ASEHA Q1d Inc.

A volunteer community organisation providing support for people with allergy, food and chemical sensitivity

August 11, 2003

Commissioner Helen Owens
Productivity Commission
Locked Bag 2
Collins St East
MELBOURNE, VIC. 8003

Dear Commissioner Owens

Re Disability Discrimination Act Inquiry Public Hearings
Supporting Data supplemental to the Submission by ASEHA Q1d Inc

ASEHA Qld Inc is a support group for individuals with allergy, food and chemical sensitivity. ASEHA is run entirely by volunteers and currently has no funding from any sources other than memberships. We offer information and support to our memberships, whilst providing a free telephone service to the general public. Our objectives are to increase awareness of environmental illness in the community and advocate for the provision of necessary services for individuals with these diseases.

Enclosed is some supporting data for our submission, which we hope, will clarify some issues, in particular the psychiatric label that has been placed on chemical illness and injury. While I understand you have spoken to individuals with MCS across the country 1 am unsure as to whether any background data was supplied with other submissions.

We thank you for the opportunity to input the inquiry into the Disability Discrimination Act.

Yours sincerely

Dorothy M. Bowes (Mrs)
President

BACKGROUND

Disability is not being applied to those with chemical illness or injury/sensitivity. These fall into an area of uninet need in disability services yet fit the classification for disability. They suffer intellectual, sensory, physical, neurological impairment and recent research indicates that there is possible brain injury from exposures to toxins. Recent research to hand indicates that exposures to some toxins causes damage to the basal ganglia area of the brain.

- Such individuals are various stages of disability in relation to mobility, communication and self-care.
- Chemical injury/sensitivity is a disorder that is characterised by severe pain and discomfort. It may be diagnosed as other disorders. Some of these are: allergy, asthma or other respiratory disease, chronic fatigue syndrome, fibromyalgia syndrome, migraine, irritable bowel disease, reactive arthritis.

The role of environmental factors in disability

In recent decades there has been serious concern in the community about the impacts of synthetic chemicals on human health and the environment. There are around 100,000 man made chemicals and this figure grows at around 3-400 per year. There are 2,3000 high production volume (commonly used) chemicals and of these only 25% have a reasonable set of toxicology data, so most of the chemicals in existence are unregulated and unassessed. While these chemicals have made a major contribution to the way we five e.g. life expectancy and living standards, we need to be more proactive in our approach in dealing with the resultant environmental and health problems.

It is not possible, ever, to separate environment from health and as our environment food and water becomes more contaminated, higher levels of disease and disability are inevitable in the population. Societal unease about chemicals can be attributed to several factors:

- accidents at chemical plants e.g. Bhopal in India,
- chemical discharges to watercourses and air, in Australia some discharges are required to be monitored on our National Pollutant Inventory
- chemical usage in the home e.g. pesticides, detergents. disinfectants, fragranced products. These are made from industrial chemicals.

As our ability to measure smaller amounts of synthetic chemicals has improved we now know that chemicals are widespread in the biosphere, including human tissue. Some examples of this are DDT and PCBs in the environment, human tissue and wildlife.

While the production of chemicals is important to our world economy and our lifestyle, the capacity of regulatory systems to anticipate and prevent unacceptable impacts is seriously being questioned worldwide. This is confirmed by the UK Royal Commission on Environmental Pollution, (www.rcep.org.uk) the European Union's Report on Chemicals in the European Environment (http://themes.eea.eu.int/showpage.php/issues/chemicals) and the USA Center for Diseases Control reports into the body burden of chemicals (www.cdc.gov/nceh/tracking and www.cdc.gov/nceh/NHEXAS). In the USA, the National Institutes of Environmental Health Sciences **(http://ehp.niehs.nih.gov** have been investigating the impacts of chemicals on human health and developing diagnostic tests. Both the European and UK reports indicate that a new paradigm is needed for regulation of synthetic chemicals. Synthetic chemicals are found in our outdoor air, indoor air, food, water, medications, clothing, personal care products, furnishings, detergents, disinfectants, fragranced products and others - every facet of our lives.

While the USA, UK and Europe have been proactive in their enquiries into chemicals, Australia has not followed this line of enquiry. Recognition of chemical illness and injury across the world is poor, with Canada taking the lead with the establishment of an Environmental Health Centre at Nova Scotia dedicated to researching and treating chemical illness and injury. In Halifax there has been a ban on the wearing of perfumes in public places and in Ottawa lawn chemicals are not allowed to be used because of their impacts on the environment and health. Multiple Chemical Sensitivity (MCS) has been recognised in Canada, the USA, UK, and Europe. However, efforts to have chemical illness and injury recognised in Australia have generally not been fruitful and until government recognises the significant impacts of chemicals on the environment and human health the numbers of those harmed will continue to rise and such individuals will continue to be disadvantaged in necessary health care, disability and social services.

Without proper government recognition and action, the cost of chemical illness and injury to the community will continue to rise as individuals suffering from chemical illness and injury require more health care, need more disability services and income support. They have special needs in health care, disability services, respite, public housing, crisis accommodation, public transport and access to public buildings. In particular they lack disability access to just about everything.

Until MCS is recognised by government m Australia, those suffering will not be able to get appropriate health care, disability services and social services. Currently, MCS is not recognised by the medical profession. There is no disability access to hospitals for those with chemical sensitive and the special needs in medication for those with MCS are poorly understood yet doctors are happy to treat what they do not understand. The result of this is that further injury can be inflicted on already unwilling victims of chemical illness and injury.

A further problem arising from the lack of medical expertise in relation to chemical injury is that those with MCS can be unnecessarily medicated and erroneously seen as individuals with psychiatric problems. This view was proliferated by chemical companies many years ago in an effort to have the word 'chemical' removed from the term Multiple Chemical Sensitivity as the chemical companies were sensitive about the damage they have caused. Their recommendation was to call the disease idiopathic environmental intolerance and to ensure that victims got psychological support (Hileman, B. 1995). Unfortunately, this attempt to minimise blame for the health impacts of chemicals on humans has done enormous damage to chemical victims. Some have had their insurance benefits cut by medical specialists who do not have the appropriate skills or tools to investigate chemical damage. This action increases the burden on the public purse, as the chemically injured person then has to depend on social welfare and the public system for support in place of insurance payments. As chemically sensitive individuals have a high level of need for special food, clothing, disability housing, disability aids, etc; and social welfare benefits do not cope with the level of need, poverty compounds the problem. Such an individual then cannot access necessary care and services, which are only available in the private sector.

Case history one - A Senior Research Scientist (M) became ill following an occupational exposure in the laboratory in Queensland. M is disabled by chemicals to the degree that she has had to isolate herself (very remote rural area) to have moderate quality of life and becomes disabled if she leaves her home. She lived on her insurance policy payments for some years until her payment was reviewed. The insurance company required her to travel from Queensland to Sydney to see a medical practitioner of their choice and as she was too disabled to make such a long journey she refused to do so. She was then required to consult with a local physician employed by the insurance company and again refused as she had already consulted that particular physician earlier, at their request, and he had a written a defamatory report about her. These actions resulted in her insurance payments being cut. One of the worst aspects of this case was that M was not even the person quoted in the letter from the insurance company - they had actually used somebody else's diagnosis. A complaint to the Insurance Ombudsman was not accepted and her payment cut. Her occupational chemical exposure was unrecognised - in spite of the growing body of evidence that the chemical in question (formaldehyde) would cause the disability she has today. That particular physician has been responsible for many such individuals losing income support from their expensive insurance policies they had paid to support them in case of such an eventuality. Others have lost insurance payments in a similar manner, which means they are now dependent on social welfare for health care, disability services and income support. They can no longer afford treatments that were proving to be useful to them and have no capacity to support themselves.

In some cases, individuals with MCS are erroneously diagnosed as psychiatric cases. While they may have an intellectual disability as a result of chemical exposures, they may also be very physically debilitated because they can be permanently damaged by their exposures or become disabled on contact with chemicals. As MCS is a condition that causes much pain and suffering, a chemically sensitive individual would not want to have to obtain assistance or services if this means they will suffer a chemical exposure. As with allergy, the only known effective treatment of MCS is avoidance of chemicals that are known to cause problems. In the case of something like formaldehyde which is used in almost everything we touch today, the avoidance regime is enormous - just about everything - and the only way a chemically sensitive individual has of maintaining something that resembles quality of life is to self-care, i.e. do the avoidances.

However, the avoidance regime can also be misunderstood as some form of psychiatric problem and some individuals find themselves having problems with public authorities such as the Legal Guardian who misconstrue their self-care avoidance program as refusal of treatment. There are cases where the need for chemical avoidance has resulted in such actions.

Case history two.
E is a very disabled and chemically sensitive person. She is having her competency questioned by the Adult Guardian. She is sensitive to most chemicals, smoke, motor exhausts and all petrochemicals, and medications. On exposure to chemicals E suffers severe allergic reactions such as excessive mucus production and throat swelling, edema (localised swellings), severe pain in various parts of her body including the soles of her feet to the degree she cannot stand on them, disabling migraine headaches, her eyes blur so she cannot see and severe weakness and fatigue to the point where she cannot even stand. Apart from the chemical sensitivities E had a motor accident, which has left her physically disabled. She walks with the aid of a walker and sometimes uses a wheelchair. She has a full time carer as she is unable to live without 24 hour a day assistance. E has made attempts to modify her rental accommodation to avoid reactions to common chemicals in her environments and is sequestered to several rooms of the unit in which she constantly runs air-cleaning devices and has medical oxygen. If she is removed from her modified environment now she could die as she is extremely fragile and very debilitated. E is perfume sensitive and suffers severe allergic reactions following visits by nurses or other in-home service providers when they arrive wearing fragranced products. These service providers have been requested not to wear fragranced products when calling upon her, yet continue to come to provide 'care' wearing fragranced products. Apart from suffering allergic reactions that may require hospital care E is also diabetic. Should a severe allergic reaction occur and warrant emergency care or E's diabetes soar above a certain point, she would need to go to hospital. However, as there is no hospital in Brisbane with an area that is safe for individuals with severe chemical sensitivities, she could die if she was transported to hospital - otherwise she would die at home - she expects likely the latter. Because of problems with chemical exposures in medical surgeries, she has had her carer trained to give her necessary injections. E's chemical sensitivity was diagnosed by a Brisbane immunologist who was unable to treat her as her sensitivity levels were too high. However, he also thought her sensitivity levels were increased due to head trauma in the accident.

As a result of the motor accident E has been trying to gain compensation but has been unable to find a solicitor to take on her case. This is complicated by her physical and chemical disabilities and E cannot attend Court to take part in the hearings. Apart from this her health has deteriorated dramatically since the accident and the stress of the Court Case. On her last attempt to gain compensation for the motor accident, E attended Court in a protective suit with oxygen. She suffered a severe reaction afterwards and collapsed at home. As there is no hospital that can provide disability access to chemical free facilities she stayed at home as was prepared to die there rather than go to hospital. She is now totally housebound and unable to attend Court to settle the case.

The Court referred the matter to the Public Trustee and the Adult Guardian stepped m to settle the case. E objected to the Adult Guardian's representative in the Court. A legal officer from the Adult Guardian's Office visited her and was supposed to represent her at the Adult Guardianship Tribunal Hearings. The legal officer was given medical documentation to present to the Public Trustee's Representative at her Court hearing, however, the medical documentation was never presented and the her medical status was never properly represented at District Court. Only the Insurance company's medical reports were presented at District Court - not her independent medical reports. There was also no claim for a Carers component. The Public Trustee's Officer claims never to have received the medical documentation. E has commenced an appeal in the Supreme Court against an order from the Guardianship and Administrative Tribunal. Her affairs are now in the hands of the Public Trustee who have control of her finances and she is struggling with that as she has no access to her money for essential aids.

Most of E's money is spent in an effort to make herself more comfortable and case her pain and suffering. What would help E the most is to be able to relocate herself to a more suitable home in cleaner air than she currently has. However, she is unable to do this without her court settlement and because of the intervention of the Public Trustee who allocates her money. She is mentally competent, engaged in Tertiary Studies and has received a distinction for one of her subjects recently. Formerly active in the

community she is now unable to leave her home and subject to the Public Trustee for no valid reason. Her Court case is still not settled. If her Multiple Chemical Sensitivity was a recognised entity she would not be having such problems. She is currently considering a complaint to the Anti-Discrimination Commission. However, with her poor health this is difficult for her.

Case history three

This situation has been mirrored by another case where a well-meaning daughter (B) has been caring for her frail aged parents in her own home. Apart from fragranced products causing B's ailing father respiratory distress, heart problems and mental confusion, she has a chemically sensitive son who suffers severe behavioural problems from contact with chemicals, especially fragranced products. To protect both her father and her son, B asked the in-home service providers not to wear perfumnes when they were in attendance, but they continued to arrive wearing fragrances, refusing her request. B has also removed her father from nursing facilities because of fragranced products and their impacts on his health. Eventually one of B's fathers providers notified the Adult Guardian that B had refused care for the ageing father. This confirms the lack of education about the serious nature of fragranced products and their disabling impacts on humans. The ageing father has been removed from his daughters' care and currently is confined to a nursing home and subject to chemicals that are impacting adversely on his health. The Adult Guardian is requesting information about the parent's financial affairs as B has enduring power of attorney. The mother is extremely distressed and has developed severe asthma. She fears she will also be removed from her daughters loving care. Adding to the mother's distress is a financial problem as she now has no access to her own money and is worried about the $750 per week it is costing to care for her husband under the control of the Adult Guardian in the nursing home. The local doctor has put the mother on steroids in an effort to control the asthma. The mother requires hospitalisation but will not go to hospital as she is afraid she will be removed from her daughters' care as happened with her husband. Husband and wife have been separated and a fi-ail aged and dying man is distressed as he would prefer to be at home with his wife and daughter. This is a cruel and unnecessary action brought about by the refusal of government and the medical profession to accept that environmental pollution is causing disease and disability in the community.

There are also cases where loving parents of chemically sensitive children who have been trying to do the best they can to protect their children and look after their health, who have been accused of having Munchausens by proxy and their children removed from their care. Some parents have actually left the State to keep their children.

Case history 4

This case highlights the problems of the chemically sensitive in the community in their endeavours to obtain disability access to health and other community facilities. P has a history of allergy, food and chemical sensitivities with her chemical sensitivity being the result of an occupational exposure to pesticides. As a young woman P was exposed to the pesticides when she and her husband ran a pest control business from their suburban home. The drums of pesticide were stored in their carport and she could always smell the chemicals. Around this time P began to developed migraines and other health problems. The marriage split and she moved to a country area where the migraines and health problems were now obvious. P was placed on a diet by an allergist who declared she had food allergy and developed malnutrition for which she was hospitalised and subsequently treated by a psychologist because of doctor error. A dietitian who specialised in allergy dietetics and who was assisting P with her food chemical sensitivity noted she was very sensitive to fragrances. It was clear by now that P's migraines, which had become disabling and accompanied by vomiting, were caused by fraganced products which are ubiquitous in the environment and hard to avoid. She was treated for the migraines with morphine injections as this was the only medication that would resolve the migraine. If migraines are not resolved they do not go away, they keep coming back and result in constant pain and greater pain sensitivity. For many years P's treating doctors provided her with morphine injections to eliminate the her migraines and while they were frequent, around two a week, at least she obtained relief from the intense and disabling pain. Some years ago, Queensland Health issued a directive to GPs that patients on narcotic medications were to be referred to Pain Clinics and no further prescriptions for narcotic substances were to be issued. This left P in severe pain with no pain relief. She made an appointment with a Pain Clinic but there was an eight month wait and with no adequate pain relief this left her in absolute agony with the development of increasing sensitivity to pain. Apart from migraine P now has a diagnosis of polymylagia rheumatica so has developed fibromyalgia like pain as a result of inadequate

treatment of her migraines. Like anyone presenting to a medical practitioner with a headache P was given an appointment with a psychiatrist. He diagnosed her as a long term substance abuser and put her on a daily program of oral morphine which did not then, and does not today, deal with her pain. Apart from the migraines she now has the added pain of the peripheral neuropathies which is excruciating. She was treated as a substance abuser at the local hospital who refused to treat her migraines. Instead they offered her medications to which she had suffered adverse allergic reactions in the past and for which they had documented evidence from previous treating doctors. These were also noted on an allergy alert sheet on the front of her medical records. As P lives on welfare benefits she was unable to access treatment in the private sector with where her chemical sensitivities are better understood. Eventually, P went to the Queensland Anti-Discrimination Commission and two conciliation conferences were held. She was always under represented as these are legal proceedings and while the State Health Department came m represented by several barristers, she had only one solicitor from a free legal service. The solicitor who represented her had his own method of dealing with such problems and at the second conciliation negotiated an agreement, which was signed by both parties and only went part of the way to redressing her grievances. Her pain medication is still unsatisfactory and she still does not have disability access to hospitals as there are no facilities in public hospitals for chemically sensitive individuals and such people are at the mercy of the hospital staff. The agreement negotiated and signed at the last conciliation conference has already been broken by the Health Department signatories and her health is steadily deteriorating. This case history shows clearly that individuals using complaints processes do not have adequate public legal representation. Instead they are disempowered by the State who use taxpayer resources against taxpayers. Some months later P's marriage broke up as her spouse could no longer deal with her disability. She was subject to abuse and required access to a refuge. Unfortunately, there are no refuges or other forms of crisis accommodation that are chemically free so she lived in a dangerous situation until the State Department of Housing found a house for her that was of reasonable air quality and low in synthetic substances. Today P is deteriorating rapidly as she is subject to fragrances and petrochemicals from neighbouring properties. She lives with constant and severe pain levels. P is still unable to access public hospitals and other health care facilities and is still not able to get adequate pain relief. The oral morphine is not as effective as the injected morphine as she has a mal-absorption syndrome. These problems would be better resolved if there was recognition of harm done by chemicals to human health and the medical profession and other providers educated m how to provide services to chemically injured individuals.