ASEHA Qld Inc

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

A participating organisation of National Toxics Network

About ASEHA QLD Inc
ASEHA Qld Inc is a volunteer community organisation, It is a support group for individuals with allergy, food sensitivities, chemical sensitivities, and disorders that are caused or exacerbated by these e.g. asthma, fibromyalgia, chronic fatigue syndrome, hyperactivity attention deficit disorder, Autism, Aspergers' spectrum Disorder.

The following ASEHA submission on the Convention on the Rights of People with Disabilities was lodged with the Australian Attorney General's Department on 28th March 2003. Unfortunately, it was done in a hurry, without adequate research and was lodged with the qualifier that the submission was developed as a result of our experiences.

Submission for a United Nations Convention on the Rights of People with Disabilities

1. TO WHAT EXTENT DO YOU CONSIDER THAT THE CURRENT INTERNATIONAL FRAMEWORK FOR THE PROTECTION OF HUMAN RIGHTS SUFFICIENTLY PROVIDES PROTECTION FOR THE RIGHTS OF PEOPLE WITH DISABILITIES?
In ASEHA's opinion, the Australian government does not adequately protect human rights as laid down in International Covenants and Charters. In spite of the Declaration on the Rights of Disabled Persons which declares the same fundamental rights as fellow citizens, equalisation of opportunity does not apply to all persons with a disability in Australia. The following submission has been developed as a direct result of our own experiences and endeavours to achieve recognition of disability arising from exposures to environmental incitents.

While the current international framework provides some protection for the rights of persons with disabilities, this largely applies only in the case of well-accepted disabilities such as blindness, deafness, intellectual disability and those disabilities that are visual e.g. physical deformities, or individuals requiring wheelchairs. However, even those confined to wheelchairs do not always have sufficient protection, as Australian government resources to assist persons with a disability are scant and spread in a limited area. Even individuals confined to wheelchairs can be discriminated against in housing and other forms of disability access.

Areas of unmet need
New and emerging diseases fall into areas of unmet need. Some diseases have both health need and disability need and there do not appear to be processes in place in Australia to identify and monitor these to allow them to become established in medical and/or disability services. Income disadvantaged individuals with unmet need tend to fall through all of the cracks in social service provision such as housing, health and disability services. They often lack access to health/disability services and because of income disadvantage may not be able to afford necessary health care, or to provide for the special needs that arise from their disability. In some cases persons with new and emerging diseases can be erroneously regarded as psychiatric cases, and because their disability is not understood they are not always treated with dignity and respect. In spite of complaint processes and legislation in place to offset this, many individuals do not have adequate redress of grievances, which includes anti discrimination processes. More importantly, they lack income to pursue grievances due to their impoverished state and the prohibitive cost of legal representation. As they have no access to an adequate level of legal representation to use Australian law to pursue a grievance, they are unable to access international law.

Consultation

ASEHA considers that the level of government consultation with the community in Australia is not adequate, especially in the area of unmet need. We are not equal partners in the participation process and because some are unable to attend planned consultations due to a disability that affects their literacy skills, or some other physical or sensory disability, they are unable to input policy. Many do not know there are consultations under way and do not always have access to a computer or the Internet. ASEHA has experienced unwillingness by Queensland Health to have a new and emerging disease/disability recognised. The Association has not been consulted when services and policies are being planned, this has happened despite many requests to the Queensland Health Minister to consult with us.

Funding

Funding of grass roots organisations representing disabled individuals in Australia is poor, as is representation of these organisations on government committees. This further marginalises those with new and emerging disabilities. As their representatives are usually persons with a disability themselves, they lack physical, human, and financial resources, to pursue their disability into acceptance; to be accepted into the consultation process (especially when policy and services are being planned); and finally to be included in service provision. Since the move to Globalisation and economic rationalism, funding has become more difficult to access as government has reduced available monies over a period of years. While a limited amount of funding is available for projects and equipment, this does not help unfunded organisations with administration costs e.g. mail, stationery, telephone and Internet connection. Some groups actually lack the ability to grow because their members are all disabled and limited in their scope. They cannot physically engage in fund raising and even if office space and equipment were available to them, they would not be able to take advantage of this as they are too disabled to leave their homes.

Environmental factors in functioning and disability

The preamble of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities makes reference to *'the commitment made by States concerning the protection of the environment'.* Recent scientific literature and the literature review by the WHO (www3.who.int.icf/icftemplate.cfm?mytitle=Literature review on environmental factors) are clear that environmental factors have a role in functioning and disability. In Australia, some effort has been made to establish a National Pollutant Inventory (NPI) to measure pollutants in our environment. However, the Australian government has not shown a strong commitment to this process. Our NPI currently requires reporting of only some 90 pollutants, while the USA equivalent to our NPI requires reporting of in excess of 600 pollutants. We are even behind some third world countries in progress with our NPI, Mexico requires reporting of around 200 pollutants. While some pollutants do require reporting, the toxicology of these and full impacts on human health are not well known. Many commonly used consumer products e.g. fragranced products and pesticides fall into this category as well. As there is poor government commitment in reporting and documenting environmental exposures, there is also poor commitment to gathering data on the impacts of contaminants on human health. In 1990 the Senate Select Committee on Agricultural and Veterinary Chemicals in Australia handed down its findings. Amongst these was the conclusion (5.93) that there was sound evidence to support the establishment of a broad based data collection scheme for poisonings by agricultural chemicals and recommended (5.94) that Federal Health examine the feasibility of a comprehensive system of reporting of accidental exposures to agricultural chemicals. 13 years later we have not seen such a scheme established. Currently a scheme has been proposed (Chemical Adverse Event Reporting Scheme) but it is delayed in the bureaucratic process and there does not seem to be much government will to progress it to implementation. Funding for the scheme is inadequate and the government currently does not want to pay for a consumer representative to take part in the Working Group process. In spite of evidence from the US and other countries showing adverse impacts of environmental pollutants on health and the environment, the Australian government appears to have a poor commitment to Australians with a disability caused by environmental contaminants, or those who may develop a disability as a result of poor regulation. In the meantime risk assessments also lack a solid foundation as they are not based on human data and sensitive individuals e.g. those with Chronic Obstructive Pulmonary Disease who are most in need of protection by risk assessments are not protected at all. This is clear from the Worksafe Standard (Pt 2, Interpretation. Part 70) on exposure standards, which cover the airborne concentration of a particular substance in the workers breathing zone. Worksafe state that exposures are expected to cause no adverse health effects or undue discomfort to nearly all workers. This is unethical as they ignore their perceived small percentage to which the standards cannot be applied. (Worksafe. 1995. Exposure Standards for Atmospheric Contaminants in the Occupational Environment.) However, at risk

groups make up a majority of the population. (Asthma affects 25% of children and 10% of adults. Hay Fever affects some 41-50% of the population. Figures asthma foundation, Victorian Allergy Report.)

Apart from lack of progress with reporting of environmental contaminants, we have signed on to various GATT and other trade agreements. We are well into economic rationalisation, which has seen progression to minimal standards legislation, privatisation and deregulation. Some problems are arising with the lack of legislation/regulation and there is not adequate protection in place for human health and safety. The right to pollute now competes with the right to clean air and a safe environment. Environmental contamination will be a major contributing factor to disability into the future if not addressed

Health and disability services are about to be further privatised as a result of GATT and Free Trade Agreements. The community is concerned there will be a reduction in access to health care and disability services. Already health services are suffering as a result of privatisation and the dismantling of Medicare, our Internationally successful universal health care service.

As pollution increases and regulation decreases, we can anticipate a higher need for health and disability services. Should government funding for these services not be maintained at a level relevant to increases in disability in the population, there will be gross shortfalls in funding and persons with a disability may be even worse off in the future than they are at the present time. Social impact statements need to be developed to devise environmental health indicators that can be used for surveillance and monitoring of the health/disability impacts of environmental pollution.

Social impact statements
Social impact statements are useful for a range of purposes e.g. to develop performance indicators for policy development and to measure outcomes at various jurisdictional levels. Such a process could be useful to progress the issue of unmet need in medical/disability policy and service provision so that persons with a disability can achieve full human and disability rights.

2. IF YOU CONSIDER THAT THE CURRENT INTERNATIONAL FRAMEWORK DOES NOT PROVIDE SUFFICIENT PROTECTION FOR THE RIGHTS OF PEOPLE WITH DISABILITIES BECAUSE THESE ARE MATTERS NOT ADEQUATELY COVERED IN EXISTING INTERNATIONAL INSTRUMENTS, PLEASE SPECIFY THESE.

International Human Rights Law has not required that all states incorporate human rights standards into their national legislation.
International Human Rights instruments should become law in all countries. It is important that International Human Rights are fully enforceable to provide protection for persons with a disability. This is essential because governments:

- do not necessarily sign on to international instruments of rights
- sometimes, when they do, instruments of rights are not enshrined in legislation that is effective and enforceable, and
- instruments of rights that are legislated are not necessarily enforced by governments

Governments must not pay lip service to human rights.

International Disability Rights Instruments
Currently, international disability-specific instruments concerning the rights of persons with disabilities are non-binding. Incorporation and enforcement of these international disability rights in all countries is important to ensure '*equalisation of opportunity as a guiding principle for the achievement of full participation of persons with disabilities, on the basis of equality in all aspects of social and economic life and development.'* (Human Rights of Persons With Disabilities. 2002. www.un.org/esa/socdev/enable/rights/humanrights.htm)

Unmet need
Existing human rights mechanisms at international level have not yet fully addressed the rights of persons with disabilities. Provision for unmet need is currently not sufficient to ensure equalisation of opportunity. People with new disabilities are at risk of being marginalised and disadvantaged in many ways. While there is a presupposition of adequate knowledge and experience of the conditions and special needs of persons with disabilities, that presupposition cannot exist in the case of unmet need/new diseases. Some international instrument needs to be put in place to ensure that new and emerging diseases, or existing diseases that have not yet found their way into disability services, can

be documented for recognition as a disability and included in the ICF and international disability rights instruments.

Disability discrimination legislation has not provided equal access for equal need to those seeking redress through the anti disability discrimination commission. An example of this can be found in a recent case study before the Anti Disability Discrimination Commission Qld (January 2002). The complaint was made in an effort to redress the lack of disability access to Queensland health facilities and inability to obtain adequate pain relief. The action was lost at conference stage and could not go to a full hearing, as the person taking the action could not afford the cost of legal representation. The services of a publicly funded solicitor were available, but he could not match the expertise of three barristers representing the state government. In effect, the government used public funding (tax payer money) to provide themselves with a high level of representation against a tax payer. The woman concerned lives in poverty, is always in severe pain and could not afford an appropriate level of legal representation to achieve what should have been her basic human right of disability access to hospital facilities and adequate pain relief. This occurred after the state government interfered in her doctor/patient relationship. It is also a clear case of inadequate participation of persons with a disability at planning level. ASEHA is now trying to establish protocols for disability access to Queensland Health hospitals (outpatient and inpatient) for persons with a disability arising as a result of exposure to environmental contaminants.

Redress of grievances

With the previous example in mind, it is clear that while some International Human Rights instruments are upheld there is a need for International Instruments to be binding to prevent the judicial system from being used by Countries to manipulate their populations or deny human rights. However, there are problems with complaint resolution mechanisms that utilise legal processes. The legal profession has been shown to have a bias towards the medical profession. (Milburn, M. 2001). When it comes to rights violations, the law should protect vulnerable citizens but this is not necessarily the case. In her book *'Informed Choice of Medical Services: Is the Law Just?'* Marjorie Milburn identified patriarchal legalism with power in human affairs and the need for guidelines for law reform. If persons with a disability cannot achieve justice at law within their own country, there is a very clear need for International Law to be a Standard and enforceable in all Countries.

There are also other problems associated with the failure of anti discrimination cases and redress of grievances. In many instances persons taking action do not have the necessary skills to bring forward an action, they do not necessarily understand all the issues involved and may not have appropriate advice. This can affect their outcome and could be avoided by the establishment of an appropriately skilled independent advocate who understands the law, health and disability services.

Promotion of the rights of persons with disability

While it is thought that the emergence of new networks and communities of disability sensitised people in response to UN activities have contributed to the universal application of norms, standards and the advancement of disability rights for all, there needs to be a firm commitment by all governments to adopt legislative frameworks that reflect International Standards and Law in relation to disability and the advancement of disability rights.

It is important to involve relevant people from a broad spectrum of disability areas on processes to incorporate international norms in domestic legislation and policies. However, there needs to be better effort to involve persons with disabilities to ensure that the policies and norms are working for them at grass roots level. People with disability often have issues that are not addressed at political level or that get misinterpreted in professional interpretation of their needs. Norms, standards and policy development should start from persons with a disability up, not from policy makers and service providers down. This is essential to ensure relevance.

The general community should be educated about the special needs of persons with disabilities and their right of equal access to services, and to take part in society. Educational campaigns should be written into public policy and effective educational information made available about the rights of persons with disabilities. Above all, effort needs to be made to assist persons with a disability to complain when their Human and Disability Rights are not upheld and Disability Discrimination Legislation does not work for them. While many think complaints are negative, they should be seen as constructive criticism and part of a strong quality assurance mechanism to ensure equalisation of opportunity for persons with a disability.

Chemical Injury/Multiple Chemical Sensitivity.
Disability services need to be in tune with the needs of disabled individuals in the community. Individuals disabled by chemical injury/multiple chemical sensitivity who have medical and disability need, cannot access medical services, disability services, public housing, hospital services, respite or refuges, in-home nursing services, or public buildings. This is because they are completely disabled by common chemicals e.g. pesticides, disinfectants, fragranced products, used in facilities or on staff. (Weinhold, B. 2002) They cannot take part in social activities, education, eat the food from the marketplace, drink the water or breathe the air without disabling symptoms. Chemical injury is an emerging pollution related disease/disability and there is no consensus on defining, diagnosing or treating the disability. In the USA multiple chemical sensitivity is recognised under their Americans With a Disability Act, while in Germany, multiple chemical sensitivity is recognised under their ICD-10* section on allergy (*International Classification for Diseases). Multiple Chemical Sensitivity is also recognised in Canada, the UK and Sweden. Individuals with chemical injury in Australia are not protected under the international framework for human rights as they are in an area of unmet need that is not addressed. Services e.g. health, that should be proactive are not, they are reactive only after they are lobbied to provide disability access and include people disabled with MCS in service provision. Reminding bureaucrats of basic International Human Rights usually falls on deaf ears.
The Declaration of the Rights of Disabled Persons AR 3447 (XXX) proclamation no, 8 states 'Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.'

Environmental factors in functioning and disability
Some disabilities can occur as a result of exposure to environmental contamination or toxic substances in water, food, or indoor air e.g. home, schools, the workplace. While such technologies are relatively new and toxicology is a developing science, it is clear that the science of risk assessment is not stringent enough to prevent problems such as poisonings and disabling birth defects. The precautionary principle should apply until there are adequate data sets and science to properly evaluate risk. Some effort needs to be made to develop international norms and standards to ensure that the Rights of Persons with Disability arising as a result of injury from exposure to environmental and other toxins are included in definitions in the International instruments. Given the known increases in pollution worldwide and acceptance that this is causing disease and disability in the population, it would be timely if there was some action taken at international level to ensure data is gathered to include those with environmental diseases/disability in disability rights norms and standards.

Tracking
States should establish systems to track the volume of toxins used, where they are used, while monitoring should be implemented for both environmental contamination and adverse human health impacts. A register of the nature of adverse human impacts of these pollutants should be kept.

3. IF YOU CONSIDER THERE ARE PROBLEMS WITH THE REPORTING AND MONITORING PROCESSES CONTAINED IN THE CURRENT INTERNATIONAL FRAMWORK FOR THE PROTECTION OF HUMAN RIGHTS OF PEOPLE WITH DISABILITIES, PLEASE SPECIFY THESE.
Individuals with new diseases/disabilities have no way of getting access to disability pensions and disability funded services, e.g. chemical injury. New methods need to be developed for gathering useful data to develop International Standards for unmet need.

As ASEHA is an organisation that represents persons with disability arising as a result of exposure to environmental incitents, we would like to be consulted by the Special Rapporteur on issues that concern us and in which we have experience. We would also like to be consulted by the Queensland Health, Federal Department of Health and other government agencies to work towards disability access to facilities, appropriate medical attention and social services. We would especially like to be consulted when policy and service planning is being done.

While we are aware that the Australian government has enacted the Disability Discrimination Act (1992), and this is a good piece of legislation, our experience shows that it is not effective in all areas. Consultation between the Disability community in Australia, legal advisors and other relevant services should be undertaken to find ways to improve its effectiveness.

Recommendations
1. International Human Rights Law should require that all states incorporate international human rights standards into their national legislation.

2. There needs to be some international norm or standard developed to ensure the inclusion of those with unmet need in International Disability Rights Law and International Human rights Law.
3. As individuals with unmet need do not have adequate protection of their human and disability rights under international instruments, they also may not have adequate redress of grievance. As most complaints involve the legal system, an international instrument should ensure persons with a disability have access to adequate legal advice to pursue their grievance to the same level as the State. This should be binding on all States as formal statutory complaints mechanisms must protect the interests of persons with a disability.
4. Further to redress of grievances, many individuals are not well versed in human rights, disability rights, health matters, disability matters or legal matters to adequately file a complaint. An independent disability advocate should be appointed to fully develop complaints for disabled persons and to assist the aggrieved to make a proper complaint. This should be a requirement under International Disability Rights Law. Such an action would raise the quality of complaints made and be a worthwhile quality assurance tool to evaluate performance and indicate the need for change in various areas.
5. The appointment of a Human Rights Ombudsman may further improve the ability of persons with a disability to achieve justice and their International Disability Rights when they cannot access legal processes.
6. Persons with a disability in areas of unmet need should have access to appropriate medical care and medical facilities. Currently, medical practitioners are trying to diagnose and treat diseases/disabilities in which they are not trained and do not understand. In many cases they do not believe patients. This urgently needs to change as some new and emerging diseases are challenging traditional paradigms e.g. chronic fatigue syndrome, phenolic sensitivity, chemical allergy induced by substances such as toluenediisocyanate, formaldehyde. Some other forms of environmentally induced disability include Asthma, Fibromyalgia, and Chronic Obstructive Pulmonary Disease. Such individuals do not have disability access to hospitals, respite services, low allergy housing, in-home services, refuges, schools, churches, public buildings, public transport or other support services. An international instrument is required to legitimise disability arising from exposure to toxic substances so those suffering with the problem can be included in international disability and human rights laws. Some such disabled individuals cannot access disability aids that improve their quality of life and ability to function e.g. air filters, air conditioning, and oxygen at home. Some chemically sensitive individuals are very isolated, as they cannot leave their homes.
7. Multiple chemical sensitivity or toxin-induced disease needs to be included as a disability in the ICF as a priority so that we can all move on with fundamental concepts in disability. We cannot have international disability rights and international human rights for some persons with a disability and not for others. This is unethical. The fundamentals of prevention, rehabilitation and equalisation of opportunities must apply to all. Organisations such as ASEHA representing persons disabled by environmental pollutants and other toxins should be funded by government, as a priority, to represent their constituents in the development of standards of access, participation in policy development and service provision. Educational programs should be implemented to warn people of problems arising as a result of exposure to environmental contaminants, or other toxins, so they can protect themselves against disability. Some organisations already have material developed for distribution to the general public but lack the resources to print large amounts and distribute them widely.
8. States should provide funding for organisations representing persons with a disability to enable representatives to attend disability and other relevant conferences. These are important for networking, the upgrading of information and reskilling.

As this submission was written from our own experiences we would like to see some solutions to the issues we have raised. When the work is being done in these areas, we would like to be consulted, as we would like to be part of a successful outcome.

Endnotes

Some individuals have medical need, some only have disability need and some have both medical and disability need. The definition needs to cross both, medical and disability need, as some individuals are accepted for disability pensions and services, yet others with the same degree of difficulty are excluded. Case history example: an individual with chronic fatigue syndrome was granted a disability pension, yet others with the same problem and degree of difficulty – or worse - have been excluded. The same provisions should apply for all.

Weinhold, Bob. Making Health Care Healthier: A prescription for change. *Environmental Health Perspectives 109(8): August 2001 p. A370-377. 'P. 371/2 refers to short term problems such as headaches, dizziness, difficulty thinking, fatigue, and irritation of the eyes, nose and throat. Longer term problems may include respiratory disease, heart disease and potentially even cancer.'* Some other problems caused by exposure to

chemicals in indoor air, outdoor air, food and water are chronic fatigue syndrome, migraine, fibromyalgia, reactive arthritis, SLE, asthma, epileptic seizures, autism/ADHD.
Milburn, M. 2002. Informed Choice of Medical Services: Is the Law Just. Ashgate, UK.
Queensland Health. A Guide to Consumer Health Rights and Responsibilities. Section on Access to Care.

People with disabilities are…

'….people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- *Self care management*
- *Mobility*
- *Communication*

Requiring ongoing or episodic support'.

The Commonwealth State Disability Agreement 1998 Clause 4(1) states……..

The Commonwealth and States strive to enhance the quality of life experienced by people with a disability through assisting them to live as valued and participating members of the Community. (We would like to see that)

Submission written by Dorothy M. Bowes for ASEHA Qld Inc with assistance from Kay Mays. March 7, 2003