

Attachment 3

Education of Students with the Chronic Illness Disability of

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

(ME/CFS).

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

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**Submission to the Draft Disability Standards for Education
from the perspective of ME/CFS.**

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To whom it may concern,

I am making this submission in response to the Consultations on the Draft Disability Standard for Education, Disability Discrimination Act 1992, Disability Standards for Education Draft.

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This submission is made on behalf of the students with Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), hereafter called ME/CFS in this submission.

I have been supported in the preparation of this submission by ME-Leaders, Australia, the national network of ME/CFS leaders throughout Australia, and the Alison Hunter Memorial Foundation, the National Association for ME/CFS in Australia, and members of six state societies for ME/CFS, thus this represents the views of these organisations, as well as my own doctoral research findings into 'The lived experience of ME/CFS: A Study in Human Rights and Equity in Tertiary Education.

My research has accessed forty participants from 24 Australian Universities and 8 TAFE/OTEN institutions, from all states and territories of Australia. It has exposed that the present system is not working for ME/CFS students. There are issues of disempowerment, and inequities. All participants had to have been enrolled in 1995 or since, and this timing of enrolment was done deliberately, as this allowed three years for the contents of the Federal Disability Discrimination Act 1992 to be implemented and be put into practice. 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 and social situation of many of the ME/CFS students. Arising out of my conduct of this research, I have become a reference person throughout Australia for tertiary students who find that they are in personal crises due to the lack of adherence to the FDDA 1992. I believe that I shall continue in this role as a reference persons to ME/CFS tertiary students, as an on-going reference person.

Introduction (brief notes only):

ME/CFS is a serious neurological condition, with many similarities to Multiple Sclerosis (MS) and Parkinson's Disease, and in the future may even be found to be a sub-set of MS.

There is no diagnostic test for ME/CFS, hence sufferers are diagnosed through various diagnostic definition - largely depending on the personal perceptions of the diagnosing doctor.

There are severe encephalitic symptoms, as well as ALL body systems which may be affected by this condition. As it affects all systems it thus has multi-presentations, so generalisations cannot be made of this multi-system disease, and there are varying levels of incapacity. A major problem is that this condition goes through cycles, where the one person may move from 60-80% functioning capacity to 0%. Thus this makes assessments unpredictable, and as well persons with this condition may be exacerbated into relapses with increased levels of disability. This creates problems for students to be adequately assessed, and the condition needs to be assessed multidisciplinary - yet an hour later another assessment result could be arrived at - that is how quickly this condition can vary.

There is a complete range of the disease - ranging from mild to completely bedridden. But this whole range may be experienced by the one person. Stress factors such as viral infections, surgery, physical or mental stress (such as experienced in examinations), noise, light, sound, chemical intolerance (environmental triggers may be paints, perfumes, etc.): but this will vary from person to person, and range from mild to very severe), can all trigger a relapse. A relapse means that a student who previously was able to function at 60% to even 80% of normal function is able function at 0% - being completely bedridden, needing assistance to eat, even possibly tube feeding. With relapse a person may be cognitively/mentally and physically non-functioning for days or weeks and thus be unable to communicate. This means that many of the deadlines for appeals by universities, and educational institutions will be missed.

These problems of the fluctuating nature, to try and address the needs of ME/CFS persons resulted in the Commonwealth Government in commissioning RACP Draft Guidelines - which confirms the problems of medical assessment, but even these RACP Draft Guidelines have fallen short of meeting this need because the literature does not enable enough evidence based material to be used.

Students Struggle for Recognition with ME/CFS.

I am aware of the problems which are encountered by students studying with a contested condition which is poorly named and poorly understood in the community. The name, Chronic Fatigue Syndrome, means that the condition is considered to be merely tiredness, instead of a serious neurological condition, closely related to Parkinson's and Multiple Sclerosis, and which has been assessed by Mathers, T., Vos, T. & Stevenson, C. 1999, *Burden of Disease and Injury in Australia*, Australian Institute of Health and Welfare, Canberra, in the severe form, as more devastating than AIDS (until AIDS enters the terminal stage). Further many people think that

Chronic Fatigue Syndrome equates to a person with the condition being a malingerer, hypochondriac, depressed and lazy.

This struggle is not unique to ME/CFS, as other poorly understood conditions in the past have also had to struggle for recognition, such as Multiple Sclerosis (formerly called Hysterical Paralysis), Diabetes, Epilepsy, Ulcers (caused by Type A personality), Polio (Infantile Paralysis) and even Tuberculosis (caused by an aesthetic personality) - being considered psychological somatisation conditions (Shorter 1987).

Students with physical disabilities, such as blindness do not have to struggle to even have their disability recognised. Many students with ME/CFS are faced with the dilemma of disclosure, they are wanting to be accepted as normal and capable to their peers and lecturers, and they wish to prove themselves. They also feel that disclosure will disadvantage them, due to the misunderstandings about the name, and the community misperceptions of this disease.

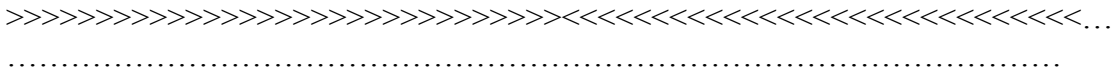
Academic Assessments seems to be a very big problem - and where the research findings regarding the cognitive dysfunction are not being addressed. With difficulties in short term memory encoding, and fragile recall, plus the variability of the brain waves (moving into sleep patterns), then the problems of the physical and mental exertion of examinations triggering serious health relapses (which may last for many weeks with 0% functioning of the student), is a serious area which is not being addressed. The Universities decide that ME/CFS students will have additional time, on the presumption that their only problem is fatigue (a misunderstanding arising from the name of the condition), and thus will allow for rest periods. Instead this accommodation only prolongs the period of the examination! Further, there is no recognition of the brain-wave changes, from alpha waves to delta and theta waves (sleep patterns) which can occur without warning to the student during the course of an examination (called 'brain fog' by persons with ME/CFS), and that it is unknown how long the brainwaves will remain altered - which could be until the next day, or if a relapse is triggered, even up to a few weeks. Additional time at examinations does not take into account this cognitive difficulty at all.

Examinations for ME/CFS students due to these problems are inequitable, and do not place ME/CFS students on an equal playing field with other well students, but in reality add to their disability. No guidelines used by the Disability Liaison Officers in the tertiary institutions in Australia address this problem.

This has been the most important finding to come out of my doctoral research, and one which needs to be addressed as soon as possible, to stop the inequitable practices. Alternative assessment, such as short written answers to questions at the end of a unit would seem the most equitable form of assessment - done with an open book, in the students own time (without time limitation stress), at their best time of day - often called "the window of opportunity".

Only when this change is implemented and enforced, will the spirit of the FDDA 1992 be achieved in this area of academic assessment for ME/CFS students.

Due to the varying presentation and the fluctuating nature of the disease, each person needs to be accepted for their ME/CFS happens to be, at that particular time.



Comments on the Disability Standards for Education:

(I shall use the sub-sections as laid out in the Draft - but also in addition giving each paragraph a number - for your ease of location - hence for example if I am referring to the second paragraph 3.5 Reasonableness - this will become 3.5.2.)

3.1.1 Adjustments:

The independent assessment: this would depend on the knowledge of the independent assessor of the condition - and may be inappropriate for the person with ME/CFS - we have found that there is a long time lag between the implementation of cutting edge research findings and the pick up and application by professionals. This is a problem with a poorly understood condition where very little is known and new research findings are being made on almost a daily basis.

Further, there are difficulties in who would be an independent assessor for a condition such as ME/CFS as it affects all body systems: it is a condition of CNS, with neurological, serious cardiological, hepaticological, immunological, endocrinological, gastroenterological, gynaecological, cognitive dysfunction, and allergic difficulties. As well as medical specialists, in their area of specialisation, there is also the need for Occupational Therapists and Physiotherapists to be involved in assessing the level of disability. An ordinary medical general practitioner does not have the expertise to assess the level of disability in ME/CFS, unless that medical practitioner has a specialised medical practice focussed solely on ME/CFS.

The use of the phrase Independent Assessor is ambiguous and without meaning, and should be changed in this context of the Draft Guidelines - because it is only in a condition of a single disability - such as e.g. blindness, deafness, that an Independent Assessor could assess disability. It is not appropriate for persons with multi-disciplinary conditions - as occurs in conditions such as ME/CFS, Lupus, and MS..

There is also the stereotyping of the condition - people are used to dealing with “fixed” conditions - such as blindness - where capabilities are immediately known, and knowledge can be extrapolated from previous experience, and so accommodations are readily made. Instead with ME/CFS - it is a poorly defined condition, and varies from person to person (a characteristic shared with many people with rheumatoid arthritis and MS), but ME/CFS also fluctuates widely for the same person - not just from week to week, nor with a steady progression or deterioration as experienced in muscular dystrophy, not even from day to day - but from hour to hour, and even minute to minute.

The devastating exhausting fatigue will occur in a moment, without any forewarning. A cause of this sudden change could be explained by the research which has found that the brainwaves of ME/CFS persons will change, as though a switch has been

thrown, from an alert stage to a sleep pattern - from the Alpha to Delta and Theta brainwaves, fluctuate and vary, and are totally unpredictable. Learning ceases when this change into a sleep pattern of brain waves occurs - and there is the phenomenon - which people with ME/CFS call “brain fog” occurs. There are difficulties with short-term memory encoding, and very fragile retrieval from long term memory - which has been researched by Goldstein and others.

Students have found that there is totally no understanding of this phenomenon within tertiary institutions. Instead they endeavour to soldier on with an accommodation of extra time being given to them. Because ME/CFS is such a contested condition, and so poorly accepted and discredited in the community, the students, even if they know of this happening to their brain, are just so grateful when a Disability Liaison Officer negotiates extra time for them. They are very grateful for any crumbs, and that their condition is even given credence of existing.

A finding arising out of my research will be that examinations are a totally inequitable form assessment for students with ME/CFS. After all, for ME/CFS students it is not measuring their learning outcomes, but rather it is measuring their cognitive function of encoding information and recall of the same.

Further examinations are inappropriate as many ME/CFS students have orthostatic intolerance - which means that standing and sitting become very problematical - as blood fails to flow to the brain adequately for full oxygenation of the brain - and Bell has separately discovered that there is a significant reduced blood volume in ME/CFS - which would exacerbate the problem.

Other researchers, such as Friedberg, Dechene and Donnay have separately found that persons with ME/CFS, particularly those who have had the condition for approximately five years or longer, are particularly sensitive to environmental chemicals. This includes the odours of paint, print, and perfumes and aftershaves.

Further there may be hypercuisis, which is an acute painful condition, where normal sound levels are magnified to the point of causing pain. Alternatively some persons will have deafness also caused by the condition - and these hearing problems can alternate in the same person!

Guidelines for disability accommodations such as Chubb, Lockhart, and Mungovan and England (1998) fail to address these difficulties which are experienced by the ME/CFS student.

So you can see that it becomes very difficult for an independent assessment to be carried out to ascertain the adjustments necessary for equity for a ME/CFS student.

3.1.2 Adjustments

The obligation being placed on the student with ME/CFS - can also be an imposition - as when many of these students “crash” they are bedridden - and their brains are unable to function - hence they cannot even get an associate to negotiate with timely and relevant advice. People do not understand what this “crash” means - assistance

for toileting, and may be an inability to eat solid foods - and even difficulty swallowing liquid foods. This is an unfair obligation which would mean that ME/CFS students in a sudden crash (one day at uni. next day totally bedridden, without a functioning brain) could not meet this obligation.

3.2.2 Discrimination.

A requirement or condition - please see comments on 2 Medical Model of Disability regarding the provisions which discriminate against ME/CFS students. Instances which have been mentioned is the impossibility of deferring a course in the first semester - and two of my research participants were too ill in their first semester - and although commencing with all the goodwill in the will - in a remission of ME/CFS - they found that they suffered a relapse in semester one of their course - and lost their place in their course - and would have to go through the whole admission procedure again.(see below)

Other policies demand that the course be undertaken on a full-time basis - and so ME/CFS students who happen to be too ill to undertake full-time study, or who think that full-time study would jeopardise their health if they become overloaded are precluded from these course - this happens especially in the fields of medicine and health courses. (see below)

Many faculty regulations did not allow changes to meet the needs of the ME/CFS students (see below).

Many research participants mentioned that they had not volunteered that they had ME/CFS - as they felt that they would be set aside in gaining a place - although it is expressly stated that this will not occur - it would only be natural that universities would select students who are more likely to complete their studies in the minimum amount of time.

3.2.3 Discrimination.

Neglects to mention environmental issues. - such as hyperacusis. Also chemical sensitivity. These issues are particularly important during renovation - as many cannot tolerate noise and paint chemicals. Students who mention problems said that they were ignored, and told that if they did not like it, well they need not go to their lectures! Like it or lump it attitude. The University did not see why they should change a lecture venue to accommodate the student (who after all was only one person - and who probably had a phobia or something which was not real but was only trying to cause inconvenience to the university). This was considered an unreasonable accommodation by the university.

Environmental sensitivity - to chemicals and noise etc. are not considered valid accommodations - and should be included in this section - although they are invisible disabilities and not visible, like a guide dog or wheelchair, they are none the less real, and disabling.

3.3.1 Substantive Equality

What happens when there are erroneous presumptions - made through ignorance - such as that ME/CFS is merely tiredness, malingering, etc.?

3.5.1 Reasonableness

Considered judgement : what is or whose considered judgement - I am very wary of this comment - due to the misperceptions of what ME/CFS caused by the poor name of the condition - see below.

3.5.5 Reasonableness

The impact of the appropriate actions or adjustments on other students and on staff - there is often a large amount of resistance to leaving off perfumed products, aftershaves - people consider this is a part of their freedom which is being impacted on. Even if it is suggested that it would be appreciated - many people decide they will test out wearing the perfumed product to see what happens to the ME/CFS person - and even precipitate the ME/CFS person into a relapse. Yet many firms are tolerant - such as the local Telstra call centre which has an employee who is affected by perfumes, and also there is one state in the USA which has made perfumes illegal in public places. Given the large numbers of people with asthma who may also be affected there is the need for it to be stressed that this is a reasonable accommodation - and one which should come before personal freedoms.

3.6.1 Harassment

The extracts from my research below will give many instances of harassment - such as intimidation and distress, as well as humiliation and offence. The continuing use of perfumes etc. I would also consider to be harassment - as it can cause such severe distress, even a relapse, which could preclude a ME/CFS student from attending the University for a number of days. There have already been court cases regarding the exacerbation of severe asthma due to perfume wearing, so it is only time before this occurs on campus.

5.2.1 Obligations of education providers

Students in my research have pointed out that they were fearful they would miss out on offers if they tell. Difficulties: full-time courses (no part-time available), no concessions for work placements - such as are required in some social work courses, health courses, etc. - part-time work is not allowed. Students are told they have to carry out this obligation, otherwise they will not obtain registration with the professional body.

5.3.2.2 Measures to enable access to enrolment for students with disabilities.

Enrolment procedures: but what of queuing with orthostatic intolerance (where the student is likely to end up on the floor collapsed). I do not understand why it is even necessary for students to have to enrol in person - surely other methods in this electronic computer age would be more efficient for the University, and this would also mean that Disabled Students would not be faced with difficulties. The physical requirements of a long procedure also cause problems - and enrolling is also problematical as there are no permits issued for parking within the university grounds. Students with a wheelchair, guide dog, etc. can indicate their "disability aid" to gain admittance to grounds etc. but students with an invisible disability are believed to be trying to get concessions, especially if they do not have a government disabled parking concession.

6.1.1 Rights of students with disabilities

Many students have commented on the problems of the architecture on campus, the steep hillsides, steps, and layout of a campus precludes them from having the same access to the full range of facilities. Many mention their difficulties reaching the library, or accessing student amenities, such as canteens, and even rest rooms - as they are located just so far away on the campus.

I have, myself, found myself sitting in a muddy gutter (it was raining) at Charles Sturt campus - as I could no longer continue my journey up the hill without sitting down to rest - and absolutely not one seat, log, piece of masonry, brickwork, was along the whole sole access pathway to sit on.

Provisions such as 6 Rights of Students with Disabilities - are written from the perspective of the social model of disability - but the medical model of disability prevails on Australian University campuses. Hills, steps, stairs, long ramps, uncovered walkways, no seating, queues, parking a long way off the campus facilities (even the disability parking), architecture, means that access is almost totally precluded for many ME/CFS students. (see below for comments).

6.2.1 Obligations of education providers

Do they have to place geographical constraints on campus - on hill sides - and locating student facilities at the bottom of the hill - this has occurred at least six Australian universities? Lack of seating on campuses for students who can only walk a short distance.

There is the need to locate rest rooms near lecture rooms, and in libraries.

Difficulties to obtain parking within reach of facilities - this is a real personal problem. Without close access of no more than 100 metres (which includes walking in the interior of the building) I am precluded from access from buildings.

6.2.2 Obligations of education providers

Parking accommodations: I have to negotiate this before attending a campus so that I can access facilities (I study off-campus - I wonder what would happen if I was an on-campus student). I travel for five hours to my campus - and the only assurance I have is that "Parking SHOULD be available" - I have found this comment comes from the faculty, and the DLO Office, and I negotiate with Grounds - but have to get to the Head of Grounds to get the assurance that "Parking WOULD be available".

My research participants have also drawn attention to this area of parking obligations. (see comments below)

6.3.2 Measures to enable substantive equality in participation.

Sufficiently flexible: see research comments below regarding the withdrawal of a science student from her course, and another student from her course also.

I have also found the same problems with enrolment timing of milestones in my research degrees - but I have cited Section 6 FDDA - and the university has then made accommodations. But students should not have to make the decision that

Section 6 applies to their particular situation, although this empowerment is one of the goals of my own research.

6.3.3 Measures to enable substantive equality in participation.

I take this paragraph to be applicable to examinations to ME/CFS students - please see what I have written above about the cognitive problems associated with this condition.

6.3.4 Measures to enable substantive equality in participation.

Here there is again the need to consider the physical capabilities of students - and provision of rest places, and time out, during a programme. The Distance Education Compulsory Residential Programmes at Charles Sturt often require very long days - from 8 am in the morning to after six pm - and they have then even scheduled assessable tests in the evening - concluding at 9 pm. Comments are made that if the pace is too much - well should you be doing the course? If you cannot hack the pressure - get out.

7.3.2 Measure of curriculum development, accreditation and delivery.

I like the comment appropriate, inclusive and accessible. Many students who study Distance Education off-campus are penalised because they are unable to access journal articles, and library books (books may be posted - but the student has to pay the return postage - which can be very costly on a big tome and postage is interstate rates: when the source of income is a Disability Pension). Comments such as a very good well planned essay, but it would have been better if you had made more use of journal articles and you could have attained a higher assessment.

7.3.4 Measure of curriculum development, accreditation and delivery

Often there can be difficulty with the print of course study materials - due to chemical sensitivity in ME/CFS to some print inks - and if the course materials arrive late there is not even time to try and outgas the materials so they can be used. Mention of this problem with the print ink gets a response that that is the ink which is used - there is no offer to even investigate to see if other types of inks could be used. (They might even find another ink which was cheaper - so it would therefore not be a costly accommodation).

There is also the problem that often library books have previously been borrowed by a smoker - and this gives headaches when students are sensitive to cigarette smoke - and books have to be put out to outgas before they can be used.

7.3.5 Activities in non-classroom situations

These often exclude - as they are not designed for the physical capabilities of students who need frequent rest periods?

7.3.6 ASSESSMENT PROCEDURES and methodologies are adapted to enable students with disabilities to demonstrate the knowledge, skills or competencies being assessed.

This certainly is not happening at present for the ME/CFS students - their cognitive dysfunction is not being catered for - see earlier discussion, and comments made by students (see below) - every single research participant mentioned this problem of cognitive dysfunction - which is ignored by all educational institutions.

How do we get this changed?

Can this be amended that information be kept up to date regarding assessment procedures and methodologies - and that as information becomes available in newer and less known conditions, that these newer discoveries are taken on board.

8.1.2 Right of students with disabilities.

What of students who do not identify as disabled? Or who are afraid to come out of the woodwork because ME/CFS is not accepted. Or of students who are ill, and have not yet fulfilled the six months criteria of having the condition before they receive a diagnosis. A whole lot can happen in a six months wait in academia.

8.2.1. Obligations of education providers

This is the medical model of disability - which disempowers persons who need enabling assistance.

What of campus design, lunch time queues, library queues, long distances from parking? The social model of disability would see that these problems were addressed. It is not the students disability, it is the disabling effects of the environment on campus which disables the student.

8.2.3 Obligations of education providers

But what of comments from the research participants of failure to pass on requests? They believe that as ME/CFS is not taken seriously, neither are their requests for reasonable accommodations.

8.3 Measures to enable the provision of student support services.

What of environmental adaptations: perfumes, noise, rest facilities close to lecture theatres, in libraries, not away in amenities areas of campus, catering for orthostatic intolerance, etc.

9.1. Rights of students with disabilities.

What of the use of the Occupational Health and Safety Act to cancel student enrolments of ME/CFS students. ME/CFS is not the only condition with environmental triggers - others are asthma, epilepsy, lupus, MS and migraines.

9.2.2 Rights of Students with Disabilities.

Many students are afraid if they entered Uni under a special admission scheme for disabled students, that to try and exercise their rights, could mean that under the provisions of these schemes, they will have their enrolment cancelled. This applies to the special admission schemes in NSW and also the University of Melbourne special admission scheme. These schemes discriminate against students with chronic

fluctuating illnesses - but are okay for students with “hard” disabilities (e.g. blind) as they are dealing with a constant disability.

9.3.3 Measures to enable the provision of an environment free from harassment and victimisation.

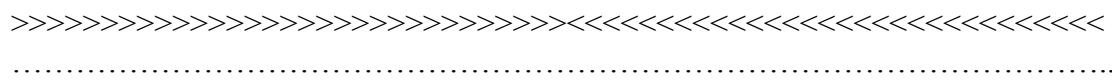
See above.

There needs to be an **AMENDMENT** to include low noise levels (which could also affect those with hearing loss), and low chemical environment (eg low toxic cleaning chemicals, termite spraying, renovation - e.g. paint work) (which affects persons with atopic conditions such as asthma, MS., Lupus, eczema, hayfever (allergic rhinitis), migraines as well as ME/CFS). .

Many students in my research are still afraid of retaliation for complaints.

10.3 Protection of public health

Most accommodations for ME/CFS students in the environmental line are actually the same as protection of public health! There is no conflict of interest in this area.



Disability Discrimination Act 1992
Disability Standards for Education
Draft Guidance Notes

5.1 Rights of students with Disabilities.

Discrimination and stereotyped beliefs are rife for students with ME/CFS - see comments of my research participants below. Only education will change this - yet with a name such as “chronic fatigue” it will be a very uphill battle for ME/CFS students. A name change must be of help - but in the meanwhile....

6.1.1 Providing Adjustments.

Accessible - what is accessible when issues of low chemical environments are not included nor addressed?

6.1.2 The statement “take into account information provided by, or on behalf of, the student with disabilities about any previous adjustments” - while this is good and would assist it is a two edged sword - as this could also create problems with a student with a fluctuating variable disability - such as ME/CFS and MS.. The student needs could be put into a category which would have become inappropriate : and this could also mean that the student would have provide new medical certification because of the changed status of their disability. With a fluctuating disability this would be an imposition on the student having to have every change documented.

6.1.3 Providing Adjustments

Listen to the student - who better to understand their condition than the student themselves? Too often DLO's and others presume to know the needs of the student - such as ME/CFS is mere fatigue, and only fatigue has to be catered for.

6.1.4 Providing Adjustments

Personnel who are making any clinical assessments - does the student have any say re clinical assessments even? Will the student be able to point out that the person chosen for a clinical assessment is inappropriate - for example, often persons with ME/CFS are sent off to psychiatrists for psychiatric assessment - on the presumption that ME/CFS is a form of somatisation/depression. This only wastes the time and energy of the ME/CFS person because such an assessment is inappropriate for the physical disability - but this would occur if the person chosen for the clinical assessment was made by a person who subscribed to a psychiatric paradigm or psychological perspective on ME/CFS.

6.1.6 Providing Adjustments

My research has shown that that many students with ME/CFS are not given credibility, and adjustments are not therefore acted on, and adjustments made in a timely manner which maximised the student's participation. There is often a “Give it a go” mentality by those who should be organising the adjustments - eg. a student who knows that oil paints (enamel paint) will trigger a severe migraine - is told to give it a go - and see what happens - you can come out of the lecture theatre if you are affected: whereas the student is trying to prevent the migraine. “Just see how you go, and come to me if you are affected or cannot cope” seems to be very prevalent for ME/CFS students - possibly because of the public perceptions that “chronic fatigue syndrome” is a form of malingering, and students don't want to do things.

6.1.8 Unjustifiable Hardship

Often an excuse is Well, as it is only you who is affected by the new paint etc. it would not be reasonable to move the lecture to another theatre. It would mean we would have to reschedule –blah blah blah - and this would be an unjustifiable hardship. Even if this were so - there is no offer to accommodate the troublesome disabled student with ME/CFS with videotaping the lecture - as that would also be too costly - and an unjustifiable hardship. This type of occurrence has happened a number of times to my ME/CFS students.

6.3.1. Alternative Adjustments

If the alternative is effective in achieving the purpose of the adjustment - who will ascertain this as effective - given the lack of understanding of ME/CFS by the public and DLO's.

6.3.2 Alternative adjustments

Would review mechanisms only reinforce stereotypes - prejudices? This presumes that others understand the nature of the disability - which is not so with a variable, fluctuating, contested, stigmatised, and disbelieved conditions such as ME/CFS?

7. 3 Legal Implications of the Standards

The obligation not to discriminate arises under the access to premises provisions of the DDA - but does this cover persons with conditions such as ME/CFS, asthma, MS who are affected with chemical intolerances? Or is this merely reinforcement of the stereotyping of disability to wheelchairs, guide dogs, etc.?

9.2 Client Service

Attitude is one of the main barriers - this is the Biggest problem of all persons with a poorly understood, badly named condition! Would false perceptions of the disease be a defence for not making adequate accommodations?

10.1.3 Due Diligence and Reasonable Precautions

Therefore inadequately addressing assessment requirements of ME/CFS based on the latest research findings would not be adequate?

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