

Evidence-based Policy or Policy-based Evidence?

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In relation to the forthcoming Parliamentary Inquiry into ME/CFS to be chaired by Dr Ian Gibson MP (former Dean of Biology at the University of East Anglia and former Chairman of the House of Commons Science and Technology Select Committee, to whom the UK ME community owes considerable gratitude for his willingness to assist where others who could have done so have declined), a number of important points have presented themselves; for the avoidance of doubt, some of these points are placed on public record.

Mindful of the misinformation that was promulgated by the Medical Research Council when it announced its Research Advisory Group (RAG) on "CFS/ME" (the MRC claimed that RAG members were "fresh" and "independent" to the issue of ME/CFS but this turned out to be untrue, in that one of the RAG members was a Member of the Linbury Advisory Panel on CFS --- the Linbury Trust having since 1991 funded a considerable number of Wessely School projects -- and at least two of the RAG members had co-authored papers on CFS with Professors Simon Wessely and Michael Sharpe), the UK ME community has understandably expressed legitimate concerns about the pressing need for absolute transparency about Inquiry members' backgrounds and affiliations. Dr Gibson has already placed on record his wish for balance in the selection of Inquiry members but it is hoped that Dr Gibson (who, as Chairman of the Inquiry, will select its members) will understand these concerns. It is also hoped that he will accept that an Inquiry panel containing Members of Parliament who although nominally non-partisan may, for whatever reason, be naïve about the underlying issues could do lasting damage to an already damaged community of very sick people. A list of Inquiry members is therefore keenly awaited.

A second point of concern is that past experience has demonstrated that documents that have been submitted to official bodies such as the Chief Medical Officer's "independent" Working Group and to the MRC RAG that are deemed not to accord with current "policy" have simply disappeared without trace; this being so, the ME community would be re-assured to have access to a list of documents that have been or will be submitted to the Inquiry. As Dr Gibson has confirmed that the All Party Parliamentary Group on ME (APPGME) is to have conduct of the Inquiry secretariat, and as an official complaint about the conduct of the APPGME in relation to its apparent pro-psychiatric bias has been submitted, this is a matter of importance.

Dr Gibson having confirmed that his Inquiry will wish to take evidence from as many people as possible, especially those with ME/CFS who have experienced problems with the "establishment", a third point relates to the selection of such witnesses. Concern has already been expressed that witnesses who might put themselves forward may not in fact suffer from authentic ME and may thus present an inaccurate and misleading picture of what ME really is. Particularly significant is the need for potential witnesses not to be vetted or approved by those unfamiliar with authentic ME. There is also concern that adequate provision is made for video-link evidence from those who are simply too sick to attend in person but whose evidence ought to be the lynch-pin of the Inquiry.

Another point of concern relates to the way in which the necessary evidence will be collated and presented to Inquiry members in an assimilable manner; given the sheer amount of such material, this would seem to be a major logistical problem.

For example, in the American Family Physician, a peer-reviewed journal of the American Academy of Family Physicians (one of the largest groups of physicians in the US), the issue of 1st November 2005 (volume 72, no. 9) features CFS in the section "Clinical Evidence Concise", this being a section that purports to provide evidence-based continuing medical education (CME) for the credits that are required to be obtained by all physicians to demonstrate their up-to-date medical knowledge; the articles in "Clinical Evidence Concise" purport to summarise current knowledge about a disorder and are used in "best practice" guidelines. In this particular issue, the topic is CFS and the authors are Steven Reid, Trudie Chalder, Anthony Cleare, Matthew Hotopf and Simon Wessely. What is so disturbing is that this is a re-run of the same authors' paper in the BMJ of January 2000, which was a shortened version of their original article in the second issue (December 1999) of "Clinical Evidence", a BMJ Publishing Group Review. For these authors to publish it once again six years later demonstrates their total refusal to pay any heed to the wealth of biomedical evidence about ME/CFS that has

been published in the intervening six years and would seem to be an abuse of the scientific process as well as an abuse of those with ME/CFS. As Jill McLaughlin noted on MEActionUK@yahoo.co.uk : “This is what is being distributed to physicians all over the country who legitimately use evidence-based medicine to treat (or in this case, shall we say, mistreat) patients. We cannot always rail at doctors when this is the information that they are receiving in mainstream, peer-reviewed medical journals”.

We have printed the 20 pages of Rapid Responses to the article in the BMJ from early 2000 and intend to submit them to the Parliamentary Inquiry because they encapsulate not only the abhorrence and disbelief that the paper engendered within the medical community at the time but also they demolish the psychiatrists’ false beliefs about CFS, which is evidence of which we believe Inquiry members need to be aware.

Without doubt, those false beliefs are now known to be carefully-constructed “policy-based evidence”, as can be seen from the 32 page Report from a Working Group of the Medical Research Council’s own Neurosciences and Mental Health Board (NMHB) Strategy and Portfolio Overview Group (SPOG) of January 2005. The aim of that Report was to consider the balance of the current MRC research portfolio and it confirms what the UK ME community has long recognised – that ever since the advent of Simon Wessely, the MRC has considered “CFS/ME” as a mental disorder and will continue to do so: at paragraph 6.2 the Report is unequivocal: “Mental health research in this instance covers CFS/ME”.

Given what is on public record about ME/CFS (see “Time for a Reality Check at the UK Department of Health?” by Margaret Williams, Co-Cure ACT: 3rd April 2004, which chronologically documents the acceptance of ME/CFS as an organic disorder from official bodies including the UK Department of Health from 1987) and given the well-publicised written confirmation of 11th February 2004 from the Health Minister Lord Warner that the correct (and only) ICD classification for ME/CFS is neurological, this significant inconsistency is a core issue which the Inquiry would surely wish to address most scrupulously.

Other points of note in the SPOG Report include the following:

- i. mental ill-health represents a significant burden on healthcare systems
- ii. improving the well-being of people with mental disorders is a major priority of the UK Government
- iii. the MRC research agenda should be optimally aligned with the injection of Government funding into this area
- iv. the Report’s Terms of Reference were to advise on research opportunities and priorities for the future
- v. the MRC affirms that by 2020, global childhood neuropsychiatric disorders will have risen by more than 50% from current levels and that neuropsychiatric disorders in adults are likely to account for 15% of the total disability-adjusted life-years lost due to all diseases and injuries (could this be because of the deliberate construction of “mental” illnesses by those with vested interests –see “An Inquiry by the UK House of Commons Health Select Committee into the influence of the Pharmaceutical Industry” by Margaret Williams, Co-Cure ACT: 31st October 2004)
- vi. mental health represents a vast potential market for pharmaceutical companies
- vii. under “Mapping the UK research portfolio in mental health”, the Report states: “The analysis will capture all peer-reviewed grants that are live at a given date, which will be classified in terms of a list of mental health conditions based upon ICD-10 classifications” (could this explain the determination of Wessely School psychiatrists formally to re-classify ME/CFS as a “mental” disorder in the ICD?)
- viii. according to the “opinion-leaders” consulted by the Report’s authors, links with industry funding in the area of mental health are “weak” compared with other areas of medicine and “Funding for mental health research in the UK is low relative to the burden of disease” (the figure of £11.1 million recently awarded solely to subscribers to the Wessely School’s beliefs about “CFS/ME” compared with the nil amount awarded to biomedical research springs to mind).

That the MRC specifically and deliberately includes “CFS/ME” under “mental health” research is at diametric variance with the Health Minister’s written confirmation given one year prior to the publication of this MRC SPOG Report and this must be an issue that the Inquiry members do not evade.

One would have thought that such written clarification from the Health Minister was sacrosanct, especially given the previous documentary evidence that the UK Department of Health has officially accepted ME as a physical, not mental, disorder since 1987 (re-affirmed by the Department of Health in 1992), but on 20th April

2004 the same Health Minister (Lord Warner) stated in a written Parliamentary answer: “The Department of Health did not say that myalgic encephalomyelitis / chronic fatigue syndrome is a neurological disease” (see Hansard HL2302). Given the extent and quality of the international evidence which demonstrates the neuroendocrine-immuno-vascular pathology that underlies the organic nature of ME/CFS, such a volte-face is seen to be not only inexplicable but also to be lacking in credibility and therefore something to which Inquiry members will be expected to pay particular attention.

Such deliberate “policy-based evidence-making” by the MRC and the Wessely School psychiatrists who dominate its thinking about ME is a core issue that Dr Gibson’s Parliamentary Inquiry must not fail to address, especially in the light of a recent article by a professor of anatomy and a doctoral student that is currently receiving wide attention both in the general and medical news media including Nature, WebMD, Medscape, UPI, New Scientist (12th November 2005) and the Wall Street Journal Science Journal (18th November 2005, page B1).

Commenting on this exposure of psychiatric fallacy, Vera Hassner Sharav aptly sums up the situation (see Co-Cure EDU: 19th November 2005): “One after another of psychiatry’s theoretical constructs and therapeutic armamentarium have been knocked down and relegated to the dust-heap of pseudo-scientific history. None of psychiatry’s claims have withstood the test of scientific scrutiny. The very core upon which psychiatry’s practice guidelines are based has been shown to be nothing but unsubstantiated speculation. When confronted with evidence refuting this mantra of biological psychiatry, Wayne Goodman, chair of the FDA psychopharmacologic advisory committee admitted in The New Scientist that the false premise is nothing but a ‘useful metaphor’, yet not only company advertisements but leading psychiatrists have deluded the public for decades with such false claims. Unsubstantiated pronouncements by psychiatry’s leadership gave the mental health industry pseudo-scientific arguments with which to equate mental illness to physical illnesses. This patently false comparison gave ammunition with which to lobby for drug budget parity. The ‘useful metaphor’ was used to deceive patients and the public and to divert healthcare funds from essential medicines. Dr Goodman admits that he has never revealed the truth to his patients – ‘I can’t get myself to say that’. The fact is that the psychiatric establishment has been concealing the truth about the lack of scientific evidence behind all of its theoretical constructs and armamentarium”.

This long-standing deception by psychiatrists, which seems to be driven only by their desire to secure ever-more massive funding for their own speciality, lies at the very heart of the politically constructed tragedy that is ME/CFS and is unmistakably obvious from the MRC SPOG Report.

Given the excoriating criticism levelled at the MRC by Dr Gibson’s Science and Technology Select Committee Report in March 2003 (see “The Work of The Medical Research Council: Third Report of Session 2002-03: HC 132), it is to be hoped that his forthcoming Inquiry into ME/CFS will be duly mindful of that criticism and will act accordingly.