REVIEW OF THE DISABILITY DISCRIMINATION ACT

HREOC and the Disability Discrimination Act (DDA)

HREOC promotion of disability has been good but DDA needs fine tuning:

- It works well for easy to deal with disability
- Is not working for new and more difficult-to-action disability and unmet need
- There is little to no support for problems of access faced by people with disability arising from chemical illness and injury such as MCS who desperately need disability access to essential health, disability services and other social services. Recently a friend, a lady aged 70 was taken to the Caboolture Hospital Emergency Department by Ambulance with a severe reaction. She had to wear a mask as the ambulance personnel were wearing fragranced products and during her time at the hospital she had numerous exposures to perfume worn by staff, all of which exacerbated her reaction. She asked the staff to read Hospital Guidelines for MCS patients but they refused, saying they did not have time and they obviously had little or no knowledge of how to protect an MCS patient. Another 75 year old lady was being taken to Nambour Hospital by Ambulance in the same circumstances. When she attempted to protect herself from aftershave worn by the ambulance officer by turning away from him, he roughly pulled her toward him by the arm and told her she was imagining things when she tried to explain to him that she was severely sensitive to perfumes. She has lodged a complaint with the ambulance service. Yet another friend whose son suffers MCS has been endeavouring for almost two years to find assistance in caring for her elderly parents at home. To date she has been unable to find any home carer who is willing to refrain from wearing fragranced products, consequently she is absolutely distraught and exhausted trying to care for her son and her disabled mother. Her father passed away in October 2003 after spending only a short period in a nursing home and then hospital. I encounter the same problems. I am unable to go to hospital when I become very ill as my sensitivity is extreme and I need to wear two carbon filter masks to adequately protect myself from exposure. Even wearing two masks does not provide complete protection, therefore I remain at home, unable to gain assistance from anyone. Because of the toxic atmosphere in hospitals etc, I am forced to face the prospect of dying at home alone, this is the truly terrifying future facing many MCS sufferers.
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Main problem for MCS - disability discrimination in the form of lack of access to essential services and social structure

Lack of recognition of chemical sensitivity as a disease state that results in disability

- Government policy is contributing to chemical illness and injury. Competition policy has resulted in weak legislation, poor regulation of chemicals and increases in pollution and unsafe products.
- Competition policy on development is causing unnecessary disease and premature death in the community e.g. asthma, emphysema, cardiac disease, cancer. The rate of development too rapid. There are too many people crammed into existing spaces, poor urban planning and too much industry including noxious industry (e.g. Narangba Industrial Estate with housing estate across the road) and the disease and disability caused by this is not being monitored. Scientific data and statistics indicate increases in disease states.
- Competition policy has led to an increase in chemical production and usage that is not sustainable. There has been an explosion of chemical products in homes and elsewhere that are not well regulated and the safety of chemicals/products is not demonstrated. Most do not have adequate toxicology data to support registration and public use (www.rceph.uk.org).

- Unsafe products e.g. household chemicals, pesticides, perfumes personal care products, furnishings, building materials have invaded our lives. Under competition policy products are supposed to be safe. Statements that chemicals are safe are not evidence based - human studies to prove safety are not routinely done and data on adverse health impacts of chemicals is not routinely gathered. Where registers are in place to gather data on adverse impacts they are poorly publicised and do not always provide educational material to warn the general public of the toxic nature of the products e.g. APVMA the Australian Pesticide and Veterinary Medicine Association.
- There are no population studies to evaluate the rate of unnecessary disease, disability and death caused by pollution levels arising from development policy
- There are no protocols or policy in place to establish new diseases causing disability (Unmet need) and recognition of these - e.g. chemical illness and injury/MCS.
- There are no protocols in the health or disability sector on how to manage those with Chemical illness or injury/MCS
- The Built environment needs study to ensure access for people with allergy, asthma or MCS. Poor indoor air quality caused by materials and products used inside can make people ill e.g. pesticides, solvents, plasticisers, synthetic materials, cleaning products, personal care products (dry cleaned clothing, perfumes and other fragranced products). Sick Building Syndrome is an important factor in disability access - not just ramps and other disability aids. Not only is this important to ensure that those with existing chemical illness or injury are able to access the built environment, but to ensure that other individuals are not injured or sensitised. Once chemical sensitisation occurs, there is no treatment - only avoidance. Failure to avoid a sensitising chemical will result in further health damage, including the spreading factor, which means the individual begins to react to many other chemicals as well as the sensitising agent.
- Once damaged by air quality (indoor and outdoor) or unsafe products, little health care is available. While Queensland Health claims that their staff can treat people with MCS this is not the case (Personal correspondence). They have no concept of the overall problem and this is evidenced by their refusal to provide disability access for MCS sufferers and their lack of knowledge on suitability of medications and avoidance of chemical exposures for MCS sufferers.
- There is no assistance from government for necessary disability aids for MCS sufferers - air filters, charcoal for filters, masks, oxygen at home, or home modifications to improve indoor air quality.
- There is little understanding of disability caused by MCS and poor assistance with public housing. MCS sufferers can't live in units and there is no 'safe' place to live. Fragranced products, paint, pesticide etc from neighbouring houses drifts into surrounding homes. Local councils also apply herbicides in the urban environment as well as aerial application of pesticides for mosquito control. These are applied in densely populated urban areas.

Disability access is a major issue for people disabled by MCS. Ecologically Sustainable Development needs to be better understood and observed e.g. more attention to air quality and safety of products.

Unsafe air and products disadvantage those in the 'susceptible' or 'at risk' groups who are likely to be a majority of the population, e.g. Sufferers of Allergy (Hay fever 41%), Asthma (25% children, 10% adults), other respiratory diseases, cardiac disease, cancer, pregnant women, foetus - adolescence, frail aged, chronically ill, those on medications such as chemotherapy, steroids, transplant rejection medication. Figures in brackets already add up to more than half of the population. Cross over rate between allergy/asthma is around 2.5%

Social problems from MCS

- no health care from mainstream medicine - problem not understood - instead they prefer to diagnose psychosomatic problems and treat us as per psychiatric patients. The problem is that the medications they depend on are more of a problem than a help and many of these are contraindicated.
- no disability access to hospitals and other essential services
- costs of special needs are probably higher than regular income. As many can't work they cannot afford private doctor visits which can exceed the scheduled fee and/or treatments that are not on Medicare or PBS e.g. dietetic fees, nutritional supplements, visits to natural therapists and treatment costs, physiotherapy visits, massage therapists. These can be quite helpful in terms of treatment and in some cases offer significant improvements in quality of life.
- Disabled people are amongst the most impoverished in the community. Many live on the lowest income with the highest level of need for assistance, especially disability support.
- Some sufferers have lost the support of family and friends who cannot deal with the constant illness and reactions to common substances. Marriages break up under the strain and many MCS spouses suffer domestic violence and mental cruelty.
- There is no disability access to refuges, nursing homes, respite or other crisis accommodation because of poor indoor air quality in the built environment/sick building syndrome.

Personal Experience of Disability Discrimination, HREOC and the DDA
I made complaint to the QADC and the HREOC in an attempt to gain appropriate treatment and disability access to necessary services - hospital, crisis accommodation, dental clinics, doctor surgeries , etc.

- There was no professional assistance to work up the complaint. Most advocacy services only do systems advocacy. Had there been professional assistance the outcome of the conciliations would have been different.
- ASEHA Qld Inc took on individual advocacy to help but are not resourced to do individual advocacy and did not have the expertise to fully develop the complaint. They were poorly funded to gather essential data to support case
- One blind solicitor was provided by a welfare legal service - he did not talk to me about the way he would negotiate any settlement and I am unhappy with the outcome.
- The Health system came in with a team of legal experts, solicitors and barristers - paid for by me (a taxpayer) who could not afford legal support for myself.
- The complaint was destined to failure from the start because of the lack of equity in legal support and the issues in my complaint not being properly established or supported (Did not have sufficient people or money to gather the data we needed on human rights, disability access and insufficient access to scientific data).
- I was not treated with dignity and respect by the opposing legal team at either of the two conciliations
- I attended the first Hearing and became extremely ill therefore was unable to attend the second, a teleconference was arranged and a consumer advocate from ASEHA attended on my behalf.

The negotiated settlement has not been respected by the hospital system.

- I am still on occasions treated with contempt/retribution and have to fight for appropriate treatment. I have been told that if I continue to request safe facilities for myself and other MCS patients this could cause problems in my relationship with my doctor at the Pain Clinic.
- I was not happy with the complaint process itself as I was treated unfairly and it was a poor outcome for me.

- While I may have got law - I did not get justice or equity - overall, the complaint process was not even fair. A Barrister representing Queensland Health told me prior to the first Hearing that I had no chance of winning. I was intimidated, interrogated and treated like a criminal. Another friend from a community help group was willing to advocate for me but was prevented from attending the Hearing. It is very obvious that I would never gain justice as I am financially disadvantaged and cannot afford to buy my justice. Queensland Health used my taxpayer funds to deny me justice and I find this situation unspeakably disgraceful in a supposedly democratic country.

I would like to see changes made to the way complaints are conciliated so that each side is equal, and those on low incomes and with disability that affects function have access to an independent consumer advocate to prepare cases for conciliation. This would result in a better standard of complaints and improved negotiated outcomes which could generate firm data to assist with changes in various areas such as Quality Assurances for the HREOC to better evaluate performance. Some such data would also be useful in other areas as well - to indicate unmet need and to assist with the development of future services.

Recommendations

- An enquiry into chemicals in products as per the US Royal Commission on Environmental Pollution 24th report. Chemicals and products: safeguarding the environment and human health. www.rceph.uk.org
- An enquiry into the built environment as poor indoor air quality impacts on disease and disability in the community. Poor indoor air quality is a major deterrent to access for a person with MCS, allergy, asthma - especially hospitals, nursing homes, crisis accommodation etc.
- Improve the DDA complaint process to ensure equity of access to legal support or remove the need for legal proceedings. An independent panel to assist with the conciliation process may be fairer - we need justice and a fair go - not law that is far removed from our needs.
- Establish an independent, individual consumer advocate to assist with the development of complaints. This would make it easier for disabled people to access and use the process of the HREOC and the DDA. Hopefully more equal as well.
- The HREOC's education and research function is an important aspect of promoting community recognition and acceptance and I would agree with this, the area of new disability is deserving of some of attention by HREOC. It would be timely if HREOC included chemical illness and injury/MCS in this function to expedite access to essential services.
- Confidentiality of conciliated agreements should be voluntary on both sides. They are not in the public interest, as the issues in some cases need to be public.
- Negotiated agreements need some process whereby they are observed - not forgotten in a few months. If they are legal and binding they should be applicable for the life of the individual. HREOC should check one year after an agreement is struck to ensure these are being observed.
- A bill of rights for Australians does not exist and we have no legislated human rights. Legislated human rights as per international charters would improve the enforceability of human rights in Australian. This should assist with observation of human rights by services and service providers and may also assist to improve the level of disability standards.
- Complainants should not be threatened with retribution should they continue to pursue disability access. Many people who make complaints suffer with retribution and as a result do not take the complaint to the next level as they cannot get service provision. The practice is common - and is rarely pursued to a complaint.

- Organisations should be able to initiate a disability discrimination complaint. This would effectively allow for systems advocacy within the DDA as well as individual cases.
- I do not support a co-regulatory approach with industry as this has already resulted in weakened regulation and legislation that is changing our culture and the structure of our society. Industry is notorious for not abiding by its own codes of practice. While Competition Policy is about reduced government interventions, services and costs, the role of government is interventionist. The government commitment should be to the welfare of its people - not industry and the making of money.
- There should be an appeal process for complaints that we feel have been badly negotiated or the negotiated agreement has been breached. Using the legal system for such processes is unwarranted because if the complaint has got to this stage the legal process has broken down.
- **Major recommendation** - the HREOC should use its function of education and research to investigate chemical illness and injury, unsafe products that cause it and the extent of the problem in the community. The investigation should focus on:

1. educating the community about the nature of the problem
2. the provision of essential medical and disability services for those suffering as a result of chemical illness and injury.
3. better regulation of products and demonstrated human safety.

The HREOC and DDA must work for all disability. Equity especially needs to apply at this level.

History of Chemical Sensitivity Health and Social Problems experienced by Barbara Prideaux

Early in 1973 my then husband and I purchased and operated a Pest Control business from our home which meant that we were both occupationally exposed to a range of pesticides and herbicides. I was pregnant at the time and within a matter of weeks I began to experience symptoms of ill health. My husband also developed health problems which eventually prevented him from working, therefore we sold the business after approximately 18 months. My health deteriorated but his improved. The government knew of the danger to human health from using these chemicals but it failed to remove them from the market or warn us of this danger, so now my health and my life are devastated. It was and still is, more important to favour industry so that the almighty dollars continue rolling into the government coffers. I cannot afford, nor have the opportunity, to fight for compensation, and I am threatened with retribution for asking for safe access to health care.

Our marriage ended in 1982, my ill health being one of the major factors. As I was unaware that the chemicals were the cause of my ever worsening health problems, for the next twenty years I continued using products to which I had become sensitised. I consulted many doctors but it was never suggested that I had been chemically injured until in 1994 a Dietitian diagnosed chemical injury and recommended avoiding all perfumed products and chemicals. Immediately I eliminated use of perfumes and chemicals my symptoms improved dramatically. Unfortunately after 20 years of exposure my sensitivity had become so extreme that major exposures have been life threatening and I am now unable to leave my home without wearing two carbon filter masks. The masks provide a good degree of protection but not a hundred percent and I am now unable to frequent public buildings or visit other people’s houses. The carbon filter masks cost in excess of $200 per year which is a major expense when existing on a Disability Pension.

In 1985 I remarried but years of continued worsening ill health placed a strain on the marriage until my second husband ended our marriage in 2001, stating that he did not wish to continue living a life with so many restrictions. Many friends decided to cease visiting as they did not want to discontinue using fragranced products to protect me from exposures. I was absolutely devastated that my husband, many friends and even relatives are not prepared to take precautions for the sake of my health. Thankfully my three children understand and are happy to do whatever is necessary so they can visit without causing more harm to my health. My youngest daughter, now 18, has chosen to live with me and is a wonderful help, happy not to use fragranced products. I am very distressed for her sake as she is unable to invite her friends to our home. Life is very lonely and restricted, people do not want to understand the problems which confront us when suffering from a particular disease unless they suffer the same disease. The public is educated about particular diseases by government or the medical profession and this needs to happen with MCS, not only to create understanding and compassion for sufferers but also importantly to warn of the dangers in using many fragranced and chemical products.

After separating from my second husband I was forced to accept accommodation sharing a house with my first husband as I could not find anywhere else to live which had not been pesticided and there is no safe crisis accommodation available for MCS sufferers. Due to his inability also to cope with my illness, a domestic violence situation developed and my daughter and I were forced to move once more. Advocacy by the Domestic Violence Counsellor and the ASEHA President managed to secure public housing which had not been pesticided for some years, for which I am extremely grateful. Living in close proximity to other houses means it is necessary to keep windows and doors closed to prevent fragrances and chemicals emanating from neighbours from entering our home. To do chores in our garden I need to wear a mask and this is extremely hot and uncomfortable, particularly in summer. If I am unable to have assistance in my home, alternatively it would help greatly if I could be given some help with the gardening.

Whenever I need to consult my GP or attend a hospital clinic, his surgery and the hospital positively reek of harmful odours and consequently my symptoms are exacerbated. Because I was treated with cortisone for many years I have now developed osteoporosis and diabetes which require specialist treatment. Knowing that I need to attend these appointments causes me a great deal of stress. If safe health facilities were available for MCS patients we would not suffer the stress and exacerbation of our symptoms. Fragrance free/non toxic alternative products are readily available for personal hygiene and cleaning purposes.

Due to ignorance of MCS by health care workers, myself and other sufferers continue to be treated with disbelief and ridicule. Because this attitude persists we no longer seek medical assistance for severe migraine. Doctors have laughed at me for wearing a mask and ambulance officers have threatened to search my home for drugs when they presumed I was suffering a drug overdose instead of believing that I actually had an excrutiating migraine.

There needs to be strict regulation of and compliance by companies which manufacture fragrance free products. A number of these claim on the label to be fragrance free but in fact are not, because they are not obliged to list every ingredient contained in the product or they use contaminated equipment.

If I were crippled and confined to a wheelchair I could still socialise, go on holidays, and most importantly be able to participate in activities with my children. In the opinion of a thirty year MCS sufferer, this is the most disabling and confining health problem. To be denied ‘safe’ access to the rest of the world is truly confronting and distressing beyond imagination.