PRODUCTIVITY COMMISSION

INQUIRY INTO THE DISABILITY DISCRIMINATION ACT 1992

Submission

by the

ME/Chronic Fatigue Syndrome Association of Australia Ltd

THE ASSOCIATION

1 The ME/Chronic Fatigue Syndrome Association of Australia Ltd. is an association comprising representatives of each of the State and Territory ME/CFS Societies and Support Groups in Australia (there being one or more in each Australian jurisdiction). The Association represents at least 150,000 patients and carers in Australia who are experiencing the challenges of CFS on a daily basis. Although the actual subscribing members of the Association's societies comprise only about 5% of the national patient estimate, the provision of support and advocacy services throughout each year benefits many tens of thousands of Australians.

2. The Association has a critically important role to play in Australia in stimulating and coordinating nationwide efforts to achieve greater awareness of CFS and better support services for those with the condition. It is in that context that this Submission is made to the Productivity Commission with respect to its inquiry into the Disability Discrimination Act 1992.

THE CRITICAL CORE ISSUE IN THIS SUBMISSION

3. This Submission addresses a critical core issue that the Association requests the Commission to address in its inquiry into the Disability Discrimination Act and that is, **the inconsistency between the definition of disability as it appears in Section 4 of the Disability Discrimination Act with the definition of disability in other legislation throughout Australia.**

4. In circumstances where legislation throughout Australia, in particular in the various Disability Services Acts in each jurisdiction, define "disability" in an

exclusionary fashion with the effect that, from a statutory definitional perspective, CFS is not accepted by service providers as being a disability, the ability of patients to seek redress in response to discrimination is at best legally problematical and uncertain and at worst unavailable. The ramifications of this situation has been to place the Disability Discrimination Act off limits to people suffering CFS as they generally have neither the financial resources nor the human physical resources (of good health and staying power) to commence the process to redress discrimination they have suffered.

CHRONIC FATIGUE SYNDROME

5. Chronic Fatigue Syndrome (CFS) sometimes known as ME (Myalgic Encephalopathy or Myalgic Encephalomyelitis) is a serious, disabling condition, which can affect people of all ages. Classified by the World Health Organisation as a neurological disorder (International Classification of Diseases ICD 10.G.93.3), CFS simultaneously affects many systems of the body giving rise to numerous symptoms including persistent profound exhaustion, post exertional fatigue, cognitive impairment, sleep disturbance, muscle and joint pain, headaches, digestive disorders, sensorydysfunction, flu-like feelings, mild fevers, sore throat, irritability, sensitive to foods and chemicals, painful lymph nodes, heart palpitations, disturbance of balance and night sweats.

6. The level of incapacity experienced varies from individual to individual but CFS is not diagnosed unless previous functional capacity has been reduced by at least 50% for more than six months. Many people remain ambulatory but are often unable to manage steps, prolonged standing or carry bags and require extended sleep and rest periods. However the more severely affected are confined to wheelchairs and/ or bed.

7, The level of incapacity experienced varies from individual to individual but CFS is not diagnosed unless previous functional capacity has been reduced by at least 50% for more than six months. Many people remain ambulatory but are often unable to manage steps, prolonged standing or carry bags and require extended sleep and rest periods. However the more severely affected are confined to wheelchairs and/ or bed.

8, The symptoms fluctuate from day to day and hour to hour and are exacerbated by physical and/ or mental exertion. For some, the level of exertion required before symptoms worsen is minimal. Moreover, recovery from overexertion is delayed and prolonged.

9. There is no known cure for the disease. However, by careful self-management of the illness, people with CFS can maximise their functional capacity without causing serious symptom deterioration. Some people make a reasonable recovery from CFS after a number of years but for others the condition follows a relapsing path or remains chronic.

THE IMPACT OF INCAPACITY

10. As a consequence of the severity of many of the symptoms of CFS, it can severely affect those who have contracted it: for instance, those in the work place can rarely maintain the level of productivity hitherto within their capacity and many must leave employment altogether. The learning capacity of students living with the illness can be severely affected, limiting their ability to take part in educational programmes that require regular attendance and sustained performance.

11. As a general overview, most people with CFS are challenged in just about every aspect of their life, so the simple tasks of negotiating public transport or the more complex challenges of maintaining personal financial viability, can often become overwhelming. In such circumstances, the individuals concerned then become reliant upon whatever support structures they can access. **Beyond the support of carers who might be available within their immediate circle of family and friends, it is when CFS patients seek the support of external providers or the understanding of those with whom they must interact, such as their employer or insurer, that they find discrimination often stands in their way.**

MISUNDERSTANDINGS AND DEFINITIONAL ISSUES

12. There is still much misunderstanding of CFS by many medical practitioners and educators in Australia. The publication in March 2002 in the *Medical Journal of Australia* of Royal Australasian College of Physicians' CFS *Clinical Practice Guidelines 2002* (which was sponsored by Commonwealth funding) has reduced the problem in some quarters, but not to any meaningful, let alone desirable, extent. The Association believes that the *Guidelines,* when read by persons with superficial

knowledge of the illness, can lead to a misrepresentation of the illness and may lead to misdiagnosis, misunderstanding and inappropriate treatment. The Guidelines are but one instance, a very significant instance, of the problems arising out of the continual misunderstanding of the nature of CFS.

13. **Misunderstandings lead to definition problems and, in turn, those definitional problems lead to serious issues with respect to disability support services. Many of the serious issues which arise with respect to disability support, or rather more accurately, the denial of such support, can amount to discrimination. In circumstances where discriminatory consequences flow from actions or decisions which are, in effect, sanctioned by legislation - due largely to exclusionary definitions of disability - there is a distinct likelihood that the <u>Disability Discrimination Act</u> 1992 can be, or will be, of little assistance to the person disadvantaged by discrimination of the kind just described.**

14. The inadequacy of accurate information on CFS in the community combined with the lack of its recognition as a disability means there is wide variation in the degree to which the disability-related needs of persons with CFS are accurately assessed. As a consequence, there necessarily follows a wide variation in the level of support services available from both the public and private sector. Within the public sector, we include the broadest range of services or support from the provision or non provision of disability pensions to the provision or non provision of consideration to students by educational institutions. Within the private sector, we also include the broadest range. from the provision or non-provision of a caring and tolerant work environment to the provision or denial of insurance or superannuation payouts.

15. The problems associated with the recognition and so the definition of CFS has led to consequential problems with the drafting of legislation, procedures and guidelines in all jurisdictions across Australia. In most instances, the definition problem manifests itself in the illness falling outside the statutory definition of a disability. It is this issue of CFS not being recognized in some legislation as a disability that forms the basis of the primary submission of this Association to this inquiry into the Disability Discrimination Act

16. CFS/ME Victoria, the Society in Victoria representing some 1800 members and some 15,000 or so people in Victoria with CFS, prepared a submission for the

Victorian Government titled "Recognition of CFS/ME as a Disability: a submission to the Victorian Government" addressing the problems associated with the lack of recognition of CFS as a disability under the definition of the Victorian Disability Services Act 1991. The problems associated with the definition of "disability" in the Victorian Act are common to most other jurisdictions in Australia: in particular, under the Commonwealth Disability Services Act 1986 one finds in Section 8 the specification of the "target group" of persons eligible for the funding of disability services which excludes those whose disability is not permanent or likely to be permanent. In short, if the interpretation of disability is continually tied to permanency then CFS patients will, more than likely, continue to be shut out from most of the available support services that would otherwise be available to them.

17. In highlighting this aspect of "permanency" as a problem with respect to the definition of disability, the Association does not need to argue that CFS is or is not permanent, that is for the medical researchers to one day establish, however, the Association does argue that the absence of proof of permanency of the illness or the more extreme symptoms of the illness, ought not operate so as to exclude the provision of disability services. This position can be justifiably stressed to the greatest degree when it is understood that within the spectrum of persons suffering CFS there are persons who are totally disabled without any independent capacity to survive without constant and on-going support.

18. In order to enable the Productivity Commission to better understand the significance of this issue regarding the definition of disability in the context of CFS, now tabled with this Submission is a copy of the Submission to the Victorian Government prepared by the ME/Chronic Fatigue Syndrome Society of Victoria regarding the review of the Victorian Disability Services Act 1991. Amongst the appendices to that Submission are letters from nine medical practitioners specialising in the treatment of CFS who set out their professional opinion regarding CFS as a serious disability.

19. The fact that CFS is not classified as a disability is out of step with international recognition of the illness. In the U. S. the National Institute of Health, The Centres for Disease Control, Food and Drug Administration and Social Security Administration all recognise CFS as a serious, often disabling illness and the level of fundingof tens of millions of dollars recognises this. In Australia, the National

Health and Medical Research Council recognises CFS as an organic physical disease affecting up to 150,000 Australians. Yet legislation throughout Australia continues to discriminate against CFS sufferers by effectively excluding them from many of the support services that would otherwise be available to them.

20. To illustrate this problem in just one area, that is in the field of secondary education, in a Report titled *"Just a Lazy Teenager"*- written in 2001 by Lesley-Anne Elbourne, in her capacity as a member of the National Youth Roundtable, she revealed inadequacy in and inequity between rural and metropolitan Victoria in support for students with CFS. (A copy of the Elbourne Report accompanies this Submission). In rural and remote areas of Victoria, 78% of young people who had left school because of CFS and were not in any form of education stated that their schools had not provided the support they needed and 11% stated they were supported only some of the time. In Metropolitan Victoria comparable statistics showed that 20% of similar students had not received the support they needed and 40% stated they were supported some of the time. This study by Ms Elbourne indicates that there is much scope for improvement in the level of provision of support for students with CFS in Victoria. It is anticipated that a similar situation is likely to occur in other parts of Australia. **Where the lack of provision of adequate support services can be traced back to a refusal by the schools concerned to accept the reality of CFS, there can be no doubt that these students, suffering from a disability in reality if not by legislative definition, were subjected to discrimination. Such discrimination ought he capable of remedy.**

THE LEGAL OBSTACLES FACED BY CFS PATIENTS

21, I have now been working within the CFS support organizations in Australia for eight years now, largely as the Victorian Chairman and the National President, and in that time I have been confronted with a myriad of instances of unacceptable circumstances confronting people with CFS throughout this country. I can't help but bring to my positions the perspective of a barrister who has largely worked within the civil rights area (although always largely in the environmental field). Without exaggeration, every month of those eight years I have been appalled at one example after another of some poor person struggling with their illness while being confronted with the additional burden of an unacceptable legal, bureaucratic or administrative block to them receiving the support, the care, the finance, the equal opportunity or just the basic dignity to go on as they should be entitled. I can elaborate, as indeed all the CFS Societies around Australia could echo, about these problems but it is sufficient for today to say, if the definitional issue regarding disability can be addressed so that people with CFS can be assured of an "even playing field" when they find it necessary to seek justice or just receive what should be their entitlements, then we will as a Nation have addressed a very serious deficiency with respect to disability.

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