Buildings) Standards should ensure access that

- safeguards human rights and disability rights;
- ensures equity of access to buildings;
- ensures equity of access to necessary services;
- ensures that people with Multiple Chemical Sensitivity/Environmental Sensitivities (MCS/ES) disability are able to take part in the community the same as people who do not have MCS/ES disability.

There are many types of disability in the community ASEHAs submission will focus on multiple chemical sensitivity (MCS) and the wider issue of environmental sensitivities (ES) which will be referred to as MCS/ES from here on. These are disabilities that are not yet included in standards, current disability planning or service provision as MCS/ES is a new and emerging area with as yet unmet need. People with MCS/ES have been poisoned by chemicals and because of their special and largely unmet need, many sufferers cannot access housing, basic health, allied care and disability services. In many instances this lack of disability access and inclusion is already creating deep personal crisis and has created great future uncertainty for sufferers who need access to low VOC housing, health and allied care services, especially nursing home care and in home service provision. **See appendix 3 for some MCS case histories.**

Multiple Chemical Sensitivity is defined as a chronic condition with symptoms that recur in response to low levels of exposure to multiple chemicals that improve or resolve when those chemicals are removed. Symptoms occur in multiple organ systems throughout the body. (NSW Health, Dept of. 2002). **See appendix 1 table 3 for examples of MCS symptoms**

The prevalence of MCS &/or hypersensitivity to chemicals ranges from approximately 5% to 34% in the general population. In Australia a 2002 NSW health survey reported 24.6% of adults with sensitivity to chemicals, while a SA 2002 and 2004 survey reported 16.4% of respondents had chemical sensitivity. **See Appendix 1 Table 1 at end of this submission for details of prevalence rates.**

Environmental Sensitivities (ES) describes a variety of reactions to chemicals, electromagnetic radiation and other environmental factors at exposure levels commonly tolerated by many people. Environmental sensitivities does not describe a single simple condition with a universal cause. (Sears, M E 2007 p. 3) Environmental sensitivities includes diseases such as allergy, asthma, other lung disease, chronic fatigue syndrome, fibromyalgia, Sjogrens Syndrome, cystic fibrosis, dermatitis/eczema, digestive allergy, coeliac disease, Systemic Lupus and others.

2. THE DISABILITY – SENSITIVITY TO THE BUILT ENVIRONMENT – INDOOR AIR QUALITY

Disability access to the built environment is limited not only by building design but is also dependent on the choice of building materials and furnishings which can greatly influence indoor air quality.

Many individuals are hypersensitive to mould, dust and other allergens, outgassing from high emission building materials, carpets, furnishings etc, air conditioning and detergents/disinfectants, pesticides, freshly painted surfaces, recently dry cleaned clothes, laundry products, fragrances and other personal care products (underarm deodorants, hair spray, mousse, shampoo, hair conditioner, make up, toilet soap etc). they can suffer various degrees of health injury and disability whilst in the built environment including medical emergencies. Individuals with respiratory disease have extremely sensitive lungs and should not be exposed to allergens and strong chemicals. However, **buildings are also workplaces and building occupants, including workers, can be affected by the same substances**. This is known as Sick Building Syndrome (SBS) which is commonly caused by levels of various contaminants in buildings, especially volatile organic compounds (VOCs).

www.epa.gov/iaq/

Sick Building Syndrome can cause MCS/ES.

Poor indoor air quality is a major detriment to MCS/ES disability access in most public buildings including hospitals and other health care facilities such as GP surgeries, imaging and X-ray facilities, pathology laboratories, nursing homes, pharmacies and housing. It greatly disadvantages individuals with MCS/ES disability in particular MCS, allergy, chronic fatigue

syndrome and respiratory disease e.g., asthma, emphysema, COPD (Chronic Obstructive Pulmonary Disease), (***but is not restricted only to those disorders***) as they are unable to access necessary services and care.

Some common chemicals that cause MCS are listed in table 2 appendix 1

Apart from chemical exposures, other detriments to MCS/ES disability access to buildings are lack of education and training in MCS/ES and more generally about the health impacts of chemicals and poor indoor air quality.

3. WHY MCS/ES SHOULD BE INCLUDED IN DISABILITY ACCESS STANDARDS

MCS has been acknowledged by human rights issues in relation to the IAQ

IN AUSTRALIA

The Australian Human Rights Commission have recognised some problems relating to chemical usage and building access and in 2007 added the following section on use of chemicals and

materials to their draft guidelines and information about access to buildings and services, but we have a long way to go.

'A growing number of people report being affected by sensitivity to chemicals used in the building, maintenance and operation of premises. This can mean that premises are effectively inaccessible to people with chemical sensitivity. People who own, lease, operate and manage premises should consider the following issues to eliminate or minimise chemical sensitivity reactions in users:

- *the selection of building, cleaning and maintenance chemicals and materials (see Note below); the provision of adequate ventilation and ensuring all fresh air intakes are clear of possible sources of pollution such as exhaust fumes from garages; minimising use of air fresheners and pesticides; the provision of early notification of events such as painting, pesticide applications or carpet shampooing by way of signs, memos or e-mail.*

http://www.humanrights.gov.au/disability_rights/buildings/guidelines.htm

The Human Rights Commission also notes:

'There are a number of relevant environmental and occupational health and safety regulations and established standards, however, as is currently the case with other standards referenced in building law, compliance with those standards may not necessarily ensure compliance with the DDA', and

'For more information on accommodating employees with MCS/ES and ways to eliminate or minimise chemical and fragrance sensitivity reactions can be found at <http://www.jan.wvu.edu/media/MCS.html> and

<http://www.jan.wvu.edu/media/fragrance.html>

Indoor air quality and more importantly the safety of indoor air to human occupants should be a vital component of the building code and urgently needs to be addressed. Disability access to safe air quality in buildings is essential to ensure that individuals with MCS/ES have equal access for equal need and can take part in society the same as those who do not have MCS/ES.

In Australia, we are struggling to have MCS/ES recognised as a physical condition. Our Human Rights Commission recognises MCS/ES and fragrance sensitivity as a disability if it can be shown that an individual has the problem

IN CANADA

In Canada, ES is a disability that is accepted by the Canadian Human Rights Commission that states 'Individuals with environmental sensitivities experience a variety of adverse reactions to environmental agents at concentrations well below those that might affect the "average person". This medical condition is a disability and those living with environmental sensitivities are entitled to the protection of the *Canadian Human Rights Act*, which prohibits discrimination on the basis of disability. The Canadian Human Rights Commission will receive any inquiry and process any complaint from any person who believes that he or she has been discriminated against because of an environmental sensitivity. Like others with a disability, those with environmental sensitivities are required by law to be accommodated.'

http://www.chrc-ccdp.ca/legislation_policies/policy_envIRON_politique-en.asp

(Wilkie, C and Baker, D. 2007). The Canadian Government includes MCS as an environmental sensitivity.

4. REASONS FOR ADDRESSING IAQ AS A DETERRENT TO DISABILITY ACCESS TO BUILDINGS

4A.ECONOMIC COST OF MCS/ES DISEASE -

The Australian Federal Finance Minister of the time (November 2006), Nick Minchin, warned of spiralling costs if the link between environmental chemicals, cancer and chronic illness was ignored. He claimed that common sense tells you there is a relationship there and its impact on the health budget 'keeps you awake at night'. He was opening a new CRC for Contamination Assessment and Remediation of the Environment (CARE) at the University of SA Mawson Lakes Campus, North Adelaide. (Roberts, J. 2006)

Canadian Information on costs of Environmental illness

Environmental Illness is one of the most expensive health care conditions in Canada along with heart disease, musculoskeletal disease and cancer. The total estimated financial cost of environmental illness to Canada is estimated at \$13 billion per year. Around 7 million individuals suffer significant symptoms, increased absenteeism and impaired abilities at work due to normally safe exposures to some of the common chemicals and moulds found in their homes and at work. Around half a million adult Canadians are unable to do paid work due to a disability associated with Environmental Illness (Sears, M E. 2007).

United States ESTIMATES

Toxic chemicals Sicken and kill thousands of people in California each year and cost the state an estimated \$2.6 billion in medical expenses and lost wages (Chea, T. 2008)

IN AUSTRALIA

The Canadian figure of one third of people suffer from some form of environmental sensitivity (Sears, M. 2007) is similar to the figure of 24.6% with chemical hypersensitivity found in the 2002 NSW Adult Health Survey. This is a significant percentage of the population being impacted by chemicals in the indoor environment. there is a need to develop standards to allow access to buildings and protect their wellbeing. We are unaware of any other research into environmental sensitivities in Australia that would give a more accurate assessment of the percentage of people who are impacted by odour or in some other way by fragrance or VOC exposure from other chemicals. The socioeconomic impact of MCS/ES on the Australian community needs to be investigated. The costs are likely to be similar to Canada but may be higher.

In Australia there is a lack of recognition of the impact of allergic and immune disorders on quality of life and even less recognition of the economic impact on society and individuals who suffer from allergic disease. Allergy is a chronic immunological disorder that occurs when a person's immune system mounts an abnormal response to allergens that do not normally bother other people. Examples of allergy are allergic rhinitis or hay fever, allergic asthma, food allergy, sting and insect bites.

Allergy costs: Australia and New Zealand have the highest incidence of allergic disorders in the developed world. 4.1 million Australians have at least one allergy, this represents 19.6 %of the population. The working aged population is most affected with 78% of people who suffer from allergy aged between 16-64 years. There are 7.2 million cases of allergy in Australia meaning there is an average of 1.74 comorbid allergies per person. ASCIA and Access Economics. 2007. The Economic Impact of Allergies. www.allergy.org.au/content/view/full/325/76/

According to a 2007 report by the Australian Society of Clinical Immunology and Allergy (ASCIA) the financial cost of allergy to the community was \$7.8 billion. \$5.6 billion was lost productivity, \$1.2 billion was direct health system expenditure, \$261.5 million was spent in other indirect costs such as allergy aids and home modifications, \$783 million was deadweight loss

from transfers including welfare payments and lost taxation revenue. The personal cost of allergy to those affected is estimated to be \$21.5 billion.

Asthma Costs: In recent years asthma has been recognised as a common health problem affecting between 8-9% of the Australian population or 1.4 million people, yet there has been little effort to ascertain the economic impact of the disease. The quantifiable costs of asthma, namely the medical related and indirect costs of lost productivity, have been evaluated by The National Asthma Foundation of Australia in an effort to fill this void and understand the total quantifiable cost and prevalence of asthma in all age groups as well as the impact of asthma severity and control on cost for adult sufferers. However, no attempt was made to place a financial value on the intangible yet significant "quality of life" costs: Direct medically related health care costs total \$320 million, indirect health care costs including lost productivity, absenteeism totaled, totaled \$260-400 million

The total cost, although substantial, is not comprehensive as the potentially significant impact asthma has on an individual's quality of life has been excluded. <http://www.nationalasthma.org.au/html/home/index.asp>

Figures from the Australian Bureau of Statistics show that the mortality rate of asthma has been increasing since 2005. The incidence of asthma has risen worldwide with Australia having the highest prevalence. <http://www.nationalasthma.org.au/html/about/index.asp>

CFS Costs: While we do not have a lot of data for MCS in Australia, we have used a CFS study due to the substantial overlap between MCS/CFS/FM and the possibility that they may be the same disease. The financial burden of CFS was calculated by direct and indirect costs related to the disorder. The statistics were drawn from a survey of patients with CFS and Medicare data on the incidence and fees charged for scheduled items for those surveyed.

Forty two patients with CFS were identified in a population-based prevalence study. The conservative estimate of costs in the Richmond Valley with a prevalence of 37.1 cases per 100,000 was \$396,000. If extrapolated to the Australian population it was estimated that CFS would generate an annual cost of at least \$59 million (Lloyd, A R and Pender, H. 1992). It is unfortunate that this study does not include lost productivity, tax dollars, disability payments, avoidable suicides and erosion of human rights

4B SOCIAL/ INDIVIDUAL COST OF MCS/ES DISEASES

Although there are many compelling models proposed for the mechanism and etiology of MCS, there has to date been no consensus on the diagnosis, management and treatment of MCS. This has hindered acceptance of the disease amongst the medical profession. As the general medical profession does not understand the mechanism and problems associated with MCS/ES, they may see the problem as psychogenic (Aust. NICNAS/OCS. 2008). This can stigmatise sufferers and add significantly to their distress and the inhumanity to which they are currently subjected.

People with MCS/ES are treated less fairly in Australia than individuals without a disability AS disability access to essential services is a basic human right. Many people with MCS/ES disability are sensitive to fragrances and volatile organic compounds, and they cannot safely access buildings and services. However, such individuals can have other diseases and medical emergencies that are not related to their MCS/ES that require medical intervention. They are misunderstood in health care settings and are therefore not able to access essential health and allied care services, aged care services, disability housing, schools, public transport and other areas.

Currently individuals with MCS/ES, especially the very severe sufferers are and will remain disadvantaged as they maybe considered as psychiatric cases and their health problems will not be taken seriously. The consequences of this are

- MCS/ES has not been included in health and disability policy,
- MCS/ES has not been included in service planning and delivery;
- MCS/ES issues of access to essential services will continue to be ignored;
- some MCS/ES individuals may even be erroneously detained by psychiatric services, further harmed or traumatized,
- their human rights will continue to be ignored and
- their fundamental needs will not be met.

All of which is unacceptable. We do not expect this in a developed country.

MCS/ES needs to be recognised as chemical poisoning with better regulation and better management of chemicals at government level. A major public education campaign initiated by the government about the dangers of using chemicals would encourage consumers to reduce their use. Such actions could reduce the number of people will become chemically sensitive and higher socioeconomic costs that would follow.

Individuals with MCS/ES disability have no opportunity to improve their lives, their health or take part in society AND are often unable to work to support themselves and because they are constantly ill. They lose the support of family and friends and can become isolated. Income support from welfare services is insufficient to provide for their special needs in housing, disability aids, medical aids, food, and nutrient support as food allergy is often a coexisting factor along with inability to take many medications. Some need extensive home modifications to reduce levels of mould and VOCs. Such assistance is given in Canada but not in Australia.

Children with MCS/ES are often unable to attend school because of lack of safe building access and materials used in the classroom (felt markers, art materials, printed matter, personal care products, carpets, pesticides). Some have to home school and the inability of welfare services to understand the problems associated with MCS/ES often mean that parents suffer discrimination and the children can be removed from their care. **See appendix 3 for some case histories of individuals with mcs: (actual names have not been used)**

5. BUILDING CODES THAT NEED TO BE DEVELOPED FOR MCS/ES

5A OVERVIEW OF THE PROBLEM

ENVIRONMENTAL CHEMICALS THAT ARE A DETERRENT TO ACCESS TO BUILDINGS

There are in excess of 100,000 man made chemicals in our environment and most of these do not have toxicology studies to support safe use. In most cases we are using chemicals and do not know what they are doing to us. However, many commonly used chemicals are sensitisers, allergens, carcinogens, endocrine disrupters or can cause other health and disability problems. More importantly, these chemicals are often found in products which are mixtures of chemicals and can have an additive or greatly enhanced effect. The toxicology of mixtures of chemicals is not well understood, nor are the impacts on human health.

We live in a chemical soup and are exposed to chemicals in our air, food, water and all environments. Currently, the only known treatment for MCS/ES is avoidance of substances that cause reactions (Reed-Gibson, P., et al. 2003). However, chemical pollutants are difficult to avoid and can be present in high levels in the workplace, home and public buildings. They can often be found as volatile organic compounds (VOCs) in building materials and furnishings as well as products we bring into our homes on a daily basis such as detergents, disinfectants, pesticides, cosmetics, fragrances, toiletries, personal care products, laundry detergents. In the case of cosmetics, fragrances and personal care products these can be applied to our skin more than once a day and are mixtures of chemicals of unknown toxicology. Fragrances can contribute significantly to VOC levels in buildings that cause sick building syndrome. (US. NIBS. 2005.)

TWO MAJOR DETERRENTS TO BUILDING ACCESS

Fragrance sensitivity

Fragrances are mixtures of chemicals and can contain up to 100 chemicals, mostly solvents. They represent a major obstacle to disability access for individuals with MCS/ES (US. NIBS. 2005). Most products are highly fragranced these days and it is difficult to find unfragranced products.

Fragrances are a major hazard to the health of individuals who are chemically sensitive or who suffer from allergy, asthma or other lung diseases. They are a public health menace and should be banned in public buildings and spaces. Their strength and life need to be dramatically reduced so that individuals who are sensitive to them can safely access buildings and services and live in their homes.

Air fresheners, fragrances and strongly fragranced products used in cleaning and disinfectant products, hand washing dispensers and on staff working in hospitals, allied health facilities and nursing homes are a major deterrent to people with MCS/ES accessing health care and essential services. Home care providers wearing fragranced products are also a deterrent to MCS/ES sufferers receiving care in their own homes. Fragrances have been banned in many hospitals overseas e.g. Canada, USA and Sweden. (Sears, M E. 2007)

Pesticide sensitivity

Pesticides are also a deterrent to building access for individuals with MCS/ES. Many public buildings are treated internally with pesticides on a regular basis for vermin control and externally for pest and weed control on grounds surrounding buildings. Unfortunately, individuals with MCS/ES can be hypersensitive to pesticides and their constant use in public buildings and domestic dwellings ensures that pesticide residues are present in sufficient quantities to cause reactions. Integrated Pest Management programs need to be implemented to reduce the volume of pesticide in and around public buildings to ensure MCS/ES disability access.

Signage regarding pesticide use should always be used to alert individuals with MCS/ES that

pesticide treatment has recently taken place and to give them the option of whether or not they wish to enter a building (US NIBS. 2005). However, prior notification of pesticide application should always be given where practicable in terms of building access.

Many with MCS/ES can be ill for months following exposure to domestic pest control. While most pesticides for this use are thought to be safe, commonly used pyrethroids are known human allergens and potent nerve poisons. Some known symptoms arising as a result of exposure to pyrethroids are asthmatic wheezing, bronchospasm, anaphylaxis, cough, hypersensitivity pneumonitis, nervous irritability, tremors, cardiac arrhythmia, chest pain, cough, flue like symptoms (Morgan, D P. 1982).

5B. BUILDING CODES THAT ARE NEEDED TO PROVIDE FOR SAFE INDOOR AIR FOR ALL BUILDINGS

Standards need to be developed for biological contaminants, VOC's and other contaminants to ensure that individuals with MCS/ES can safely access premises. A base line for low toxic, low VOC buildings, building materials and products, furnishings and cleaning products needs to be established to reduce toxic emissions in buildings. This should apply to all public buildings, workplaces and the domestic environment, especially rental properties. **See also appendix 2 guidelines for disability access to public housing prepared by ASEHA Qld Inc.**

Fragrance free policies for public buildings need to be developed to accompany cigarette smoking policies for all the same reasons and in some cases the same chemicals. This will ensure that those with MCS/ES and other diseases that are adversely impacted by fragrance chemicals:

- are not disadvantaged in building access;
- can be safe in buildings i.e. not exposed to substances that cause or contribute to ill health;
- can take part in society the same as those who do not have MCS/ES.

Fragrances can add significantly to VOC levels in indoor air.

The US NIBS Indoor Environment Quality Report <http://ieq.nibs.org/> provides information on implementing a fragrance policy. Such things can be negotiated in employment agreements. However, any decent minded person when told their fragrance can cause ill health would abstain from using fragranced products.

Housing needs to be included in standards for access to premises

There is a significant body of data in existence about indoor air quality. Standards exist for air levels of pollutants, chemicals and biological contaminants in the workplace and these need to be developed for the residential environment as people spend a lot of time inside their homes. This is crucial as the domestic dwelling can have levels of air toxics higher than the workplace, particularly new dwellings. There is a market for clean, green and sustainable buildings.

Housing that is low in VOC emissions and biological contaminants needs to be developed and implemented to ensure that residential buildings are safe for human habitation. Currently, individuals with MCS/ES are unable to access housing that is safe for them due to building materials and products. To prevent homelessness caused by lack of access to housing with indoor air quality safe enough for those with MCS/ES, it is imperative that housing standards are developed as a priority to allow MCS/ES disability access.

Standards for rental premises especially need to target mould, pesticide and cleaning chemical emissions.

In recent years the Indoor Environmental Quality field has seen a surge of interest and innovation and provides building owners and designers with many new tools for ensuring high quality indoor environments. Much of this work can be found in the Indoor Environmental Quality section of the DSA's Sustainable Schools Website:

<http://www.sustainableschools.dgs.ca.gov/SustainableSchools/sustainabledesign/ieq/ieq.html> .

For information on low and no-Volatile Organic Compound (VOC) emitting materials the Collaborative for High Performance Schools (CHPS) has tested building products and maintains a list of tested products as well as testing protocol on their website: http://www.chps.net/manual/lem_overvw.htm

Signage

Signage needs to be developed to denote:

- clean air – low VOC environment that is safe for those with MCS/ES;
- to warn of pesticide treatments indoors and on building surrounds.
- Clean air signage should be available for display when buildings reach the required standard.
- An annual accreditation to support the clean air signage should be necessary to ensure the continuation of the clean air standard.

Sanitary facilities

Standards are needed to ensure that:

- there are no air fresheners or strong cleaning products used that will contaminate facilities and prevent access by individuals with MCS/ES;
- IPM is implemented to reduce pesticide residues in sanitary facilities
- signage is required to warn of pesticide treatments.

Further information about indoor air quality can be found at www.epa.gov/iaq

Information specifically relating to indoor air quality and MCS/ES can be found at <http://ieq.nibs.org/>
A copy of this will be provided as part of this submission.

6. AUSTRALIAN INITIATIVES TO IMPROVE IAQ DISABILITY - HOW WE CAN MAKE THINGS BETTER IN AUSTRALIA

The Queensland Housing Department has made some effort recently to reduce harmful and toxic materials in their homes. They initiated a 'Smart Housing' project. Unfortunately, they lacked the expertise to do this properly in the development stages and errors were made that preclude individuals with MCS/ES from being able to access Smart Housing. Some of these errors were:

- The inclusion of gas appliances which contribute to nitrogen dioxide levels indoors and are contraindicated for those with MCS/ES, especially lung disease;
- Carpets which are unacceptable for those with chemical sensitivities, dust/mould allergy and lung disease;
- Latex underlay, airborne levels of which can impact very adversely on latex sensitive individuals or sensitise susceptible individuals;
- Methyl methacrylate bench tops and sinks. Methyl methacrylate is a known sensitiser and skin contact can exacerbate existing sensitivity or actually initiate sensitisation in a susceptible individual. It is contraindicated for those with existing chemical/environmental sensitivities and as these are an 'at risk' group who make up a significant percentage of the population the use of this material is ill conceived. Stainless steel is a more inert and suitable material.

While the choice of these materials is an effort to reduce contaminants in air quality associated with sick building syndrome it shows poor understanding of the issues and diseases caused or exacerbated by chemicals and pollutants. This is disappointing because of the large body of data available to support clean, green, healthy buildings.

The South Australian Experience

South Australia has begun to make inroads into the MCS problem. In 2005 a Parliamentary Inquiry into MCS conducted by the bicameral Social Development Committee tabled its findings in the Legislative Council. The report concluded that “MCS is very real and that many individuals experience considerable suffering, particularly in light of the lack of recognition surrounding this condition.”

A complete copy of the Inquiry is available at <http://www.parliament.sa.gov.au/Committees/Standing/LC/SocialDevelopmentCommittee/CompletedInquiries/22NdReportMultipleChemicalSensitivity.htm>

Since that time the South Australian Government has regularly convened an interdepartmental committee, the MCS Reference Group, to guide debate on MCS and oversee the implementation of the recommendations arising from the Inquiry.

The MCS Reference Group is currently:

- Considering the need for ongoing monitoring of the prevalence of MCS in South Australia.
- Developing herbicide/pesticide No-Spray Registers with local governments in order to better identify and protect people in the community with MCS and chemical sensitivities generally.
- Considering a range of education brochures to provide information on MCS to the public and relevant professional groups, such as general practitioners.
- Ensuring that the Department of Primary Industries and Resources' Chemical Trespass Unit is aware of MCS issues and is able to deal fairly with the needs of people with MCS in complaints where neighbour's pesticide use is impacting on their health and their ability to enjoy the amenity of their own homes.
- Attempting to address MCS disability access issues with respect to services and public spaces. In 2006 the Department of Administrative and Information Services included MCS in its Disability Action Plan. Since then the Department of Families and Communities has included several MCS related questions in its disability access checklist guide for government owned and leased buildings.
- Developing hospital protocols for the care of patients with MCS. These are based on

existing draft guidelines first developed by the Royal Brisbane Hospital. When completed the protocol will be adopted by all public hospitals in South Australia.

- Progress on these issues has been slow but is continuing.

In addition to the work of the MCS Reference Group, there are other government departments and institutions in South Australia attempting to address MCS issues.

ACCOMODATION

The Department of Families and Communities' Housing SA has conducted several staff education workshops on MCS. Housing SA has attempted to provide reasonable accommodation when initially housing some clients with MCS but the response has been inconsistent. People with MCS are routinely denied access to public housing due to claims of lack of housing stock suitable for their needs. There is no purpose built housing for Housing SA clients with MCS. However, the Whalers Housing Cooperative from the South Australian Community Housing Association has built several environmental apartments suitable for people with MCS in Port Elliot, a seaside town 80 km south of Adelaide. Despite these developments public housing for people with MCS in South Australia is consequently entirely inadequate. People with MCS are routinely left in completely substandard accommodations such as tents, caravans, tin sheds and cars.

MEDICAL AND ALLIED HEALTH

The South Australian Dental Service, including the Adelaide Dental Hospital, has adopted a policy which provides information to staff on MCS and clarifies organisational requirements in managing clients with this condition. The policy includes public notification asking that clients and visitors to the hospital avoid using strong fragrances.

The Royal Adelaide Hospital is just beginning to recognise the need for fragrance controls in the hospital environment. The hospital's Health Promotion Unit requires its staff and volunteers to refrain from wearing "perfumes and powders" when working in the unit.

THE IMPORTANCE OF EDUCATION - The Community Response in South Australia –

In addition to the work of the MCS Reference Group there have been other developments in the South Australian community that assist people with MCS with their disability access needs. It appears that the broader community is becoming more informed of issues surrounding MCS and more willing to implement reasonable accommodation measures, notably in the areas of controlling the use of personal fragrances, ensuring good indoor air quality, using fragrance free cleaning/sanitation products, selecting least toxic renovating materials, and adopting integrated pest management systems.

A number of community based organisations have included MCS within their disability access plans and occupational health and safety policies. These include Disability Information and Resources Centre, Disability Advocacy and Complaints Service SA, Disability and Rehabilitation Professionals Association, AIDS Council of South Australia, Relationships Australia (SA), Art Gallery of SA, ME/Chronic Fatigue Syndrome Society of SA, Health Consumers Alliance, Catholic Education Office, and Unions SA Occupational Health and Safety Committee.

Although South Australia has finally started to respond to the MCS problem, in practical terms these developments have not yet resulted in significant improvements in the actual lives of people with MCS, who are routinely denied access to basic services and public spaces due to chemical barriers and general public ignorance of the issues. However, continued developments will hopefully lead to more valuable progress in time. There is an urgent need for a nationally coordinated program recognising the basic human rights and disability access requirements of people affected by MCS. Such a program would have immense benefits not only for people with MCS but also for the large percentage of the population who suffer with other types of environmental sensitivities.

More information on how we can make things better for individuals with MCS/ES in Australia can be found in the publication by Pamela Reed Gibson 'Understanding and Accommodating People with Multiple Chemical Sensitivity in Independent Living' www.ilru.org/html/publications/bookshelf/MCS.html

7. RECOMMENDATIONS

Recognise MCS/ES as a disability and ensure that safe air (low biological contaminant/VOC) is included in Building Access Standards.

Observe the UN Convention on the Rights of Persons with Disabilities – including access to buildings for individuals with MCS/ES

End the disability discrimination currently experienced by individuals with MCS/ES. Take immediate action to ensure that IAQ issues are addressed in the disability (Access to Premises) Standard to ensure that individuals with MCS/ES have access to buildings.

Establish guidelines for the indoor environment to ensure that persons with MCS/ES disability and other 'at risk' groups in the population have necessary safe access to buildings and services and do not suffer discrimination. The US National Institute of Building Sciences, in collaboration with MCS community groups, medical researchers, and national environmental health and disability access institutions, has already developed comprehensive guidelines on access to buildings for people with MCS and environmental sensitivities generally. These are available at <http://ieq.nibs.org/>

The building code needs to be altered to ensure that materials used in new buildings and renovations do not contribute to biological contaminants, VOCs and other indoor air pollution that can cause or contribute to ill health. There needs to be a baseline of low emission products and materials in the building code to ensure that all buildings are accessible by those with MCS/ES. The aim should be healthy buildings so that we have healthy occupants as **IAQ AFFECTS ALL BUILDING OCCUPANTS – NOT JUST THOSE WITH MCS/ES.**

Such an action will put downward pressure on the chemical industry to produce less toxic and sustainable chemicals and products. This is highly desirable.

Building products, materials and furnishings in health & allied care facilities and public buildings need to be of low outgassing materials. Floor coverings should be of inert materials that do not act as a sink for mould, dust, lead, persistent bioaccumulative substances and other contaminants (no carpet).

Better government regulation of indoor air quality is necessary to ensure that people are not being poisoned and are not gathering a body burden of toxic chemicals (US Center for Disease Control. 2005)

Encourage chemical companies to develop green (less toxic) chemistry and reduce the level of toxic chemicals they produce. There is a market for such products.

Remove all air fresheners and fragrance dispensers from public buildings especially sanitary facilities.

Develop standards for a fragrance free and low chemical environment as per no smoking policy.

Regulate to reduce the strength and life of fragrances so that they are not discernable any

further than one metre from point source and they degrade in a few minutes. Currently, some fragrances take years to degrade. Fragrances can adhere to seating and other furnishings that come into contact with them. They can remain on fabrics and other surfaces indefinitely and contribute significantly to poor indoor air.

Implement an enforceable fragrance free policy for health and allied care facilities and other public buildings. This needs to be legislated as per cigarette smoke free policy and be promoted in the same way. (US. NIBS. 2005) People with MCS/ES **MUST** be able to access health and allied care. The use of fragrances is not a right, nor is it a hygiene issue but an interest (Wilkie, C & Baker, D. 2008, p.17).

To assist with the implementation of fragrance free public buildings, an educational campaign will first need to be established to educate the public as to the toxic nature of fragrances and the dangers of solvent exposure.

Replace cleaning products with products that are low in toxicity, odour and are MCS/ES friendly. Steam cleaning does not need detergents/disinfectants; peroxide based cleaners are also strong disinfectants as well as effective cleaners. In recent years fibre technology has produced a more simple system of cleaning and these cloths only need water to work. Steam can also be used for pest and weed control.

Implement an Integrated Pest Management program (IPM) in and around all health and allied care facilities and public buildings to reduce the volume of pesticide used and indoor air contamination.

Signage prior to pest control should be highly visible and warn individuals entering buildings of impending or recent pest control treatments.

Pesticide treatments on grounds surrounding buildings should also be subject to signage provisions to alert those with MCS/ES of treatments.

Material safety data sheets relating to pesticides used in and around buildings should be freely available to those requesting them.

Air levels of VOCs and other toxic substances need to be established for the domestic environment. These already exist for the workplace. This is especially relevant for rental premises.

Pesticide levels need to be established for residential premises, especially rental premises as these are subjected to pest control and carpet cleaning each time a tenant leaves. This is a requirement of tenancy agreements. If a residence has several tenants in a year this can result in excessive pesticide residues that are harmful to the health of occupants. Some MCS/ES sufferers have been unable to find rental premises that are safe for them, because of high pesticide residues and other VOCs.

IAQ standards for residences and all buildings need to be developed to ensure safe and healthy

buildings. IAQ standards are not only for MCS/ES sufferers but the whole population who are at risk of poisoning.

Individuals with MCS/ES must be taken into account when standards are being devised.

Prepared for ASEHA Qld Inc by Dorothy M. Bowes 27 Feb. 2009 with assistance from Peter Evans, RN **Convenor SA Task Force on MCS and Dr Sharyn Martin, PhD.**

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www.epa.gov/iaq US Environmental Protection Agency, Indoor Air Quality.

APPENDIX ONE. ADDITIONAL MCS INFORMATION

TABLE 1. Chemical hypersensitivity/MCS diagnosis Prevalence Rates

MCS Prevalence Rates

Percentage of respondents

Reference source

National Academy of Science

15%

Mitchell F, ed. 1995 Multiple Chemical Sensitivity: A Scientific Overview. Atlanta: US Department of H

*California Dept Health Services

15.9%

Kreutzer R, Neutra RR, Lashuay N. 1999 Prevalence of people reporting sensitivities to chemicals in a

*Atlanta, Georgia, metropolitan area

12.6%

Caress SM, Steinemann AC. 2004 The prevalence of multiple chemical sensitivities in a population based

*State of New Mexico

16%

Voorhees R. 1997 Results of Analyses of Multiple Chemical Sensitivities Questions. New Mexico Behavior

Conversations with medical personnel in clinical settings

2 – 10%

Mooser SB. 1987 The epidemiology of multiple chemical sensitivities (MCS). Occup Med.;2:663– 681

Arizona study Young college students

15%

Bell IR, Schwartz GE, Peterson JM, Amend D. 1993 Self-reported illness from chemical odors in young

Arizona study Elderly persons

37%

Bell IR, Walsh ME, Goss A, Gersmeyer, Schwartz GE, Kanof P. 1997 Cognitive dysfunctions and disability

Rural Arizona population survey

33%

Meggs WJ, Dunn KA, Bloch RM, Goodman PE, Davidoff AL. 1996 Prevalence and nature of allergy and disability

UK Military Personnel

1. Gulf War veterans deployed
2. Gulf War, not deployed
3. Bosnia War

1. 28%
2. 14%
3. 13%

Reid S, Hotopf M, Hull L, Ismail K, Unwin C and Wessely S., 2002. Reported chemical sensitivities in a

Caress and Steinemann National survey. 2005

Caress S and Steinemann A. 2005. National Prevalence of Asthma and Chemical Hypersensitivity: An

Hypersensitivity to chemicals

11.2%

Diagnosed with MCS

7.4%

Older adults

34%

Bell I R, Schwartz GE, Amend D, Peterson JM, Stini WA. 1994. Sensitisation to early life stress and

Older adults

17%

Bell et al. 1993. Possible time-dependent sensitisation to xenobiotics self reported illness from chem

Australian Population, SA Health Monitor Survey, 2002 and 2004.

Australian Population, SA Health Monitor Surveys 2002 and 2004

Chemical sensitivity

16.4%

Diagnosed MCS

0.9%

Australian Population, NSW adult health survey 2002

Australian Population, NSW adult health survey 2002

Overall hypersensitive to chemicals

24.6%

Rural population (hypersensitive)

23.7%

Urban population (hypersensitive)

24.8%

Diagnosed with MCS

2.9%

German population

Hausteiner C, Bornschein S, Hansen J, Zilker T, Forstl H. 2005. Self-reported chemical sensitivity in G

Self reported sensitivity

9%

Diagnosed MCS

0.5%

TABLE 2. Common chemicals that can cause MCS

- Pesticides,
- Fragrances/ Fragranced products,
- Solvents,
- Petrochemicals,
- Natural gas,
- New carpet,
- Renovation materials (Ex. MDF, particle board, chipboard),
- Adhesives/ glues,
- Fiberglass,
- Carbonless copy paper,
- Fabric softener,
- Formaldehyde,
- Glutaraldehyde,
- Cleaning agents – Ex Carpet shampoo,
- Isocyanates,
- Combustion products (Ex smoke from fires, poorly ventilated gas heaters),
- Medications (Ex antibiotics, anaesthetics),
- Terpenes and terpenoids,
- Personal Care Products. Including cosmetics, deodorants, soaps, shampoo, perfumes
etc,
- Household aerosols,

**TABLE 3. Symptoms of MCS taken from ASEHA workshop respondents, June 1995.□
(Bowes, D M., 1997)**

Body system

Symptoms

CNS/ Neurological

Migraine; Headache; mental confusion, memory impairment, emotional lability; cannot stay awake; sud

Neuromuscular

Tic; seizures; tremors; muscle cramps; muscular spasms;

Sensory

Ears:- Tinnitus; itchy ears; ear ache; blocked ears;

Eyes:-dry, itchy eyes; eye pain; weepy eyes; sore eyes; lumps in eyes;

Vision:- visual disturbances; blurred vision

Integumentary

Rashes; skin irritation; dark circles under eyes; spontaneous bruising

Inflammatory/ mucosal

Throat swelling; laryngitis; dry & sore throat; mouth ulceration; tongue swelling; bloodshot eyes; swollen

Respiratory

Sneezing; coughing; asthma; wheezing; shortness of breath; breathing difficulty; respiratory irritation; r

Gastrointestinal

Stomach cramps; constipation; diarrhoea; incontinence (anal leakage); vomiting; nausea; decreased liv

Skeletal / Articular

Joint pain; reactive arthritis

Metabolic disorders

Toxic acidity; food intolerance; chronic food addiction; intolerance to medications; inability to tolerate heat

Genitourinary

Incontinence; kidney pain; increased frequency of urination; urgency of urination; painful urination; nocturia

Cardiovascular/ circulatory

Toxic poisoning shock (coldness); mitral valve prolapse; palpitations; chest pain of no known origin; an

Endocrine

Thyroid imbalance; PMT symptoms

APPENDIX TWO. GUIDELINES FOR DISABILITY ACCESS TO PUBLIC HOUSING FOR INDIVIDUALS WITH ENVIRONMENTAL SENSITIVITIES/CHEMICAL SENSITIVITIES

TARGET GROUP

People on low incomes with environmental sensitivities (ES).:

- “ Asthma, chronic obstructive pulmonary disease, other respiratory diseases

- “ Allergy

- “ Chemical injury/chemical sensitivity

- “ Occupational poisonings to specific products e.g. formaldehyde

- “ Reactive arthritis

Disability access to public housing

Public housing authorities are required to house people with a disability and have a responsibility to provide housing that does not make people ill. For people with chemical sensitivities/environmental sensitivities, that means meeting their need for housing free of chemicals and other substances that make them ill, contribute to their existing disease states, or may increase their sensitivity levels to chemicals in the future. As allergy can be a predisposing factor for both, asthma, chemical and other environmental sensitivities, individuals who suffer from these problems can also have specific needs in housing that require similar considerations.

Location and choice of materials can create poor indoor air as the quality of indoor air starts with the quality of the outdoor environment. The same air pollutants in outdoor air are also found indoors, with indoor air further polluted by substances brought into the dwelling. These include building materials, paint, adhesives, consumer products such as cleaning chemicals, fragranced toiletries, recently dry cleaned clothes, synthetic materials in furnishings and floor coverings, chemicals used for pest control, books and newspapers etc. (www.epa.gov/air). People with chemical sensitivities/environmental sensitivities vary in their degree of sensitivity to different chemicals and products, they generally need to avoid such products in order to prevent immediate symptoms and further deterioration in their health.

The following are some basic suggestions to assist with housing for disability arising from allergy, asthma or chemical sensitivity:

LOCATION - Preferably in clean air but this is difficult with current pollution levels. Housing should be available in a suitable location and away from heavily trafficked areas or industrial estates.

Suggestions

Close to sea to take advantage of sea breezes and clean air.

On a hilltop or high position to take advantage of breezes and improve airflow indoors

As far away as possible from:

- **Neighbouring houses** - this is essential if sensitivity levels are severe and fumes from fragranced products e.g. laundry products, detergents, disinfectants, personal care products, perfumes, pesticides, wood smoke, paint, hobby products etc. . Ideally, chemically sensitive individuals need to be housed in areas that are not built out. Where this is not possible, the surrounding properties should be materials that do not require painting.

- **Weatherboard houses or houses built from other materials that require painting** - these can create major health problems to chemically sensitive individuals when they require re-painting or renovations. Many chemically sensitive individuals become severely ill when exposed to paint fumes and as some paints take a long time to outgas e.g. oil based enamels, all surrounding dwellings need to brick or some other finish that does not require painting

- “ **Coastal wetlands** - where coastal wetlands are present individuals will be subject to large volumes of chemicals or live bacterium (biological control agents) for mosquito treatments. These can be human allergens, respiratory irritants and neurotoxins. The health impact of the mixture of these with city pollution is unknown.

- “ **Canal developments** - these are often sprayed for midges and mosquitoes.

- “ **Industrial estates, particularly where zoned for noxious industry and engaged in waste destruction, asphalt plants, CCA treatment facilities, Oil recycling, Fertiliser plants**
- these can contain very toxic substances that are respiratory irritants, carcinogens, human allergens e.g. sulphur dioxide, toluenediisocyanate, furans, dioxins.

- “ **Hospital incinerators, Council incinerators, Dump sites**, - these can seriously contaminate air quality with very toxic substances that include human allergens, respiratory irritants, neurotoxins, carcinogens.

- “ **Parks, Creeks, Playing fields, Golf courses** - a lot of herbicide and insecticide can be applied. These can contain human allergens, respiratory irritants and neurotoxins.

- “ **Power stations, electric generators, Overhead power lines, Mobile phone towers**. Some individuals are sensitive to electromagnetic radiation and need to take these into consideration when choosing a suitable location.

- “ **Petrol stations, Main roads, a heavily trafficked road, or freeway** - exhaust fumes contain respiratory irritants, neurotoxins, can cause high blood pressure, cardiac disease, cancer, childhood leukemia and affect the birth weight of infants.

- “ **Schools** - these are frequently painted, treated with pesticides inside and around the grounds, which are also treated with herbicides. (www.oztoxics.org/)

“ **Shopping centres** - heavy motor traffic around shopping centres can cause respiratory irritation, neurological problems and cancer.

“ **Train lines - these are regularly treated with pesticide and herbicide.** Pesticides and herbicides can cause many health problems including respiratory depression and neurological problems.

“ **Farms** - agricultural chemical usage has caused many health problems. Some problems are allergic reactions, respiratory disease, neurological disorders, cancers, endocrine disruption, developmental delay, low birth weight babies, still births, birth deformities. Some agricultural chemicals can bioaccumulate in the human body and affect genetic material (DNA) which in turn can affect future generations.

A person with severe chemical sensitivities may need to live in a house for twelve months before they know whether the house is suitable for them. All four seasons need to be experienced.

BUILDING MATERIALS

Suggestions

Low emission building materials and products are necessary to ensure that any materials capable of contaminating indoor air and affect health are not used in the dwelling. Building products and paints that are low in Volatile Organic Compounds (VOCs) are essential to reduce contaminant levels inside the dwelling. Discussions with public housing authorities are essential at this point as each individual will have different sensitivities or sensitivity levels and may need to define which materials need to be avoided. It is essential to ask the person with a disability what they know about materials they tolerate and don't tolerate. In these discussions, it is

important that the client is heeded as poor choice of materials can severely exacerbate existing health problems and inflict high medical costs on an individual who is poorly resourced to deal with any increased costs.

If there is any question about the suitability of materials, getting a material safety data sheet from the manufacturer should be the first basic step. This will give further information about a product and assist to assess product suitability (<http://siri.org/msds/mf/cards/> or www.cdc.gov/niosh/).

Assistance from the treating doctor may also be required. Further information about building materials and products is available on the Internet from a variety of sources such as www.epa.gov/iaq

Building materials should be low maintenance materials as much as possible because products used for maintenance or painting may trigger reactions and cause ill health.

BUILDING MATERIALS - as much glass, metal, solid timber (tolerated timbers) and ceramic material as possible.

External walls- brick, cement brick. While timber is an acceptable material it may require painting which can greatly exacerbate disabling health conditions. While painting outside is less of a problem than painting inside, an individual with multiple chemical sensitivity (MCS) would have to move out for a period of time. This raises the question of where would such an individual go? There is no crisis accommodation suitable for individuals with MCS.

Roofing - terracotta (clay) tiles, whirly birds in roof to increase air exchange. Some individuals with chemical sensitivities react to electromagnetic radiation. They may not feel well under a metal roof.

Flooring - ceramic tiles, solid timber. Carpet should always be avoided as should cement floors. Cement floors can be a source of cement dust that can be highly irritating. An added problem with cement is that it contains additives such as chrome and formaldehyde (both sensitisers). Timber flooring is a better option. For a client with arthritis or joint disorders, hard concrete floors will exacerbate their pain state.

Internal walls - tolerated materials only - no board products. Some individuals do not tolerate plasterboard.

Wet wall areas - ceramic tiles

Cupboards - solid timber (Kitchen and Bathroom). Avoid any form of chipboard e.g. MDF as it is a major source of formaldehyde contamination. Melamine can also cause severe reactions in chemically sensitive individuals.

Bench tops - stainless steel or ceramic

Electric stove, cooling, heating and hot water service - no gas on premises. Some of these may be better run on solar energy if available. Gas contaminates the air with nitrogen dioxide and seems to seep from the appliances. If gas appliances are unavoidable they must be well vented although the general experience is that gas is not tolerated on the property.

Bath and basin - porcelain, enameled metal, stainless steel (no fiberglass or plastics)

Shower Base - stainless steel or ceramic

Laundry tub - stainless steel

Taps - stainless steel. Some may tolerate powder coatings.

Objective - to reduce VOCs and other indoor air contaminants that can provoke reactions in sensitive individuals

The following materials are not acceptable for people with allergy/chemical sensitivities

- “ Chipboard – a source of formaldehyde, VOCs. Should never be brought into dwelling.

- “ Carpet – dust, mould, VOCs from synthetic materials in underfelt, adhesives and materials in the carpet.

- “ Plastics/Synthetic finishes – VOCs

- “ Melamine - VOCs

- “ Laminated chipboard - VOCs

- “ Fiberglass products - VOCs

- “ Fluorescent lighting – flickers, causes melanoma, migraine and epileptic seizures

- “ Gas - VOCs

- “ Gyprock – additives, VOCs.

- “ Solvent based products – water based products should be used in place of these.

- “ Pest control - housing for individuals with allergy/chemical sensitivity/respiratory disease should not be treated with pesticides.

- “ Cleaning - if a dwelling has been previously occupied and needs to be cleaned, it is essential that the client must be consulted prior to any cleaning to ensure that only tolerated cleaning products are used. Should the dwelling have carpets care must be taken to ensure that no scented products or solvent based products are used.

- “ Maintenance - should a dwelling require maintenance prior to occupation by a chemically sensitive individual, the individual should be consulted as to tolerated materials.

Note: Many substances used in domestic dwellings are known to be injurious to human health. Some such substances e.g. formaldehyde are known to be higher in the domestic environment than in the workplace. While acceptable air levels of some such substances are set for the occupational environment, no levels are set for domestic dwellings. Further domestic dwellings are not routinely sampled for these toxins and the medical profession is not trained to diagnose injury arising as a result of exposures in the home. In the absence of any known treatment following a sensitisation, as with allergy, avoidance is the only known method of health care. Some nutritional substances and medications are helpful to control symptoms but there is no known cure. Problems associated with indoor air quality have been known for a very long time.

HOUSE DESIGN

- A detached house with a minimum of 2 Bedrooms for a single individual is essential as items of furniture and clothing in the sleeping area are likely cause adverse health impacts. As an allergy sufferer/asthmatic or chemically sensitive individual will spend more time in their bedroom than an individual without these disabilities, they need a room devoid of materials that cause reactions. The bedroom should be a safe haven where they can retire for rest and recuperation. This is essential for maintaining health and being able to get on with day to day activities.
- Detached – as far away from neighbours as possible to offset health problems

exacerbated by cigarette smoke, wood heaters, pesticides, strong detergents/disinfectants or laundry products, fragranced products including scented candles, incense and essential oils being burned.

- Open plan - with good cross flow ventilation to maximise air exchange.
 - Entrance area that can be closed off from rest of house
 - Kitchen that can be closed off from the rest of the house. This is essential as the odours from appliances and cooking may make a chemically sensitive person ill.
 - Built up off ground to allow good cross flow ventilation under house (must be dry at all times for mould control) and not have concrete floors.
 - Concrete stumps and ant caps or Termimesh - no pesticides inside, around or under dwelling.
 - A dry, secure outside storage area is essential for storage and offgasing. New furnishings/electrical appliances/products may need to be left outside of the house for a period of time to allow them to offgas before they can be brought inside and not impact adversely on health. Things like mowers also need to be securely stored well away from the dwelling.
 - Windows and doors should seal adequately to allow for efficient air filtering or air conditioning. These work inefficiently if the windows and doors do not seal properly.
 - Power points - persons with allergy, respiratory disease and chemical sensitivities may need more power points to run respirators, vaporisers, air conditioners, air filters or other air cleaning devices.
 - Exhaust fans in kitchen and bathroom for mould and odour control are essential.
- Ventilation can also be assisted by a whirlybird in the roof.

- Lighting - Incandescent only. Fluorescent lighting may cause melanoma, migraines or epileptic seizures.

Note: Chemically sensitive individuals should not be accommodated in units or townhouses as their health will be compromised by close proximity to individuals who may smoke, use pesticides, fragranced products, burn scented candles or incense. Some substances such as pesticides and fragranced products may cause life-threatening allergic reactions.

If you are unsuccessful in achieving the required level of disability accommodation for your special needs, you have the right of appeal to the Queensland Department of Housing. If you are still unsuccessful following an appeal to the Queensland Department of Housing, you can lodge a complaint on the grounds of disability discrimination to the Queensland Anti Discrimination Commission, or the use the processes of the Human Rights and Equal Opportunities Commission and the Disability Discrimination Act.

Contacts:

“ Queensland Anti Discrimination Commission free call 1300 130 670

- Human Rights and Equal Opportunities Commission. Complaints infoline 1300 656 419 or website: www.humanrights.gov.au

Dorothy M. Bowes for ASEHA Qld Inc

September, 2004

APPENDIX 3 SOME MCS CASE HISTORIES: (ACTUAL NAMES HAVE NOT BEEN USED)

Case study one: Dora is a 40 year old woman with severe MCS and EMS who cannot find a house in which she can safely live due to poor indoor air quality caused by residues of pesticides, building materials, paint etc. She lives in her car most of the time because the house she is currently renting causes reactions as it is not a low toxic home. While looking for another more suitable house, a real estate agent disbelieved her and thought she was a psychiatric case. He called the police who notified local psych services. Dora's mother said she was schizophrenic and she was detained against her will for seven hours while subject to a psychiatric assessment. Dora is not schizophrenic according to her GP. Her mother, like the real estate agent and the police do not understand her problems. The latest development with Dora is that she has become traumatized since she was detained and is now suicidal because she cannot get any help, she is very ill, cannot find a safe place to live and since she was detained by the local psychiatric service is now constantly visited by police in her area. Recently, she drove off into the bush to end her life and the local police, a TV station crew and some individuals drove around the area looking for her. She was found, safe, but in a highly volatile and distressed state and taken to a house in the local area occupied by another chemically sensitive person. She did not tolerate the house and became unstable again. We are unable to find her a safe place to live, rest and recover and be able to care for herself. We fear for her life. As far as we know Dora is still homeless. Housing should be subject to IAQ Standards that allow MCS/ES disability access.

Case study two: People can die from fragrance exposure. Valerie was a 78 year old woman with emphysema and severe chemical sensitivities. Her lungs were particularly sensitive to fragrances and many other chemicals. She could lose consciousness on contact with fragrance and would need to be revived. She could not find air that was clean enough for her lungs to tolerate so spent a lot of time on oxygen struggling to breathe. She lived in a rural area but was constantly exposed to smoke from wood stoves and people burning rubbish etc. Because of the smoke she had several emergency admissions to hospital. She would ring the ambulance and ask them not to wear any fragrances or fragranced products when they came to transport her to the hospital. However, they invariably arrived smelling fragranced and on several occasions she arrived unconscious at the Emergency Room and needed to be resuscitated. She would then be placed in a ward with poor indoor air quality and would suffer more fragrance exposure as almost everything in the hospital is fragranced e.g. hand washes, staff that tended her, surgical scrub and disinfectants/detergents. Unfortunately, she was not believed and her efforts to protect herself from losing consciousness were mistaken for somatisation disorder. Eventually she would have to discharge herself from the hospital and go home where she lived alone and struggled to cope without any medical care. In September of 2007, she suffered smoke inhalation from surrounding human burning and called an ambulance to transport her to the local hospital. Once again her request for fragrance free ambulance staff was ignored and she arrived at the hospital unconscious. Yet again she was revived and placed in a ward where she was subjected to fragrances from staff and products, so she demanded to see the hospital administrator and had herself moved to another part of the hospital where there were to be no fragrances. Unfortunately the air quality in that area of the hospital was worse than what she had left behind and she resigned herself to the fact that she would die in the hospital. (She communicated this to ASEHA executive) We suspect she was subjected to fragrance through the night, lost consciousness and either nobody noticed or there was nobody to revive her in time..... we will never really know. She was dead the next morning when an ASEHA executive rang to check on her. Over a period of days the hospital ignored all of ASEHA's efforts to ensure Valerie was safely accommodated and nursed. (For around 12 months prior to this event ASEHA had provided the hospital with information about MCS, nursing notes, information about fragrances/fragranced products and fragrance free products, we had even met with Queensland Health – all ignored)

Case study three: Mary grew up on a farm and has a history of pesticide exposure. Mary worked as a nurse until the sterilising agents caused her health problems. She re-trained in

another profession and was subsequently employed by a government department. Mary was subject to a chemical (solvent) spill in her workplace which resulted in the building being evacuated and staff members transported to hospital. Some have not recovered to this day. Later in another workplace a pesticide treatment permeated the building which had to be evacuated with some staff being transported to hospital. Mary is now severely sensitive to solvents and pesticides. She is currently unable to work and support herself or take part in society. She has to wear a respirator when she leaves home. Worsening air levels in the inner suburbs resulted in Mary relocating to an outer city suburb with lower pollution levels some years ago. That suburb is now well developed and heavily polluted. In recent years, a carpet factory in her area caught fire and caused Mary further health damage. She is severely allergic to most chemicals, foods, nutritional supplements and medications. She is severely sensitive to pesticides and fragrances and is constantly ill, she can smell fragrances used by her neighbours as they drift across the fence line and permeate her house. This exposure keeps her ill with migraines, respiratory problems, and digestive problems. Mary urgently requires hospital care due to ongoing and severe digestive problems but cannot access this care (1) due to her pesticide and fragrance allergies because health care facilities have poor indoor air quality and are not pesticide or fragrance free; and (2) she is also severely allergic to many medications, anaesthetics, and the preparations and antibacterial agents used in the procedure she requires. Her last attempt to have this essential procedure resulted in a medical emergency and she was discharged from the hospital untreated as the specialist refused to deal with her allergy problems. Mary is unable to eat a balanced diet and is now very emaciated. Sometimes when she goes to the shops or banks etc she passes out. She is in urgent need of medical care but her MCS is not recognised/accepted and several hospitals have sent her home untreated in the last 6 months. One doctor referred her to an immunologist who was supposed to refer her on for dietetic assessment. However, he commented on her respirator and decided she was a psychiatric case. She was never referred to an allergy dietician to assist with her food allergy and food chemical sensitivity. She is struggling to survive.

Case study four: Dana has a background of allergic disease and digestive disorders from childhood. As a child and teenager she was an athlete and spent many hours training in the local swimming pool that was heavily chlorinated. She is now very allergic to chlorine. Her Father was a French polisher by trade and she was constantly exposed to paint. At 15 years of age, Dana was referred to a dermatologist for eczema. Some of the patch tests that were positive were fragrances and metals. Dana is unable to wear cosmetics or use personal care products. Dana worked in a research facility where the smell of chemicals was always very strong on the premises. Her absenteeism rate was high largely with upper respiratory allergy and migraine. She has a very high body burden of organochlorine pesticides, solvents and plasticisers and is now unable to work due to her sensitivity to many chemicals. Dana suffers severe food allergy and phenolic sensitivities, has very sensitive skin and cannot use detergents, disinfectants, washing powders and other laundry aids. She is also unable to tolerate wool or synthetic fabrics on her skin. She can only wear cotton and silk provided these are not dyed with strong colours. Dana has severe drug sensitivities and has reacted severely to anaesthetic (heart stopped). She now lives in an area with coastal wetlands and suffers badly when pesticide treatments are under way. In the last fifteen years,

her health has been further damaged by three chemical fires in close proximity. Two fires were pesticide storage facilities; the other was a grass fire which set fire to a fence formed from old car tyres. This fire has permanently damaged her lungs. In a neighbouring suburb, there is an industrial estate that has toxic waste disposal; asphalt plant, CCA timber treatment plant; oil recycling, tannery. There are always fumes, especially in the evenings. Some leave her very debilitated. In recent times (February 2006) Dana was driving down the freeway alongside the swamp when aerial treatment for mosquitos was underway. A helicopter flew over her car and minutes later her car was full of spray drift, her throat began to swell instantly, she broke out in a rash and has been very ill since the incident. Many people report similar problems with spray drift when mosquito control programs are underway alongside the freeway. Dana has serious neurological problems for which she is unable to get any assistance from the medical profession. She has lost count of the number of times doctors have told her they cannot help her. She is in a great deal of pain which is constantly exacerbated by fragrances, scented candles and incense used by her neighbour. Dana needs to relocate but lacks the resources and physical ability to shift house. Dana is unable to access a house with suitable air quality in a clean environment for a person with MCS/ES. She also experiences difficulties with indoor air quality in the hospital environment, when she has to consult her doctors and cannot access in-home services due to fragrances worn by staff delivering these services..

Case study five: Sarah lived in a sugar growing area for many years and was exposed to agricultural chemicals. Her chemical sensitivities became very severe after the family acquired and operated a pest control business. She has allergy that requires ongoing medication, food sensitivities and severe chemical sensitivities, which have destroyed two marriages. She must wear a mask when she leaves her home to protect herself from chemical exposures and as she lives in suburbia, she is subject to noxious fumes that drift across the fence line from her neighbours' laundry detergents and personal care products etc. The result of the chemical drift is severe disabling migraine and joint, muscle pain. On most days the medications she must take in an effort to achieve something that resembles pain relief are causing secondary problems and reducing her life span. She has osteoporosis as a result of prednisone use for her allergies and recently has broken her foot twice. She is unable to achieve disability access to chemical free medical and allied care facilities and doctors have decided she is a substance abuser with psychiatric problems because the only medication that will relieve her migraine is morphine. As a result of not being believed she is unable to access adequate pain relief. She has suffered discrimination in a hospital emergency when a doctor tried to remove her mask and treated her in an undignified manner. More recently she has had problems with several neighbours as in desperation she asked them not to use such strongly scented products because they threatened her life and left her in great pain. The neighbours refused to stop using the strongly scented products, as they do not believe the products make her ill. However, in reality these products threaten her life on a daily basis. More recently we suspect the neighbours have been snooping around her property and harassing her by spraying fragrances and other chemicals around the property and near the air conditioner intake to purposely make her ill. Her water supply has been turned off and she has been bullied by one of the neighbours who approached her in an aggressive manner. Sarah is already in crisis accommodation in the public housing system but unsatisfactorily housed. She is physically

disabled and unable to move house and deteriorating on a daily basis. She also does not have the financial resources to relocate even if there was a safer place for her. Sarah is unable to access public buildings because of chemical contaminants, especially fragrances and pesticides.

Case study six: Karen is/was a research scientist with a PhD in Biochemistry/Immunology following twenty years of research and study. During all of this time she worked within research laboratories connected to either universities, hospitals or private industry, initially as a laboratory assistant, then as a research scientist, and finally as a senior research scientist at her last job. In 1992 following years of handling a variety of chemicals Karen developed MCS and by 1993 had to leave her position as a senior research scientist with a Biotechnology Company in Brisbane. In 1995 Karen finally received her doctorate of philosophy and although she now has a PhD. She cannot use it as intended in the medical-scientific field because she is disabled by chemical exposures and cannot leave her isolated property. Having paid into an insurance fund to protect herself financially from work related injury, the insurance company initially provided income and sent Karen to all nature of specialists - respiratory, psychiatric, physicians, as well as receiving monthly reports from her treating doctor. Things went OK until the company Karen had been working for closed down their research department, which meant that she had to resign from the company. Once this happened it seemed that the insurance company decided to cut off her income support and terminate her policy. They requested that Karen attend consultations with a notorious physician known as the 'Queensland Hatchet Man' because of his involvement in insurance cases that resulted in people losing insurance benefits. Karen was also asked to see a psychiatrist interstate. She refused to go because she is chemically sensitive and unable to access buildings or travel in public transport, including aircraft, or to stay in hotels. Her reason for refusing to see the Queensland specialist was that she had been sent to see him by the Worker's Compensation Board (WCB) and he had already formed an opinion about her. His opinion was demeaning and derogatory given her scientific credentials and medical research background and was not within his field of expertise. Apart from this, the visit to him would leave her severely debilitated and it would take a long time for her to recover from leaving her 'safe' home environment. The 'Queensland Hatchet Man' is listed as a toxicology specialist but his conclusion was based on psychiatry - he concluded "that this woman had MCS if MCS is a synonym for serious psychological disorders". His opinion was used primarily by the WCB to dismiss Karen's case. The fact that his hospital notes and the WCB report did not match was not of any concern to anyone. The insurance company demanded that Karen see him for assessment, but for Karen, going to this doctor was a no win situation. Both the insurance company and Karen already knew what he would report and therefore she would have her case dismissed. Karen was not willing to go through the humiliation! Not to mention the disability, pain and suffering. After much correspondence the insurance company used false evidence - information from someone else's file (different case numbers) - and reports from doctors Karen had never been to see as grounds for closing her case. Any attempts made to have this reviewed were fruitless. Karen has lost her career and been stripped of all income. She has had to rearrange her entire life and is effectively unable to participate in, or attend most social events because of her chemical sensitivity. She has been demeaned by some members of the medical fraternity that she once trusted. Various official bureaucrats have dismissed

Karen as a crank and she has encountered obstinate resistance from those who have a financial or other vested interest in the continued sale and distribution of chemical irritants. Karen has also been failed by and ripped off by lawyers. Effectively a brilliant career has been ended because of chemical poisoning which has since impacted on every aspect of Karen's life. She lives in a remote area in a modified house, away from family and friends and is grieving for the loss of her life.

APPENDIX 4 –US NIBS REPORT attached with submission

APPENDIX 5 – Californian Clean air fact sheet. PDF attached with submission.