

"Double Disability, lived experience of Australian tertiary students with ME/CFS"

My doctoral research has addressed the applicability of, and compliance with, the Disability Discrimination Act 1992 by Australian tertiary institutions as applied to tertiary students with the chronic illness of ME/CFS. *

1. I found that the Act is an excellent piece of legislation and meeting the needs of my research participants fully. My forty research participants came from 24 of our 39 Australian universities, and also included 8 TAFE/OTEN colleges.
2. Prior to my research the quality of the guidelines used in the disability area of ME/CFS had not previously been assessed to see if they:
 - a. represent the full-spectrum of the condition;
 - b. the actual needs of the students being met by accommodations which were offered ;
and
 - c. the difficulties with the contested acceptance of ME/CFS.All three areas have added up to the second disability finding of my research.

3. I found that
 - (a) inflexible bureaucratic regulations;
 - (b) due to poor educational guidelines used by the Australian tertiary institutions for compliance with this act construct a second additional disability for tertiary students with ME/CFS. The result has been that there is no compliance with the Disability Discrimination Act 1992: ALL Australian tertiary institutions are apparently infringing the requirements of the Act (especially sections 22 or section 6).

Guidelines used for disability accommodations in Australian tertiary institutions.

In the case of ME/CFS the guidelines for accommodations contain inaccurate information regarding the organic nature of the condition (which is considered by research as cognisant with MS and Parkinson's Disease with damage in the same area of the brain). The present guidelines trivialise the condition, do not address the cardiac involvement, the neuro-cognitive dysfunctions, etc. and only attempt to accommodate for the statistically most common but often minor symptom of fatigue. (If diabetes was called 'Chronic Thirst Syndrome' as the most common symptom of diabetes is thirst, this would similarly trivialise the serious nature of diabetes.)

The very diagnostic criteria of ME/CFS relies upon the presence of cognitive dysfunctions.(1) The absence of the defining symptoms of ME/CFS from all guidelines which are presently in use in education encourages and promotes infringement of the Disability Discrimination Act 1992.

The cognitive dysfunctions and learning difficulties which impinge on educational outcomes and equity are not addressed and completely omitted from all guidelines currently in use. Students not only have the chronic illness disability of ME/CFS, but they also have a condition which is not understood nor explicated in guidelines, and the rigid

nature of university guidelines fail to meet the needs of students with a fluctuating medical condition (and this finding would also be applicable to students with other chronic illness medical conditions such as MS, severe Asthma, etc.) - thereby creating a second disability with attitude.

Many of the issues which I have found in this research are addressed in the various papers and publications listed below.

*Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome.

Reference:

(1) Carruthers, B., Jain, A., De Meirleir, K., Peterson, D., Klimas, N., Lerner, A., Bested, A., Flor-Henry, P., Joshi, P., Powles, A., Sherkey, J. & van de Sande, M. 2003, 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols', *Journal of Chronic Fatigue Syndrome*, K. De Meirleir & N. McGregor (eds.), Haworth, New York.vol.11, no.1, pp. 7-115.

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Some peer-reviewed papers and submissions by Dorothy Morris:

Morris, D. 1999a, 'Method and Madness or from Madness to Method!', paper presented at *Method and Madness*:

Deakin University Postgraduate Association Conference, Geelong, October 1999.

Morris, D. 1999b, 'A discussion of the preliminary findings arising from the research on the lived educational experiences with ME/CFS: a study in human rights and equity in tertiary education', presentation for the Allison Hunter Memorial Foundation *Perspectives on ME/CFS* consultation, Victoria University, Melbourne 26th November.

Morris, D. 2000a, "A study of chronic illness and agriculture: The lived experiences of farmers with ME/CFS". Paper presented at Glenormiston College, University of Melbourne, Terang, May, 2000.

Morris, D. 2000b, 'Submission to the Draft Disability Standards for Education from the Perspective of ME/CFS,' Draft Disability Standards for Education, November 2000.

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

Morris, D. 2000c, "Dilemmas of the Research Journey", Paper presented at the Deakin University Postgraduate Association Conference, *Dimensions and Directions*, Geelong, October 2000.

Morris, D. 2000d, "Stories of ME/CFS* and Tertiary Education: The Lived Experience and Quality of Life", Paper presented at the 2nd Australian Quality of Life Conference, Melbourne November 2000. Australian Centre on Quality of Life
<http://acqol.deakin.edu.au/>

Morris, D. 2000e, 'Into Uncharted Waters: Considerations with Chronic Illness Research', Paper presented at the *CSMEE Symposium: Contemporary Approaches to Research in Mathematics, Science, Health and Environmental Education*, Deakin University, Melbourne, 27-28 November, 2000.

Morris, D. 2001a, 'Research into ME/CFS and tertiary education' *Politics, Action & Renewal: Proceedings of the 4th Australian Women's Health Conference Proceedings*, 19-21 February, H. Keleher, G. Gray, D. Jones, G. Wilson (eds.), Australian Women's Health Network, Strathfieldsaye, Victoria, pp 246-254.

Morris, D. 2001b, 'Electronic Mail: Breaking Down Access Barriers in Chronic Illness Research', *Health Communication and Information Technology: The Electronic Journal of Communication/La Revue Electronique de Communication*, G. Kreps, (ed), vol.11, Nos.3-4.

<http://www.cios.org/www/ejc/v11n3.htm>

Morris, D. 2001c, Report on the findings of 'The Lived Experiences of tertiary students with ME/CFS.

Part 1: Introduction to research into 'The Lived Experiences of Tertiary Students with ME/CFS; Part 2: Standards for education practice in Australia; Part 3: A brief review of related disability literature; Part 4: The symptomatology of ME/CFS. Papers presented and distributed to the South Australian Youth with ME (SAYME), ME/CFS Society of South Australia, Inc., Fullarton Community Centre (Adelaide), February 2001. <http://www.sayme.org.au>

Morris, D. 2001d, 'Issues of Human Rights and Equity for students with ME/CFS: arising from research findings into ME/CFS and tertiary education'. Paper presented and distributed to the academic and disability officers of the South Australian Universities, at Disability Information Resource Centre, Gilles Street, Adelaide, 12 noon, 21st February 2001

Morris, D. 2001e, 'Analysis from the Perspective of Education of the Chronic Fatigue Syndrome Guidelines (Revised Draft 2001),' Royal Australasian College of Physicians, Sydney, NSW, 30 July, 2001.

Also at <http://AHMF.org.g-morris.html>

Morris, D. 2001f, 'What does academic assessment assess : the case of ME/CFS?', paper presented at 'Tertiary Teaching and Learning: Dealing with Diversity', Tertiary Teaching and Learning Conference Darwin, July 9-12, 2001. May 2001, <http://www.ntu.edu.au/tlc/papers3.html>

Morris, D.2001g, 'Perseverance and Perpiration and Other P's', paper presented to Deakin University Student Association Post-graduate Research Conference, September 2001 at Toorak Deakin University Campus.

Morris, D. 2002a, 'Education, Equity and Cognitive Dysfunction Dilemmas', *The Medical Practitioners' Challenge: Proceedings of the Third Sydney International Clinical and Scientific Meeting 2001*, Alison Hunter Memorial Foundation, Bowral, NSW, pp.135-142.

Abstract at <http://AHMF.org> also published at Co-cure 31st December, 2001 <http://www.co-cure.org/http://listserv.nodak.edu/scripts;>

full-paper Co-cure 17th January, 2002 <http://www.co-cure.org/http://listserv.nodak.edu/scripts.paper> . Also at

<http://www.cssa-inc.org/Articles/DMorris.htm>.)

Morris, D. 2002b, 'Submission to the Senate Employment, Workplace Relations and Education Reference Committee of Inquiry into the Education of Students with Disabilities on the Education of Students with the Chronic Illness Disability of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS),' *Inquiry into the Education of Students with Disabilities*, Senate Employment, Workplace Relations and Education Reference Committee, May 2002.

<http://www.aph.gov.au/Senate/committe/EET>

http://www.aph.gov.au/Senate/committe/EET_CTTE/ed_students_disabilities/index.htm

Morris, D. 2002, 'Insider Research, a window or a mirror?' Paper presented at the CSME Symposium: *Contemporary Approaches to Research in Mathematics, Science, Health and Environmental Education*, Deakin University, DecemberMelbourne.

Morris, D. 2002, 'Insider Research, a window or a mirror?' Paper presented at the CSME Symposium: *Contemporary Approaches to Research in Mathematics, Science, Health and Environmental Education*, Deakin University, DecemberMelbourne.

Morris, D. 2003, 'Looking out of a window or into a mirror in insider research?', *Paper presented at Higher Degree by Research Summer School, Education Faculty, Deakin University, Geelong, February 2003.*

Morris, D. in press, 'What does Academic Assessment Assess? The Case of ME/CFS', *Tertiary, Teaching and Learning: Dealing with Diversity*, G. Shaw (ed.), NTU Press and the Centre for Teaching and Learning in Diverse Educational Contexts, Darwin, NT.

Peer-Reviewer:

TEACH-ME Task Force 2002, *TEACH-ME: A Sourcebook for Teachers of Children with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia*, Nepean, Ontario, Canada: National ME/FM Action Network.