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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

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Disability Discrimination Act Inquiry
The Productivity Commission
Locked Bag 2, Collins St East
MELBOURNE 8003.

Review of the Disability Discrimination Act (DDA). Submission 3.

Effectiveness of the DDA

The DDA has generally increased awareness of disability in the community. It has made a substantial contribution to the rights of people with a disability by reducing disability discrimination and providing a forum for complaints. However, while the DDA seeks to eliminate disability disadvantage caused by discrimination, there is insufficient focus on unmet need, in particular issues relating to recognition and service provision for disability arising as a result of new and emerging diseases e.g. chemical illness and injury such as Multiple Chemical Sensitivity. The success of the DDA in more obvious forms of disability e.g. sight and mobility impairment, is largely due to the effort of those groups to gain recognition and service delivery. It may also reflect a high level of financial and human resourcing than is available to other forms of disability. In spite of improvements in disability awareness, lack of disability access to essential services for those with MCS has not necessarily improved by the use of the HREOC process. Support groups made up entirely of individuals with disability are not in a good position to progress their cause due to lack of well human volunteers and their inability to fund raise. This situation is not helped by government policy which is economic based, lacks a social focus and has resulted in funding cuts to social services such as health, public housing and disability.

Recommendations

1. **More promotion of disability by the HREOC is essential to 1) raise awareness of disability discrimination in the community; 2) educate the community about the existence and function of the HREOC and the DDA and 3) encourage individuals to use the processes available via the HREOC and the DDA.**
2. **More focus is essential in areas of Unmet Need to ensure that the human rights of individuals with new and emerging diseases are observed and that such individuals can access essential health, disability and other human services.**
3. **Government funding for disability should be increased, in particular, government should fund support groups who identify an area of unmet need and who are struggling for recognition and acceptance of that need. Funding should be available for administrative support, equipment and maintenance. Some funding should also be available for such groups to do research and attend conferences to upgrade their knowledge base and their skills.**

Competition Policy Agreement

While the DDA is based on a 'social model of disability', it has been subjected to a CPA review to ensure that the legislation does not unnecessarily restrict competition. ASEHA Qld Inc believes that the DDA should not be subject to Competition Policy and that community services such as health, housing and disability and other human services are best provided by government to ensure universality i.e. equal access on the basis of equal need and that equal attention is given to special needs groups in the community. This should ensure that those disadvantaged in the community with unmet need can access necessary services in tune with their needs. Such individuals often fall through all the safety nets as their disease and disability is not officially acknowledged, they can find access to necessary services poor or unaffordable. As income disadvantage is an acknowledged determinant of poor health and disability, it is appropriate for government to ensure equitable access and an acceptable standard of service provision for those with unmet need. While market forces are thought to be important for improving consumer responsiveness and efficiency, this may not necessarily be the case e.g. the Banking Industry where services have fallen, charges have risen and many jobs have been lost. It may also not be the case with the DDA where market forces do not necessarily apply.

Human services such as health and disability do not operate like a typical market. Consumers cannot necessarily make informed judgements about whether they need a service or not, whether the service will be effective or what the consequences will be. The push for private insurance has resulted in many dropping out of their health insurance fund, despite the government rebate, as individuals found they could not afford gap and other out of pocket payments. A two-tier system has been established and income disadvantaged individuals find private health insurance unaffordable, they have poor access to essential health and disability services when needed. Instead, there has been marked deterioration in public health care service provision with significant waiting lists and income disadvantaged individuals have been effectively priced out of health care and special needs for their disabilities.

Market forces and choice has not kept health services affordable, nor has it increased choice. As with the banking industry, the opposite has occurred. Medical specialties often restrict entry to those specialties to keep income high. Specialist services can be expensive and unaffordable for the disabled and low-income groups and there is no alternative source of supply. Those with new and emerging diseases find the medical workforce does not understand their disability and special needs and that help is often only available in the private system and unaffordable for those with low incomes. Disability aids are also unaffordable for income disadvantaged individuals who are not able to have good quality of life as they cannot provide for their special needs. Governments should always provide human services. Competition policy and privatisation is unacceptable - it cannot necessarily be applied across the board.

Currently, we have a weakening of legislation and standards as we move to minimum standards legislation and co-regulation with industry. While industry is expected to develop codes of practice to set standards, industry does not always abide by its own codes of practice. Further, the codes are not legal and binding, they are not enforceable at law. Australians expect their elected governments to govern for the people - not downgrade legislation, regulation and relegate to industry. Australians expect governments to provide necessary welfare services as it represents their share of Australia's natural resources and wealth and is best provided by government. Legislation should be a balance of economic and social policy.

Recommendations

1. **Health, disability and other human services should not be subject to Competition Agreements but should be adequately funded and run by governments to allow income disadvantaged individuals access to essential services on need**
2. **Legislation and regulation is the domain of government. Any standards or Codes of Practice should be established by government and enshrined in legislation to ensure a high standard of service that is legally enforceable.**
3. **Legislation should always be a balance of economic and social policy.**

Improving the complaints process

While the Draft Report claims the DDA has been effective in reducing discrimination, access to the complaint process has not been equitable. Making a complaint can be prohibitive because of:

- poor health and disability, the distress of being subject to discrimination and then taking part in the complaint process
- lack of advocacy services to ensure complaints are sufficiently developed prior to conciliation or a hearing, and to physically take part in these processes with complainants.
- Individuals with physical or sensory disability can lack access to most community services and supports
- income disadvantage and lack of access to legal support,
- fear of court costs if the case is lost as property or money cannot be recouped due to disability.
- People do not always know about complaints processes - providers do not always tell them about such processes

Advocacy services

Many advocacy services only do systems advocacy - not individual advocacy. In the interests of equity, a consumer advocate should be established for individual advocacy. Adequate government funding should be available to the consumer advocate to ensure complaints are properly developed for conciliations and hearings. Consumers do not necessarily know all of the implications of their complaints and if a complaint is not sufficiently developed with all the issues brought forward, opportunities for reducing disability discrimination, gathering data on new and emerging diseases/disabilities and providing high quality services in tune with consumer needs may be lost. This is particularly important in the area of unmet need, new and emerging diseases/disability. Having an individual consumer advocate may assist to remove some of the strain of making a complaint and should assist to put the complainant on a more equal footing with services and service providers.

Conciliation

Conciliation to resolve problems may be best undertaken initially at the point of service. Complaints resolution at the point of service has a role as a quality assurance mechanism and can assist with the development of protocols for the management of future complaints at that level. Protocols for making complaints should be highly visible.

The issue of access to adequate legal support may be dealt with by all complaints being subject to conciliation by an independent conciliator or independent panel of conciliators. However, the anti discrimination body, be it a State based body or the HREOC, should be resourced sufficiently to fund legal support for complainants unless some other method of dealing with disability discrimination is found. The protection of a complainant from legal costs of a failed action is an absolute necessity as this acts as a barrier to making a complaint. Either no costs should be awarded against the complainant if the case is lost or the legal action should be adequately funded by government or by the HREOC itself. This could be a good incentive to make the DDA work better as it has not resolved issues at the point of service. A review of complaints and practices may need to be undertaken.

Confidentiality clauses relating to Anti Discrimination or HREOC hearings should be removed and the issues open to community scrutiny unless both sides agree to confidentiality. Confrontation by Barristers can intimidate complainants as in some cases the Barristers are overbearing. Complainants do not necessarily achieve what they set out to achieve by going through anti discrimination processes, one commented that law and justice are two entirely different matters. Complaints would be better resolved at the point of service by an independent panel and consumer advocate rather than subject disabled persons to more distress in their lives.

Some mechanism needs to be developed to ensure that negotiated settlements are observed. In the public hospital system, individuals who sign agreements to abide by HREOC negotiated settlements can be moved around and the settlement becomes void. This increases the distress of going through the anti discrimination process as it has all been in vain and is a most unsatisfactory situation.

The complaint process should always act as a quality assurance mechanism of the DDA so their claims of efficacy are evidence based and they have some firm basis on which to plan future amendments to the DDA.

The issue of equitable access for people with MCS to health and other allied services, including disability services, under the DDA has not been satisfactorily addressed in the review process thus far. Many individuals with MCS suffer disability discrimination, they do not have disability access to health care facilities, disability support services and allied services e.g. respite, public housing and crisis accommodation. They may also be disadvantaged by lack of disability access to other public services such as transport and schools, while some individuals are disadvantaged in the workplace. Efforts by individuals with MCS to achieve disability access to health and allied services using the process of the DDA have not been successful. Such individuals need to be fully supported by the DDA and all of its processes. Some process for ensuring that new and emerging diseases/disabilities are detected early and included in service provision is essential. It should also reduce complaints to HREOC.

Some individuals, who have officially complained about lack of disability access or unfair treatment, have suffered retribution or have been threatened with retribution. Requests to meet with Health and Allied Service providers to pursue disability access are not always fruitful. They do not necessarily result in the requested meetings and correspondence sometimes goes unanswered. Such action effectively reduces any chance of pursuing and achieving disability access. Ministerial responses to requests for consultation in an effort to achieve disability access to essential services, usually results in dismissive responses with requests for consultation and meetings ignored. The community has no recourse to redress of such behaviours by health ministers, hospital administrators and other service providers. In some cases, some individuals with MCS get excellent treatment at health care facilities. However, when another MCS sufferer presents, they do not necessarily get the same courtesies. Protocols need to be developed to ensure that those with new and emerging diseases/disabilities especially MCS, are all treated the same and to ensure equal access for equal need.

The medical profession often denies the existence of new and emerging diseases and this can be disempowering for individuals with such problems. Medical training cannot teach students about new and emerging diseases that are poorly understood, especially when paradigms are challenged, as is the case with MCS. This means that medical people do not actually have any basis to deny the existence of new diseases and in most cases, they claim lack of data to support the existence of the problem. However, claims of lack of data simply mean that appropriate evidence has not been gathered and their denials are not evidence based. Sometimes 'expert' committees are established to deal with certain issues, yet they mostly have no expertise to do this, preferring instead to find a case for somatisation disorders.

An inordinate amount of damage is done by the attitude that someone with MCS or Chronic Fatigue Syndrome has psychological problems. Once this is written into medical records, individuals become disadvantaged in health care, as their problems are not taken seriously. Problems related to pain, fatigue and other serious issues that affect health and levels of disability and function are then not addressed.

Recommendations

1. **An consumer advocate should be established and funded by government to do individual advocacy and properly develop consumers complaints**
2. **Conciliation should be undertaken first at the point of service in an effort to avoid further action or legal proceedings**
3. **In an effort to avoid legal proceedings an independent conciliator or panel of conciliators should be considered. A panel would need to consist of people with expertise in health, disability, ethics, social sciences and health consumers.**
4. **Should a case go to a hearing, nobody should have costs awarded against them and funding could be provided for the legal teams by the government or the HREOC.**
5. **Confidentiality clauses should be removed from HREOC proceedings unless both sides agree to such a clause. Complaints are a good process for streamlining systems.**
6. **Some incentive should be given for complaints to be dealt with at the point of service.**
7. **There should be an enquiry into the satisfaction of negotiated settlements to see whether this process is working well or needs to be replaced by some other mechanism.**
8. **The complaints process needs to be standardised to ensure that individuals complaining of lack of disability access are treated equitably, have access to administrators and are not treated with contempt for complaining.**
9. **Service providers need to be better educated about disability discrimination, the HREOC and the DDA to ensure that they comply with the Act.**
10. **Some framework needs to be developed for dealing with new and emerging diseases to ensure that individuals with disability arising from them are not missed in service provision**
11. **All individuals with disability should be treated with the dignity and respect they deserve as human beings with a disability.**
12. **A better consultation process between government and individuals that suffer with new and emerging diseases/disability is essential. Ministerial and other bureaucratic access should not be denied as this is essential to progress access to care for those with unmet need. Access to administrators of health, disability and other essential services should also not be denied.**
13. **Training in recognition of new and emerging diseases/disabilities at medical school and in social services needs to be developed.**

Government policy, environment and illness.

The issue of disability arising because of chemical illness and injury has not been addressed. This is also known as Environmental Illness and reflects the level of contaminants in our food, air, water and environments. While Australian authorities acknowledge there are individuals in the community who may be sensitive to chemicals, they have:

1. not established programs to monitor for blood and other biological indicators of the presence of chemicals in the human body, and
2. there is little research undertaken in Australia to understand the health impacts of these levels of chemicals in the human body.
3. There is little effort to establish what percentage of the Australian population is affected by chemicals in their environment, (air - indoor and outdoor including the workplace, food and water), or the contaminants to which they are subjected.
4. There are no initiatives to regulate allowable levels of chemicals in the domestic environment. While air quality in the workplace is monitored and regulated, some studies have shown that the domestic environment can contain levels of some chemicals e.g. formaldehyde that are higher than in the workplace.
5. Legislation in relation to environmental contaminants has been consistently weakened under Competition Policy as previously identified. As many of these contaminants have not been adequately tested, safety has not been adequately proven. Using lack of evidence as proof of safety simply means evidence of adverse health impacts has never been gathered or assessed. Mostly no methodology exists to test for levels of most chemicals in the human body or interpret their meaning.

In the United States, reasonably well funded government programs have been implemented to gather data on the body burden of environmental chemicals and the relationship between these and human diseases. www.cdc.gov. In Australia, the federal Health Department's enHealth Council released the National

Environmental Health Strategy in 1999 which claimed that *'Australians are entitled to live in a safe and healthy environment'* and introduced the Australian Charter for Environmental Health. The guiding principles for the Australian Charter for Environmental Health are:

- Protection of Human Health by identifying threats posed by environmental hazards early and introducing safeguards that are ideally sustainable and cost effective.
- Interrelationships between economics, health and environment which establishes a link between economic development, protection of human health and the environment. These are supposed to proceed hand-in-hand and promote high standards of environmental protection and human health.
- Sustainable development which requires that development meets the needs of the present but does not compromise the ability of future generations to meet their needs. (World Commission on Environment and Development, 1987)
- Local and global interface where changes can significantly impact on human health. Environmental health programs need to ensure that we think globally but act locally.
- Partnership requires that all involved work together e.g. consumers, government, industry and business, NGO's, health and scientific communities.
- Risk based management uses tools such as risk assessment and risk management to address existing or potential environmental threats to human health, adverse effects on people, communities and economic interests. Risk based management also includes the development and implementation of strategies for prevention, minimisation or removal of environmental threats.
- Evidence based decisions which are based on careful analysis of available scientific evidence about potential environmental risks to human health. The absence of conclusive evidence is not an excuse for inaction, the precautionary principle should apply.
- Efficiency in the delivery of environmental health services, encouragement of innovation, examination of how environmental health services are provided, relevant costs and benefits of each alternative for optimal environmental health outcomes.
- Equity to reduce the gaps in health status between different population groups by way of equitable access to appropriate environmental health services, acknowledging that income disadvantage and other social factors such as access to community networks, family support and education are all determinants of health. (The National Environmental Health Strategy. Implementation plan. 2000)

AUSTRALIAN CHARTER FOR ENVIRONMENTAL HEALTH

Individuals and Communities

Entitlements

Individuals and communities are entitled to live in a safe and healthy environment. This includes:

- Safe and adequate supplies of water
- Safe and nutritious food
- Safe and adequate sanitation
- Clean air
- Safe and sustainable shelter
- Urban and housing designs that promote environmental health
- Environmental management systems that protect environmental health
- Safe occupational and work practices
- Safe and adequate recreational facilities, including water
- Information about environmental health issues
- Being consulted on plans, decisions and activities likely to affect both the environment and health, and to open and transparent decision making on these issues.

Responsibilities

Individuals and communities are responsible for:

- Ensuring their own actions contribute to the protection of the environment in the interests of their own health and the health of others
- Participating in decision-making processes on matters likely to affect both the environment and health
- Ensuring its environmental health services are delivered to a high standard

Business and Industry

Entitlements

Business and industry are entitled to:

- Management systems (legislative, regulatory and other) that:
- Promote health and the environment while recognising business interests
- Recognise industry capacity for self management in a co-regulatory environment
- Provide access to appropriate support, advice and information on environmental heatlh
- Consultation on environmental health decisions that affect business

- Guidelines and standards which:
  - Place a reasonable regulatory burden on industry
  - Support industry capacity to manage environmental health
  - Are developed transparently
  - Are consistently and fairly applied.

<u>Responsibilities</u>

Business and industry are responsible for ensuring that they:

- Use opportunities and practices that minimise adverse impacts on human health
- Seek and use alternatives to hazardous agents and practices wherever possible
- Reduce levels of pollution and waste wherever possible
- Maintain a high level of occupational health and safety
- Ensure consumer and product safety
- Have a contemporary knowledge of the potential environmental health risks arising from their processes
- Recognise that they are an integral part of the community and therefore have community obligations

Government

<u>Responsibilities</u>

While the charter recognises the responsibilities of individuals, communities and business, government has an obligation to make a major contribution to progressing this charter. Government has been and remains responsible for most of the investment in the infrastructure that underpins the delivery of environmental health services.

Government at all levels is responsible for providing direction and leadership on environmental health policy and management through:

- Setting clear management standards that are consistent across governments
- Ensuring effective mechanisms for linkages between agencies to achieve improved environmental health outcomes
- Ensuring appropriate environmental health infrastructure and services are available and effective
- Ensuring seamless transition between jurisdictions and agencies especially in management of environment and environmental health.
- Ensuring that planning and regulatory decisions recognise that the integrity and sustainability of the ecosystem must be maintained.
- Transparent and consultative decision making processes.
- Development of consistent legislation , standards and approaches to enforcement.
- Planning, preparing and responding to environmental health challenges
- Aiding community involvement
- Facilitating investment in strategic environmental health research

While the Charter and its' Guiding Principles are good statements that should result in clean air and a safe environment, research shows that the current levels of development have already produced disease and disability in the community. (Simpson R, London J. 1995). Such research is ongoing. For the Charter to work, sustainable development must be observed to preserve human health and the environment. Currently, planners and regulatory authorities are not observing sustainable development or observing their duty of care to the populations they are sworn to serve. Governments and health services need to be proactive and dedicated to the implementation of the Charter, not reactive when problems arise that should never have happened.

Government legislation and policies relating to development and ecologically sustainable development need to be investigated as there are instances where community concerns about environmental pollution causing disease and disability have been ignored, or dismissed, by Government with an economic agenda that is not ecologically sustainable. The community has no access to redress of grievance if individuals cannot afford litigation costs. Further, an inadequate level of State and Federal Budgets has been allocated to address funding for disability and health services, yet the demand on these has increased as a result of the rapid growth and development favoured by current economic policies. Better legislation to address ecologically sustainable development and a higher level of funding for health and disability services needs to be addressed. This is essential to ensure equity for those suffering disability and disadvantaged as a result of current government policies.

Recommendation

In making assessments to identify the magnitude of the social and environmental or other economic problems that the legislation seeks to address, some attention to the following is essential:

1. **The magnitude of social, economic and environmental issues that impact adversely on those disabled by chemical illness or injury such as MCS should be investigated and addressed by government.**
2. **The investigation should ensure that the objectives of the Act in regard to those in the community with unmet need such as MCS are met i.e. equity of access and a more accessible complaints system that does not rely on the affordability of legal representation.**

Finally, I believe that National Competition Policy is not necessarily in the best interests of the community. In particular, the economic model is not appropriate for people with a disability and disability services. Since the adoption of National Competition Policy, legislation has been systematically weakened then followed by further weakening once an industry co-regulatory approach is adopted. I do not support a co-regulatory approach as industry has already interfered with the efforts of people with MCS to obtain appropriate health care and disability services. The DDA must be exempt from National Competition Policy and human rights under the DDA fully observed. Overall, industry and essential services such as health, housing, disability and allied services, must not be able to claim it is too difficult for them to provide equitable access for individuals in the community disabled by MCS.

Recommendations

- **An inquiry into competition policy in Australia should be undertaken to assess its impact on employment, income, progress in industry, environment, health, disability, and other social impacts.**
- **Consultation should be undertaken with the Australian people as to whether or not they want an economy that is competition based.**

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