

Senate Inquiry

Senate Employment, Workplace Relations and Education References Committee

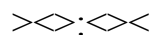
Inquiry into the Education of Students with Disabilities

Education of Students with the Chronic Illness Disability of

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

(ME/CFS).

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Education of Students with the Chronic Illness Disability of
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).
Dorothy I.W. Morris

Preamble:

This submission relates to the problems of students with the chronic illness **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).**

ME/CFS is a major disability for student who suffer from it. It reportedly accounts for more than fifty percent of all persons with a disability registered with the disability liaison offices of New South Wales Universities.

Given that the symptomatology of this condition is not yet adequately addressed even by them medical profession especially cognitive dysfunction and learning difficulties, this submission addresses a serious and important area. In fact, due to the lack of research the full impact of ME/CFS on education is still unknown. Worldwide, there has no funding directed into research in this area. For current policies and programs to meet the needs of students with ME/CFS there must be detailed research into education, so that appropriate accommodations and adjustments may be made for these students.

I am the only doctoral researcher in Australia into ME/CFS and Education. This submission contains some of my research findings (work in progress), peer-reviewed papers and other papers written on the basis of my research findings. But as mine is the first research into the area of ME/CFS and education it is of necessity only preliminary and has barely scratched the surface of this complex field. It has, however, indicated areas where further research is required.

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The following areas of the Terms of Reference will be addressed.

- (1)** Inquire into the education of students with disabilities, including learning disabilities, throughout all levels and sectors of education, with particular reference to:
- (a)** whether current policies and programs for students with disabilities are adequate to meet their educational needs, including, but not limited to:
 - (i)** the criteria used to define disability and to differentiate between levels of handicap,
 - (ii)** the accuracy with which student's disability related needs are being assessed,
 - (iii)** the particular needs of students with disabilities from low socio-economic, non-English speaking and Indigenous backgrounds and from rural and remote areas,
 - (v)** access to and adequacy of funding and support in both the public and private sectors,
 - (vi)** the nature, extent and funding of programs that provide for full or partial learning opportunities with mainstream students,
 - (vii)** teacher training and professional development, and
 - (viii)** the legal implications and resource demands of current Commonwealth and state and territory legislation; and
 - (b)** what is the proper role of the Commonwealth and states and territories should be in supporting the education of students with disabilities.

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(Some of these documents are still under peer-review processes or are a part of work in progress for my thesis, and currently are therefore not available for publication. This will be indicated where applicable).	
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Note: I shall make general reference to the Education of Students with Disabilities, as well as specific reference to the Education of Students with the chronic illness disability of ME/CFS.

Education of Students with the Chronic Illness Disability of
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 Dorothy I.W. Morris

1. Introduction.

This Senate Inquiry into the Education of Students with Disabilities is both timely and appropriate. The terms of reference are also very appropriate and reflect my own doctoral research findings into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and tertiary education.

I am a reference person in the field of ME/CFS and education throughout Australia and also overseas (having reviewed the Canadian publication by the TEACH-ME Task Force (2002), *TEACH-ME: A Sourcebook for Teachers of Children with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia*(1). I am also cited in education papers by Jane Colby in the United Kingdom.)

I have three education/teaching qualifications in the areas of secondary teaching and vocational education and training. I have made ME/CFS and tertiary education the area of my PhD. research at Deakin University and I currently hold a Deakin University Post-graduate Research Scholarship (DUPRS). Most importantly I also have the condition, and thus write from personal experience and my own understanding, both as an educator and student.

My research is into **“The Lived Experience of ME/CFS: A study in human rights and equity in tertiary education.”** My research has been limited to those students who have studied post-1995 at Australian tertiary institutions. The forty participants have come from all states and territories of Australia and have been enrolled at twenty-four Australian Universities and eight TAFE/OTEN colleges. The focus was on ascertaining the lived experience of tertiary students with ME/CFS, allowing issues of equity and human rights to emerge from the student stories. This research has been conducted in the context of the present disability situation, and the research data was collected in the second half of 1999. My research has uncovered gaps in the services for students and problems in the academic, quality of life and social situations of many of the ME/CFS students.

Attachment 2

Morris, D. (2001), “Report on the findings of ‘The Lived Experiences of tertiary students with ME/CFS’ to the ME/CFS Society of South Australia and SAYME2001, 18 February 2001 as guest speaker.

Paper 1: Introduction to research into ‘The Lived Experiences of tertiary students with ME/CFS p.5

Attachment 7

This attachment contains work-in-progress from my unrepresented doctoral thesis. There are no references appended to these excerpts.

The contents of this Attachment are NOT for public viewing, and are submitted to this Inquiry for Private Viewing only by the Senate Select Committee.

Education of Students with the Chronic Illness Disability of
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2. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

ME/CFS is a poorly understood chronic illness condition. It is primarily a neurological illness closely related to Parkinson's and Multiple Sclerosis, with well-documented variable encephalitic features, and including dysfunction of the endocrine, immune and cardiac systems, as well as variable involvement of all other body systems (2,3). There is presently no cure, and ME/CFS is likely to continue for the rest of the life of the person with the condition (4).

ME/CFS has profound effects on the quality of life of persons with the condition (14). The effects of severe ME/CFS has been unfavourably compared with the suffering of patients with terminal AIDS (15).

Since the mid-1980's, either carelessly or deliberately, number of research definitions of ME/CFS coined which have promoted much unhelpful blurring of the realities of the condition, with emphasis on the non-specific and often minor ME-symptom "fatigue" (5,12). At present there is no diagnostic test for ME/CFS, diagnosis being made 'by exclusion' and according to the medical practitioner's clinical judgement. The incidence of ME/CFS in the general population is estimated at between approximately one and five percent, but Australian epidemiological studies have not been carried out (6). Seventy-five to eighty per cent of persons diagnosed with the condition are female (7,8). All age groups may be affected.

The lack of understanding of this disabling condition, compounded by the misleading name "Chronic Fatigue Syndrome" has been commented on by many (2, 9, 10,11).

The unique socialising forces that affect the professional conduct and the 'imagination' of medical practitioners who learn ritualistic ways of seeing and defining disease influence professional understanding of the illness experiences of

patients. The dominant paradigm of rational, positivist, bio-medical scientific has refused to legitimate diseases that fail rigorous scientific methods of detection, and as a consequence ME/CFS sufferers are denied medical closure and usually suffer social stigma when identified with the condition (11, p.63).

The political and psychiatric constructions which have been placed on this physical condition have led to the disempowerment of persons with ME/CFS, especially as regards their ability to negotiate or to obtain appropriate understanding and accommodations. (12,13)

Attachment 1 :

Morris, D. (2001) , “Research into ME/CFS* and Tertiary Education: from politics, through action, toward renewal?” in peer reviewed Proceedings of the 4th Australian Women’s Health Conference. *From Politics, through action, toward renewal*, Adelaide. 19-21 February 2001.

Many students in tertiary education in Australia have a diagnosis of ME/CFS, although the incidence has not as yet been quantified. Dr. Jane Ross, Disability Support Officer, indicated that ME/CFS is the most common disability in Australian universities, amounting to more than half of those registered with the university disability offices (pers. comm. April, 2001). Mungovan and England (16) 1998) found that there were discriminatory attitudes and other difficulties which students with ME/CFS had to cope with when endeavouring to negotiate better understanding and conditions in their educational institution yet, without justification asserted that existing accommodations were appropriate to meet the needs of ME/CFS students. Accommodation for the serious cognitive dysfunction aspects of ME/CFS was not addressed by Mungovan and England.

Presently, all accommodations offered are made on the supposition that they help in some way. However some accommodations, such as additional time in examinations (supposedly to allow for rest to assist with fatigue) resulted in certain students having their examinations so prolonged that they have suffered health relapses as a result. (From my research findings). There has never been any research into ME/CFS to even ascertain whether examinations *per se* are appropriate for students with ME/CFS. My research suggests that they are not appropriate.

Most important is the lack of acknowledgment in all guidelines of how seriously ME/CFS impinges on learning outcomes. Presently the accommodations offered to ME/CFS students relate only to attempts to allow for fatigue (statistically the most common symptom, but probably the least important one for learning). There has been no research into appropriate multi-symptomatic accommodations for students with ME/CFS.

Attachment 2:

Morris, D. (2001), "Report on the findings of 'The Lived Experiences of Tertiary Students with ME/CFS'" to the ME/CFS Society of South Australia and SAYME2001, 18 February 2001 as guest speaker.
 Paper 2: Standards for education practice in Australia. p.15

Bastien (9 p.454), discussing her research sample, says that she found

the following neurological impairments: word-finding problems; subtle problems with receptive and expressive aphasia, including intermittent dysnomias; decreased concentration; distractability, problems in recall, verbal more than visual, including a remote memory disturbance; dyscalculia ...; both gross and fine motor problems; spatial-perceptual dysfunction, including losing their way while driving; some abstract reasoning disturbance, primarily non-verbal; decreased visual discrimination; and problems in sequencing. In addition, the patients had trouble making decisions and planning. Many of the patients had a personality change from a previously even-tempered individual, to someone easily frustrated, irritable, impulsive, angry, sometimes verbally out of control.

This list of some of the documented symptoms indicates that the impact of ME/CFS on sufferer's education is very considerable. Other problems such as cardiac problems, profound sensitivity to sound (hyperacusis), sensitivity to environmental chemicals (outgassing from paintwork, cleaning products, cigarette odours including those lingering on smokers, perfumes and personal toiletries), flickering fluorescent lights, the inability to walk distances or to cope with stairs and the problems of relapse of health for indeterminate periods after minimal mental and physical exertion have not been addressed in the above list.

Buck (19) and Flynn (20) found that some severely affected ME/CFS students have had their medical condition made worse in the classroom and thus been forced to remain at home for tuition. In South Australia there were plans (since shelved) to build a low chemical school to accommodate the special needs of these students, which suggests that it may not be possible to accommodate all of the affected children within the traditional classroom structure (22).

Some students were found to have enrolled in their courses prior to contracting ME/CFS or receiving a diagnosis. For others admission to post-graduate courses was made on the basis of earlier successful study when the participant did not yet have ME/CFS.

Attachment 7.

The following is an extract from my unpublished thesis (work in progress) and as such it is private information and is not available for publication:

This therefore brings me to the terms of reference of this inquiry

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1. Terms of Reference:

Each term of reference is now dealt in turn in relation to ME/CFS.

Part (a)

(i) the criteria used to define disability and to differentiate between levels of handicap

The term ‘Chronic Fatigue Syndrome’ immediately conjures up images of fatigue or tiredness. For most in the population fatigue is the only symptom of which they have heard. The supposition is therefore made in education that as long as students obtain time to rest then adequate accommodation for these students has been provided. All guidelines currently in use in Australian tertiary institutions adopt this ill-informed and inadequate stance.

Attachment 2 :

Morris, D. (2001), “Report on the findings of ‘The Lived Experiences of tertiary students with ME/CFS’ to the ME/CFS Society of South Australia and SAYME2001, 18 February 2001 as guest speaker.

Paper 2: Standards for education practice in Australia. p.15

This perception falls far short of the needs of students with ME/CFS. Every single participant in my research drew attention to the impact of cognitive dysfunction on their studies although no directions had been given to them to address this area. My research has shown that participants’ needs are not being adequately addressed. There are serious deficiencies which means that the lived experience of students with ME/CFS involves constant denial of equity and equal opportunity enshrined in DDA 1992 for students with a disability. This is particularly so in relation to cognitive dysfunction, which is completely ignored in all guidelines. **The ME/CFS symptom of cognitive dysfunction is a learning difficulty, but is not listed in any guidelines as such, or at all.**

Attachment 2 :

Morris, D. (2001), “Report on the findings of ‘The Lived Experiences of tertiary students with ME/CFS’ to the ME/CFS Society of South Australia and SAYME2001, 18 February 2001 as guest speaker.

Paper 1: Introduction to research into ‘The Lived Experiences of tertiary students with ME/CFS

p. 5

Paper 2: Standards for education practice in Australia.	p.15
Paper 3: A brief review of related disability literature.	p.17
Paper 4: The symptomatology of ME/CFS.	p.20

In my submission to the “Draft Disability Standards for Education from the perspective of ME/CFS” of November, 2000, I drew further attention to problems with the definition of disability and the failure to differentiate between degrees of individual handicap. Students with ME/CFS have a fluctuating, usually non-visible, chronic illness which, due to its lack of acceptance by the community, means that these students are often considered lazy or ‘malingerers’. There is often a complete lack of appreciation of what happens to students with a contested chronic illness, many requirements being impossible for ME/CFS students to fulfil (such as taking action when in total relapse, within a specified number of days). This difficulty arises particularly for students confronting rigid educational institutions regulations.

Attachment 3 :

Morris, D. (2000), Submission to the Draft Disability Standards for Education from the perspective of ME/CFS. November, 2000.

<http://www.ozemail.com.au/~ddasp/Submissions.htm>

(original Draft Disability Standards for Education document is at:

http://www.detya.gov.au/iae/analysis/Draft_Disability_Standards.htm

According to the findings of my research the needs of ME/CFS students are not being met, particularly in respect of cognitive dysfunction, assessment procedures, attendance requirements and regulations which, when applied to students with ME/CFS, either directly or indirectly discriminate.

(ii) the accuracy with which student’s disability related needs are being assessed

There are no guidelines in use in Australian schools or tertiary education institutions which are written on the basis of research findings. All guidelines for ME/CFS in education have been written from ill-informed suppositions about the nature of ME/CFS (that it is predominantly fatigue and that fatigue is all that has to be catered for). None of the guidelines presently used, has been written by trained educators who are also very familiar with the condition. Educational and learning outcomes have not been assessed. Extrapolations from other conditions and suppositions about the intrinsic nature of ME/CFS cannot possibly produce appropriate or effective accommodations. Only academic research projects by educationalists who are very

familiar with ME/CFS (persons with the condition would be very appropriate) will progress this area of knowledge. **Research funding is therefore necessary for the accurate assessment of ME/CFS student's disability related needs.**

This therefore leads to where the greatest difficulties for students with ME/CFS arise. Rather than the educational institutions meeting the needs of the student with a disability, the student with a disability has to meet the institution's needs. The needs of the student with ME/CFS are either unknown or, if the student has made his/her needs known they are told that to accommodate them would involve unreasonable demands and hardship for the institution. A survey (16) conducted in 1998, required students with ME/CFS merely to tick boxes to indicate which predetermined accommodations had been accessed, instead of asking "Do the accommodations offered meet your needs as a student with ME/CFS?"

Attachment 2 :

Morris, D. (2001), "Report on the findings of 'The Lived Experiences of tertiary students with ME/CFS'" to the ME/CFS Society of South Australia and SAYME2001, 18 February 2001 as guest speaker

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The greatest difficulty, other than those of the chronic illness experience itself, are those caused by cognitive dysfunction. My research participants all drew attention to this symptom. The Royal Australasian College of Physicians has just released a set of ME/CFS Guidelines for Doctors (6 May 2002) which nowhere address this symptom of ME/CFS (6). My submission to the Royal Australasian College of Physicians, commenting on an earlier draft of their Guidelines, is Attachment 4. The new guidelines do not address most of the many criticisms of earlier drafts. Nor do they include references to cognitive dysfunction.

Attachment 4 :

Morris, D. (2001) 'Analysis from the Perspective of Education of the Chronic Fatigue Syndrome Guidelines (Revised Draft 2001) of the Royal Australasian College of Physicians, Sydney NSW 2001, submitted to the Royal Australasian College of Physicians, Sydney, NSW 30th July and also to the Allison Hunter Memorial Foundation for inclusion with the other critiques of the Revised Draft 2001. <http://www.ahmf.org/>

The problems of accommodations for ME/CFS students are not confined to students alone. Educators are also faced with difficulties as they endeavour to meet the needs of their institutions, e.g. in regard to assessment, regulations, attendance requirements while trying at the same time to meet to disability legislation *minima* (DDA 1992, especially section 6).

After assessing research findings from the student perspective, I viewed the same data from the perspective of the educator. I found that the educator is placed in an unenviable position, often torn between the requirements of their institution and of current disability legislation. I have addressed this issue in Attachment 4 where I investigate the problems which arise in academic assessment as a consequence of the cognitive problems and physical symptoms of ME/CFS. I have been unable to come to a solution, other than advising the educators to take heed of the requirements which the student makes known. (Attachment 5: **this paper is still under peer-review for publication in the Conference Proceedings and so is not yet available for publication in this review.**)

Attachment 5 :

Morris, D. (2001) "What does academic assessment assess : the case of ME/CFS?" Abstract and paper for Tertiary Teaching and Learning Conference "Tertiary Teaching and Learning: Dealing with Diversity." Darwin, July 9-12, 2001. Submitted 10 May 2001, presented July 12, 2001.

Currently under peer-review for peer-reviewed publication of Conference Proceedings, contents not available for public viewing.

Further difficulties arise in making accommodations. Disability officers generally state that they will implement whatever accommodations the student's doctor recommends. With ME/CFS, a medical practitioner may for instance state that their patient has Chronic Fatigue Syndrome but omit to mention the significance of the symptom of cognitive dysfunction (which is both complex and fluctuates over time). As fatigue may therefore be the only ME/CFS symptom which is named, that is the only symptom for which any accommodation is attempted. I investigated this difficulty and presented this in a paper to the 3rd Sydney International ME/CFS Meeting held in Manly NSW, in December 2001, a medical conference for researchers and clinicians only. This paper, Attachment 6, still awaits publication in the proceedings of this conference.

Attachment 6

Morris, D. (2001), peer-reviewed abstract 'Education, Equity and Cognitive Dysfunction Dilemmas,' paper presented at The Third Sydney International Clinical and Scientific Meeting, 'The Medical Practitioners' Challenge' at Manly Pacific Parkroyal, Sydney, Australia, held 1-2 December, 2001 for Researchers and Clinicians. Sydney, convened by Alison Hunter Memorial Foundation. CME points awarded to conference attendees.

One issue is that the persons recruited as disability/special needs officers are not trained in the fields of education. Most appear to have academic qualifications in the social work/paramedical areas, such as counselling, speech therapy or occupational therapy. This has led to the medicalisation of disability - as though people with disabilities need assistance in dealing/coping with their disability. This is the medical model of disability not the social model preferred by those with disabilities.

To meet the needs of the DDA 1992 there is the need for disability officers to be qualified and experienced as educators and so able to assess learning outcomes. Only when disability/special needs assessors have such backgrounds is it likely that accommodations will be made that reliably meet the DDA 1992 requirements. Subsequently research will still be required to fully ascertain the needs, accommodations, etc. that are appropriate for that particular ME/CFS student, bearing in mind that it is a chronic fluctuating condition with more than ninety documented symptoms.

A further problem is that the disability/special needs officers are employees of the institution, with a first loyalty to their employer rather than to the student with disabilities. Yet these same people claim that they are "advocates for the disabled student." This dualism is not appropriate - this places disability officers in an impossible situation - to advocate for the student with a disability, and also meet the needs of their employer. Hence the tendency to try to compel the student to fall in with their employer's interests, rather than vice versa. Only when those who oversee disability advocacy in institutions are independent is it likely that the needs of disabled students will be met in a way which fully meets the spirit of the DDA 1992.

Thirdly there is the stereotyping of the needs and requirements of students with a disability: e.g. a particular school counsellor advised a student with ME/CFS who had talents in mathematics not to study senior mathematics at school. No recognition was

taken of the student's skills or career aspirations. The advice was given solely on the basis that dyscalculia is a common symptom of ME/CFS - and that persons with dyscalculia may have difficulty with mathematics. The school counsellor and course adviser just took a 'one size fits all' approach without first ascertaining whether or not the student had this symptom. The school would not enrol the student in the desired course (as it was acting on the advice of the school counsellor) and the student's professional parents were ignored. After I pointed out the individuality of the symptoms of ME/CFS I was able to have the student's course reassessed. (Perhaps the school was more interested in achieving good overall year 12 results, than in the needs of the individual student?)

A fourth area of concern is that a plethora of people appear to deal with disability in many educational institutions. Not only are there Disability Liaison Officers (Special Needs) but Faculties may also appoint insiders to deal with disability. Then, of course, individual lecturers have to be approached to make accommodations. Hence there tends to be no consistency in the accommodations actually made. Students with a disability often are faced with having to negotiate with numerous people, with uncertain outcomes. This is leading to apparent infringements of the DDA 1992, particularly in the area of Indirect Discrimination. This is a weakness that many research participants drew to my attention.

When the condition is a chronic illness, such as ME/CFS which is poorly understood and accepted in the community, the magnitude of the issues raised is compounded. Issues of quality of life, human rights and equity emerge as issues of credibility and misunderstanding often because of the name of the condition which inappropriately stresses its most common, but often unimportant symptom 'fatigue'.

In conclusion, there are persistent difficulties in the way in which disability is addressed in most Australian educational institutions. These comments are based on (a) data obtained from my research and (b) information provided when I have been approached by students for assistance.

(iii) the particular needs of students with disabilities from low socio-economic, non-English speaking and Indigenous backgrounds and from rural and remote areas.

There are particular needs for students with disabilities particularly ME/CFS. Poverty is one of these issues. Many students come from low socio-economic backgrounds. Many also come from non-English speaking or Indigenous backgrounds. Many students are from rural backgrounds, and remote areas. Additionally many are isolated due to the debilitating nature of ME/CFS itself.

Students currently have to have had ME/CFS for six months before they can even obtain a diagnosis. **Austudy** is frequently lost. They do not qualify for other benefits. And they have to wait an indeterminable length of time hoping that they may be successful in obtaining a Disability Support Pension. Adult students with ME/CFS have to return home and depend on their parents or else move in with friends for support. They are also often unable to afford medical treatment. Many students find that in addition to ME/CFS, that their living conditions induce secondary depression. Many have told me they have contemplated suicide.

Many students from rural backgrounds were studying on-campus prior to diagnosis. Many are subsequently forced to return home, completely withdrawing from their on-campus courses. Unfortunately, Distance Education course availability is limited as only a few institutions offer this form of education.

(iv) the effectiveness and availability of early intervention programs.

This aspect of the Terms of Reference is not applicable to ME/CFS.

(v) access to and adequacy of funding and support in both the public and private sectors

There is far from adequate funding at all times for all students with disabilities. There is a lack of equity scholarships. Studies at the undergraduate level qualify for the **Pensioner Education Supplement**. There is no comparable supplement available to

students at Graduate Diploma, Masters or Doctoral studies. The governments' perception appears to be that students with disabilities are incapable of pursuing higher degree studies.

It may be suggested that students with a disability are able to apply for **Australian Post-graduate Awards**. But no allowance is made for the fact that often the student with a disability lacks the necessary educational background. For instance, the need for a first class honours degree will preclude many from a scholarship, although it may be the very nature of the disability, or the lack of sufficient accommodation which has prevented the student with the disability from attaining this qualification. No allowance is made for extenuating circumstances. There are no equity APA scholarships. The message to students with certain disabilities is that they are not as worthy as other recipients.

Students with a disability therefore attempt to fund themselves from their **Disability Support Pensions**. For students with an expensive chronic illness (e.g. ME/CFS, which affects every body system) this can mean going without essential medications/treatments, yet paradoxically it may be these various treatments which alone can support student's health to be a level permitting them to undertake their studies!

There is **APA and scholarship awards** made on 'track records' of peer-reviewed papers, etc. - but it is usual for a student with a disability to be well along with their research studies before they will have sufficient academic curriculum vitae accumulated to be considered for an award. This is particularly so for the ME/CFS student - often excluded over years from employment and academia by their chronic illness and disability.

Even if the student with a disability is able to gain an **APA scholarship** (or similar) there is the problem of the student's enrolment affecting the award. If the student is enrolled part-time due to their disability, they receive a part-time award which is taxable. Not so for the full-time healthy student, whose award is non-taxable! This is

certainly an equity issue. This differential suggests complete and culpable misunderstanding of the needs of disabled students.

(iv) the nature, extent and funding of programs that provide for full or partial learning opportunities with mainstream students

Distance education (correspondence, off-campus) opportunities are limited, whether in the primary, secondary or tertiary education sectors. Few universities offer distance education courses and what is offered is often **limited in choice and scope**. The Universities cry of “funding” is the main problem. But whatever causes the problem for the University, it is the students with disability obliged to study off-campus who must bear the brunt of this limitation on courses. The new plans by the Federal Government to limit funding for humanities and classics courses which have few students enrolled, could see the closure of many courses currently available by Distance Education. It will be the remote and disabled students who will be the most affected by this Federal Government decision.

Generally **distance education** is offered by universities **located outside major metropolitan areas**, e.g. Southern Cross University, University of New England, Charles Sturt University, Deakin University, University of Southern Queensland, Northern Territory University, James Cook University. The locations of these Universities create greater access difficulties for compulsory residential schools, due to the capital city focus of the public transport networks in Australia. So location of a university often creates access difficulties for students with a disability. Many of my research participants chose to study at a University outside their home state, due to the lack of Distance Education facilities in their own state or in an endeavour to find a course which was suitable. Further, they tended to choose courses without compulsory residential components, as this meant that there were fewer physical and financial costs involved (compared with attending in person).

Universities now are requiring distance education students to have **computer access**, but no consideration is given to funding disabled students with computers. This is an additional problem for isolated rural students as these students often have **sub-standard telephone infrastructure**. There are currently problems with newer

and faster computer equipment and incompatibilities with rural telephone lines. The frequent service 'cut-offs' caused by interference on poor old bush telephone lines means that telephone accounts are much larger than they should be because of far more frequent 'dial ups'. No allowance is made for the additional **STD telephone calls** made by students with a disability who study by distance education to contact lecturers and supervisors. City students receive exactly the same **Pensioner Education Supplement** as rural and isolated students but the additional costs incurred by rural and isolated students are not taken into account.

No allowance is made for the **costs of accommodation** at residential schools for Distance Education students, nor is there any allowance for these students to be accompanied by their **Carer**. When chronically ill students are in receipt of the **Pensioner Education Supplement**, only **one return trip to the educational institution is available per annum**, and this is paid at the **lowest rate** for transport, whether or not the student is able to access this transport due to the nature of their disability. Moreover, most tertiary institutions require one residential school per enrolled subject (if there is a practical component). For a part-time enrolled student this may mean four trips for compulsory attendance at their educational institution per annum. So for three of these trips all costs must be borne by the distance education student. No allowance is payable for accommodation at all. **No allowance is payable for the Carer** who has (or may have) to accompany the disabled student. Due to the fluctuating and debilitating nature of ME/CFS it is often essential to be accompanied by a Carer to residential schools. With the cost of return postage for borrowing library books often amounting to \$30+ per week, there is nothing left of the **Pensioner Education Supplement** to cover these costs of **transport and accommodation**. **These costs therefore can limit or terminate the academic progress of the student with a disability who is reliant on self-funding for their studies.** Allowances payable under the **Pensioner Education Supplement** fail to take into account the high costs of library borrowing and also the necessity of accommodation and travel to 'distance campuses'. **GST** has added to these costs and made everything so much more expensive. Even if a student decides to purchase a textbook, which is not prescribed, **GST** is also payable. (Due to lack of access to libraries and the cost (postage) of borrowing frequently accessed book and also the lack of availability of a

popular book, most Distance Education Students will find they have to purchase more books than the internal on-campus student. The real purchasing power of the **Pensioner Education Supplement** has not kept pace with the costs incurred in real terms, and except for a small adjustment for GST, no increase has been made in this allowance for the past decade.

There seems to be no specific funding available for the education of students with severe chronic illness such as ME/CFS.

HECS & PELS

Guidelines for HECS make it very difficult for the student with a chronic illness disability. Even the brochure that is distributed to all students does not mention illness in the index. A very ill student, with visual and cognitive dysfunction is left trying to read every word trying to find out what happens when (or if) they withdraw. There is no provision for a student to withdraw from one semester and recommence the subject where they left off when the subject is next offered. This becomes an imposition for a student with a chronic fluctuating illness like ME/CFS. Instead the student is faced with ‘miles of red tape’ trying to obtain equity when they are least able to negotiate. The HECS administrators may say they will accept a letter from a doctor, but many students have to travel many kilometres to access the nearest doctor who is familiar with this condition. There is a lack of understanding that ME/CFS students, when in relapse, may even be unable to remember their own name and address, are too ill to access telephones, let alone attempt to write a coherent letter. They may also be so ill that they are unable to feed themselves. Many research participants drew attention to these and other perceived difficulties with HECS.

Students were avoiding **courses with up-front fees** as they believed they could not afford to enrol in these courses. As up-front fees apply apparently to most graduate diplomas and because of the automatic loss of **Pensioner Education Supplement**, students are not enrolling in graduate diplomas and coursework masters degrees. Some students have limited themselves to doing only one subject at a time because of the up-front fees. I have found it very difficult to obtain information about **PELS** as this loan scheme is not widely publicised. According to my investigation, currently

no student in my research was aware of **PELS**. The attitudes of my research participants, I believe, would also preclude them from borrowing from **PELS**. This would be because they would not be able to foresee their ability to repay this loan. For very many students with a disability there is the practical and ethical issue of borrowing for fees when they cannot see themselves ever repaying the loan. ME/CFS students, having a condition which is stigmatised and often equated to ‘malingering’ in the eyes of the public, would be even more reluctant as they try and counteract this stigma in their personal conduct.

Special admission schemes: by their very wording preclude students with a chronic fluctuation illness. Attachment 8 addresses some Victorian and New South Wales schemes.

Attachment 8

This attachment contains work-in-progress from my unrepresented doctoral thesis. There are no references appended to these excerpts.

The contents of this Attachment are NOT for public viewing, and are submitted to this Inquiry for Private Viewing only by the Senate Select Committee.

Issues raised include Special Admission Schemes, Compulsory Attendance and HECS.

Students with disabilities that preclude them from full-time study are still being affected by many **regulations** within Universities and in Secondary Education.

Regulations such as the requirement that some courses may only be undertaken on a full-time basis place unreasonable stress on ME/CFS patients. Where such students have been forced to comply with this regulation, their health has suffered severely. Some have completed their courses, but are still paying the price for their persistence with consequentially severely impaired health, even years later. This is applicable, for example to post-graduate (Masters) courses in Dietetics at more than one Australian University.

Other courses that discriminate include medicine and dentistry at the University of Melbourne. These courses are expected to be attended on a full-time basis, and failure in a subject, I am given to understand, means that the complete academic year has to be repeated, including subjects already been passed! The student with a chronic fluctuating illness is in practice completely excluded.

The emphasis on **integration of students** with a disability in school classrooms, impacts adversely on students such as those with severe ME/CFS. The severely ill students, if they attend educational institutions, find that they are likely to suffer a relapse. This is particularly so in relation to students with environmental (e.g. chemical) sensitivities as a part of their ME/CFS. The emphasis on the ‘social value’ of very ill ME/CFS students mixing with their peers reflects complete disregard for the potential health consequences of such mixing.

Nearly all children who are severely affected and many who are moderately affected will require home tuition, distance learning, or both. Children are commonly told to attend school for social contact, but schools these days can be pressurised, academic hothouses, where the physical and intellectual stress is unsuitable for many healthy children, let alone those with a disabling illness that affects the brain and central nervous system. Repeated relapses typically occur, undermining doctors’ medical management and the child’s achievement. Education can be more efficiently given via home tuition or distance learning until the child becomes strong, with social contact provided separately (31).

Distance Education counsellors/assessors in schools remove or limit distance education opportunities in favour of school attendance, yet show no comprehension of the impacts on the student's health. I have had to deal with several instances of this abuse of power by student counsellors and schools. (‘Abuse of power’ is the only expression that accurately describes the serious health repercussions, long lasting relapses (years) and even life-threatening anaphylactic reactions which often result from high handed dealing with severely ill and environmentally sensitive ME/CFS students.) I have had to refer parents to the Director General of Education in their state to obtain resolution as no conciliation at a lower level of the hierarchy was forthcoming. Flynn also found similar situations in Australia (20).

Reference guidelines (17, 18) omit all reference to environmental sensitivities. They often dwell on ‘school phobia’ and inappropriately, stress the alleged need for the student to become ‘more motivated to return to the school environment’ - subscribing to psychological paradigms that are based on mere suppositions lacking any research

basis. These guidelines, written almost a decade ago, are still being used as a standard today. They do not address the issues of cognitive dysfunction and some other symptoms that impinge on educational outcomes either. Arzomand's research in the United Kingdom into primary school education has refuted many of the recommendations contained in these guidelines (27). Unfortunately the new RACP Guidelines for ME/CFS (6) cite these old references for education of students with ME/CFS instead of newer, more accurate data (22,23,24,25,26,27). There is anecdotal evidence that the use of the old references has caused harm to students with ME/CFS. (These comments are based on my research findings and observations made by parents.)

(vii) teacher training and professional development

No Australian teacher training course assists teachers to deal with integrating seriously chronically ill students into their classrooms. The National ME/FM Action Network in Canada has endeavoured to address this short-coming with the publication of their book (1) which I was asked to review. Teachers seem to not accept the condition, as it is outside experience and imagination. Most cannot understand how the condition impacts on all areas of education, especially cognitive dysfunction, short term memory, encoding, etc. as well as the triggering of relapses when an inappropriate learning environment is experienced (22, 23, 24, 25, 26)

(viii) the legal implications and resource demands of current Commonwealth and state and territory legislation;

Many of these issues have been addressed in the above attachments, especially Attachments 2, 3, 4, 5, and 6.

The Disability Discrimination Act (1992), if applied wholeheartedly in education, would mean that a new deal in education could occur. This Legislation is excellent. In relation to my research the Act, in principle, covers all issues that arose. Yet today, a decade later, there is still ignorance on the part of the educational institutions (and of students) of their legislative rights enshrined in this act. Section 6,

particularly is often overlooked, though compliance with Section 22 seems to be adequate.

My research reveals that many ME/CFS students are still unaware of their rights under the Disability Discrimination Act (1992). When speaking in Adelaide to the 'ME/CFS Society of South Australia' and 'South Australian Youth With ME' (see Attachment 2), in response to a questionnaire I distributed the most common comment made by students was "I did not know I had rights".

Unfortunately my research demonstrated that there is still widespread ignorance of the disability requirements of the DDA 1992. Many universities have in place protocols for complying with the Disability Discrimination Act 1992, reference to which is contained in 'Students with Disabilities: Code of Practice for Australian Tertiary Institutions (28) but official protocols seem either not to be enforced, or else contents are unknown to their academic and administrative staff.

One student with ME/CFS had her enrolment cancelled because she had asked for a video (which she offered to provide) and for another student to do the videoing of a chemistry demonstration. The student was sensitive to a chemical (known from previous hospital testing as an in-patient) which commonly causes problems for ME/CFS students, such as migraines, nausea and can even trigger relapses of the condition. The University decided to cancel the student's enrolment under the Occupational Health and Safety Act rather than accommodate the student's reasonable request for a video. The University said it "took this action to protect the student." The University was unaware that environmental sensitivity may be a part of ME/CFS. The student was devastated with the actions of the University. The student was returning to study after a number of years of being severely ill with ME/CFS, and had hoped to carve a future career pathway with these academic qualifications and achieve independence i.e. not have to rely on the Disability Support Pension. The student provided me with copies of the correspondence and I assisted her in her battle to be reinstated in the course.

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Part (b)

(b) what is the proper role of the Commonwealth and states and territories should be in supporting the education of students with disabilities.

I shall first of all address general disability issues, and then address issues specific to ME/CFS.

The proper role of the Commonwealth and States and Territories should be first of all to see that no scheme which they fund or support means that a student with a disability is disadvantaged. Problems arising include:

1. The provision of **Pensioner Education Supplements** (as outlined above) for **all** tertiary students, **should be extended to include** students enrolled in studies higher than the undergraduate level.

2. The **Pensioner Education Supplement allowance of only double time** to complete studies discriminates against students who are unable to work at the rate of 50% of an academic workload. Students who take longer to complete their studies are currently denied the **Pensioner Education Supplement**, and are forced to try to complete their studies on Disability Support Pensions. This regulation particularly affects the **most disabled** students, especially those with chronic illness disability. Those with ME/CFS, due to the fluctuating nature of the condition and/or severe relapses forcing withdrawal from courses, can be seriously affected by this regulation. Appeals may be made, but for the very ill, this is a burden that is too difficult. Most ME/CFS students, because of their health status give up all ideas of appealing and 'taking on the system'. Regulations need to be more flexible and to take into account health fluctuations and vagaries of chronic health conditions such as ME/CFS. The student with a disability has to comply with all the regulations governing the **Pensioner Education Supplement**, yet these **regulations are not flexible**, often failing to meet the needs of students with a disability.

3. The **Pensioner Education Supplement** has been continually eroded in value and has remained the same for the past ten years. This value therefore needs to be reassessed and based on realistic costs incurred.
4. There must be acknowledgment of the **additional costs of Distance Education** for the severely disabled, especially those with chronic illness conditions which preclude on-campus attendance (such as ME/CFS). Also recognition that this is the only way in which many rural and remote students with a disability are able to study, especially in areas of attendance at compulsory residential schools (travel and accommodation). There should also be provision for the **costs of Carers**.
5. There must be a flexible enrolment provision for **Carers** in enabling the Carer to study when duty of care is heavy and time consuming. Presently the amount of study they must do to obtain the **Pensioner Education Supplement** is a fixed provision (double time). The caring load and commitments should be considered and given priority, not just be based solely on the enrolment load for deciding on eligibility for the Carer to obtain this allowance.
6. There must be provision for **reimbursement of expenses** incurred when a person **needs a Carer** - such as when attending Residential Schools. Whether this should be an additional payment to the **Pensioner Education Supplement**, or a payment in advance to cover costs (similar to the book allowance of the PES). Many months now elapse from the time of claiming the **travel allowance (allowable under PES)** and actual payment (and it is usual to have to make a number of follow up phone calls) - and the student in the meanwhile is out of pocket and struggling unable to fund their study costs. Often the student has attended the Semester 2 residential schools, before the claim for Semester 1 residential school travelling is paid.
7. The rules and practices governing **HECS and PELS** (as outlined above) need to be clarified - and issues such as sickness and illness need to be listed in the index of the information booklets (presently they are not there).

8. The rules and provision of **APA and related scholarship conditions** of award need to be made equitable for students with a disability (this has been outlined above).
9. Additionally there is a need for **Equity Scholarships**, if these rules and regulations for **APA** cannot give equity, justice and equal opportunity to students with a disability.
10. There needs to be adequate funding for the training of **persons who can assess learning outcomes**, and understand fully the range of accommodations required by students with a disability. This area must be taken out of the paramedical/psychological/social work field and into the mainstream education area (i.e. not rest with the present Disability Liaison/Special Needs Officers).
11. Persons employed to determine disability accommodations need to be employed on a **full-time basis**. Additional funding may be required for this. (Some students with a disability attend on-campus on a part-time basis - so their attendance often does not coincide with **the working hours of the disability officer!**).
12. Persons working in the area of disability need to be **employed** by either state or Federal governments so that they do not feel beholden to their employer, the tertiary institution. This would ensure their **impartiality in negotiations** with the student with a disability.
13. There is a need for **equity issues of disability in education to be viewed as social and education difficulties** and not as part of the medical construction of disability. (Separate first aid personnel and nurses can care for students who need medical assistance on campus.)
14. A **number of programs** implemented by institutional disability officers are seen

as paternalistic and as detracting from the autonomy of the student with a disability. Students with ME/CFS (from my research data) are often keenly aware of this attitude. Many are newly ill, and have lived their lives as independent healthy people. To be treated in a condescending way is alien to their life experiences. Students adjusting to a new limitation need to be treated with understanding not condescension. Better training of disability officers is clearly required.

15. According to my research data many students with ME/CFS did not access disability officers as they did not perceive themselves as being disabled, but suffering a chronic illness which is hampering them. This would indicate the present ideas of disability, such as wheelchairs (reaffirmed by that wheelchair symbol), visual and hearing impairments, etc. are considered to be disability, whereas chronic illness is not given the same credence. This again points to the need for funding of appropriate training programs.

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4. Conclusions and Recommendations

Disbelief in the symptoms of ME/CFS too often emerged in my research data, many participants reporting that their sensitivity to chemicals, noise and lighting is not taken on board. Instead, foolishly, the student is often requested to 'give it a go' to see how they cope - as though these symptoms of their illness are delusion or an aspect of 'willpower!'. My research has identified several **quality of life issues** as well as many issues of **equity and human rights** (29), again reinforcing a need for properly funded educational and training programmes for all who deal with disabled students.

The biggest issue identifiable from my research is how little is known about how cognitive dysfunction, memory encoding difficulties, recall and fragile retrieval from short-term memory and similar deficits of ME/CFS impact on educational outcomes. [Attachments 4 and 5 contain details]. This means that there is no information to guide students in negotiating accommodations or for educators in endeavouring to meet the provisions of the DDA 1992, especially Section 6, 'Indirect Discrimination.'

Given that the symptomatology of the condition is not being adequately addressed (especially cognitive dysfunction and learning difficulties) this submission addresses a serious and important area. **In fact, due to the lack of research the full impact of ME/CFS on education is still unknown.** Worldwide, no funding has yet been directed to research in this area. For current policies and programs to meet the needs of students with ME/CFS detailed research is required so that appropriate accommodations and adjustments can be made for these students.

I am the only doctoral researcher in Australia into ME/CFS and Education. The present submission contains some of my research findings (work in progress), peer-reviewed papers, and other papers written on the basis of my research findings. As my research is the first research into the area of ME/CFS and education it is of necessity only preliminary, having barely scratched the surface of this complex field. (30) Importantly, however, though it has revealed major problems and, equally areas where future research is required and should be made (and funded).

Not one cent has ever been invested by an Australian government into the impact of ME/CFS on educational outcomes for students with the condition. Nor has there been any comparable research funding overseas.

Given the significance of the fact that over fifty per cent of all students registered with the Disability Office/Special Needs in New South Wales universities have ME/CFS there needs to be an investigation into their educational needs. My research found the only half of my participants were registered with the disability office of their institution because of the stigma of ME/CFS or because respondents did not perceive that Disability Office/Special Needs were applicable to their severe and chronic illness. The problem therefore may be far larger than is yet realised.

Only appropriate research in the field of education (not medical nor psychological research) will reveal how students with ME/CFS are to obtain the equity presently enshrined in DDA 1992, especially Section 6.

Institutions and those assisting students with disabilities, such as ME/CFS all too often try to adapt the disabled student to their rules rather than ensure that the rules and environment of the institution meet the needs of the disabled student. Nowhere is this more so than for the student with ME/CFS. **The very nature of this multi-system chronic illness means that students with this condition fall outside all current guidelines so that their needs for equity, social justice and human rights are not being met.**

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5. The appended documents. (Some of these documents are under peer-review processes, and currently are therefore not available for publication. This will indicated).

Attachment 1 :

Morris, D. 2001, "Research into ME/CFS* and Tertiary Education: from politics, through action, toward renewal?" in peer reviewed Proceedings of the 4th Australian Women's Health Conference. *From Politics, through action, toward renewal*, Adelaide. 19-21 February 2001.

Attachment 2 :

Morris, D. 2001, "Report on the findings of 'The Lived Experiences of tertiary students with ME/CFS' to the ME/CFS Society of South Australia and SAYME2001, 18 February 2001 as guest speaker.

Paper 1: Introduction to research into 'The Lived Experiences of tertiary students with ME/CFS	p. 5
Paper 2: Standards for education practice in Australia.	p.15
Paper 3: A brief review of related disability literature.	p.17
Paper 4: The symptomatology of ME/CFS.	p.20

Attachment 3 :

Morris, D. (2000), Submission to the Draft Disability Standards for Education from the perspective of ME/CFS. November, 2000.

<http://www.ozemail.com.au/~ddasp/Submissions.htm>

(original Draft Disability Standards for Education document is at:

http://www.detya.gov.au/iae/analysis/Draft_Disability_Standards.htm

Attachment 4 :

Morris, D. (2001) 'Analysis from the Perspective of Education of the Chronic Fatigue Syndrome Guidelines (Revised Draft 2001) of the Royal Australian College of Physicians, Sydney NSW 2001, submitted to the Royal Australian College of Physicians, Sydney, NSW 30th July and also to the Allison Hunter Memorial Foundation for inclusion with the other critiques of the Revised Draft 2001. <http://www.ahmf.org/>

Attachment 5:

Morris, D. (2001) "What does academic assessment assess : the case of ME/CFS?" Abstract and paper for Tertiary Teaching and Learning Conference "Tertiary Teaching and Learning: Dealing with Diversity." Darwin, July 9-12, 2001. Submitted 10th May 2001, presented July 12, 2001.

Currently under peer-review for peer reviewed publication of Conference Proceedings, contents not available for public viewing.

Attachment 6

Morris, D. (2001), peer-reviewed abstract 'Education, Equity and Cognitive Dysfunction Dilemmas,' paper presented at The Third Sydney International Clinical and Scientific Meeting, 'The Medical Practitioners' Challenge' at Manly Pacific Parkroyal, Sydney, Australia, held 1-2 December, 2001 for Researchers and Clinicians. Sydney, convened by Alison Hunter Memorial Foundation. CME points awarded to conference attendees.

Attachment 7:

This attachment contains work-in-progress from my unrepresented doctoral thesis. There are no references appended to these excerpts.

The contents of this Attachment are NOT for public viewing, and are submitted to this Inquiry for Private Viewing only by the Senate Select Committee.

Contains information on courses studied, and modes of study, duration of ME/CFS.

Attachment 8

This attachment contains work-in-progress from my unrepresented doctoral thesis. There are no references appended to these excerpts.

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Issues raised include Special Admission Schemes, Compulsory Attendance and HECS.

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