**Summary of Key Points in the Report of the Gibson Parliamentary Inquiry**

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The Gibson Report is a 35 page document that represents a significant milestone in the history of ME/CFS in the UK and much gratitude is due to the people responsible for its production, notably Dr Ian Gibson MP and his Norfolk constituent Kevin Short, who was the prime mover in securing this Parliamentary Inquiry.

The Press Release

The Report is to be launched on Monday 27th November 2006 and the accompanying Press Release states:

"*Over the past year, the Inquiry has received thousands of written submission of evidence from medical experts, scientists, patients and patient groups across the UK and internationally. Patient Groups refer to themselves as the 'ME Community' and consider CFS to be a term invented by psychiatrists who do not believe their condition exists. The Gibson Inquiry argues that we must invest massively in research into biomedical models of this illness. It is still unclear whether CFS/ME is one illness with a spectrum of severity or whether it is two separate illnesses. Many of the most severely affected find GET (graded exercise therapy) massively worsens their condition. Researching the possibility of subgroups is essential. One problem is that the "Oxford Criteria" is very vague and focuses on fatigue. As such, the knowledge we do have may have been gleaned from people who did not have the condition. The NICE (draft) guidelines have been widely criticised. Chair (of the All Party Parliamentary Group on ME) Dr Des Turner described them as 'not fit for man nor beast' (and) Dr Ian Gibson described them as 'useless'. ME patients have questioned the independence of reviewers in previous inquiries and believe that the psychosocial school has received unfair advantage in terms of funding for research. The Inquiry calls on the government to rectify this historical bias towards a psychological model. The UK is falling behind the rest of the world when it comes to CFS/ME and it is the patients in the UK who are paying the price. Dr Ian Gibson MP, Chair of the Inquiry, says: 'There is a wealth of published and evidence-based research on this subject. Canada and the US are leaving us way behind on this issue' ".*

The Report in its entirety was submitted to NICE before the expiry of the deadline (24th November 2006) and written assurances have been received from Professor Sir Michael Rawlins, Chairman of NICE, that even though not submitted on the NICE on-line pro forma, the Gibson Report will be considered in the formulation of the NICE Guideline on CFS/ME.

It is known that one member of the Gibson panel wanted to re-write the Report and remains of the opinion that there is no evidence that the views of the Wessely School are incorrect: the Press Release draws attention to this division of opinion amongst the Inquiry's own members.

Terminology

The Report uses the term "CFS/ME", not because it condones such a term, but because it is the recognised term in the UK (being used by Government bodies such as the MRC and NICE).

Aim of the Report

From the outset, the Report is clear that the current state of affairs in the UK is unsatisfactory to the Gibson Inquiry group and notes that some of the CMO's Report's recommendations for further research have been ignored.

The stated aim of the Report is "*to highlight the ongoing struggle of the CFS/ME community and to ensure that the voice of the patient is heard".*

It emphasises that *"money invested in discovering the causes and potential treatments now could save money in the long term".*

The Group believes that *"physical aspects have received less attention or support then they deserve and that this shortcoming must be addressed".*

The Report is clear: "*CFS/ME can be a severe incapacitating illness and those who suffer from it may have their lives completely ruined. Carers and families are equally affected. In the absence of known causes or cures, patients require considerable care, compassion, understanding and support and, in particular, acceptance that they have a genuine and serious illness. Dismissal of symptoms is unhelpful".*

History of the disorder in the UK

Reviewing the history of CFS/ME, the Report notes: "*In the course of our investigations, we were made aware of research that has been done internationally. In Britain, there has been a clear historical bias towards research into the psychosocial explanations of CFS/ME. This is despite Parliament recognising ME as a physical illness in the ME Sufferers Bill in 1988".*

The WHO position

The Report demolishes the commonly held belief that the WHO categorises CFS/ME under both neurology and mental / behavioural disorders: "*Indeed this is reported in medical textbooks. The Group found this assertion to be incorrect".*

Medical textbooks

The Report is critical of medical textbooks such as "Clinical Medicine" edited by Kumar and Clark that is endorsed by the British Medical Association and notes that CFS/ME is placed in the psychological medicine section (by psychiatrist Peter White); the Report notes that this widely-used textbook teaches that: "*two third of patients with a symptom duration of more than six months may have an underlying psychiatric disorder"* and the Report states unequivocally: "*While CFS/ME remains only in the Psychological section of medical discourse, there can be little chance of progress".*

Children with CFS/ME

The Report records its concern that children with CFS/ME are being put on the at-risk register or even made Wards of Court and removed from the family home.

The Oxford case definition

The Report is critical of the "Oxford" 1991 case definition that was compiled by Wessely School psychiatrists: "*due to the general nature of this guideline it is possible that patients with a spectrum of fatigue symptoms who are unlikely to have ME will be included in research. The Group found that the international criteria paid far greater attention to the symptoms of CFS/ME while the Oxford criteria focus very little on any symptoms other than long term tiredness. There is concern that the broad spectrum of patients who may be included in these (Oxford) criteria may lead to inaccurate results in studies of CFS/ME. The Group feels that the criteria should be updated in the light of peer-reviewed and evidence-based research done both internationally and in the UK in the past 15 years".*

The Canadian Guidelines and the US CDC "CFS Toolkit"

The Report praises and recommends the Canadian Guidelines and the US CDC "CFS Toolkit", noting that the latter "*highlights the importance of recognising the serious nature of the condition in order to validate the patient's experience. It is an extremely useful resource".*

The Science

The group calls for a further Inquiry into the scientific evidence on CFS/ME by appropriately qualified and independent experts such as virologists, immunologists, biochemists and geneticists who can "*objectively assess the relevance and importance of the international scientific data".* The Report states: "*The origins and causes of CFS/ME will only be found through further scientific research"* and that "*This Inquiry should be commissioned by government. In the UK, at least, sufficient research has not been done to verify any one cause. The Group feels the necessary research must be funded immediately".*

The Report notes: "*numerous studies have suggested that cardiac abnormalities occur in CFS/ME patients"* and states: "*This has serious implications for GET. As such, the Group would recommend that the heart function is examined, especially in the severely affected, before GET is recommended".*

Evidence of abnormal brain scans is mentioned, as are viral effects, and the Group is clear: "*the Group recommends, firstly, that these studies and others like them must be examined by an independent scientific advisory committee such as the one proposed above. Secondly, many studies we received were conducted on a very limited scale and their findings need to be confirmed or refuted by large-scale investigation. Until this happens, the field will remain confused".*

Professor Simon Wessely

The Report states: "*There is great dispute over the findings and beliefs of Professor Simon Wessely. Many patients believe Wessely and his colleagues are responsible for maintaining the perception that ME is a psychosocial illness. There is conflicting evidence available regarding Wessely's true opinions. The Group invited Wessely to speak at an Oral Hearing, however, he declined. The Group were disappointed not to have the opportunity to discuss this important issue with such a key figure".*

Potential causes of CFS/ME

The Report discusses infective agents, immune system abnormalities, inflammatory changes, environmental exposure to organophosphates, and gene changes, and states: "*Future research needs to focus on efforts to categorise the illness".*

Treatment

The Report notes that a consistent pattern of what is helpful has not emerged and that although anti-depressants are often prescribed, they are only of benefit to those who are depressed or anxious. The Report states: "*Drug therapies are uniformly disappointing in the treatment of severe CFS/ME".*

It notes that patients selected for trials of psychosocial therapies (ie. the MRC PACE and FINE trials) are likely to have been selected using the Oxford criteria.

The Report states that there is a role for CBT and notes that it is used "*as an adjunct to treatment for organic disease".* The Report is clear that "*no matter how successful or unsuccessful CBT may be, it is at best only a partial answer".*

The Report does, however, express doubts about GET: "*GET is an area for particular concern".* Referring once again to the cardiac problems seen in CFS/ME, the Report states: "*The Group is concerned that the NICE guidelines are recommending these treatments without caveats. Some of our evidence suggests that GET carries some risk and patients should be advised of this".*

The Report notes that if CBT and GET are prescribed, *"they should be regarded as symptomatic treatments, not as cures. These methods simply help patients deal better with their symptoms".*

Overall, the Report states: *"Until we have more knowledge about the cause of CFS/ME, any suggestion of empirical treatments such as the Perrin technique require independent assessment in a controlled environment".*

Government provision

The new Centres: The Report welcomes the new Centres funded by government but emphasises the need to use these Centres for appropriate research purposes, for example, for research into causation, for study of the spectrum of the illness over time, for therapeutic interventions and for models of care: "*The existing Centres would be ideal places to undertake large-scale epidemiological research studies of the type the Group feel are vital in this field, providing they were conducted according to acceptable criteria. The (Group) welcomes the recognition of the need to sustain (the) centres, however, exactly which treatments should be used on which patients remains disputed. Provision of resources for biomedical research is urgently needed".*

The MRC: the Report notes that the Minister indicated to the Inquiry that few good biomedical research proposals had been submitted to the MRC, but that the Group had been told of proposals that had been rejected, with claims of bias by the MRC against biomedical research. The Report notes that the MRC itself has confirmed that since April 2003 to date, it has turned down 10 biomedical applications relating to CFS/ME but has funded five psychosocial applications. The Report states: "*It is important for the MRC to be seen to be balancing this with support for high quality research into potential causes*". The Report is unequivocal about the need for research into causation and not just into "treatment", stating: "*The Group were concerned about the MRC Research Advisory Group (RAG) paper (which) diverted attention away from the need for research into causation and diagnosis. The Group feels that ME/CFS (sic) cannot be viewed in the same light as other illnesses of unknown cause. The crucial issue with CFS/ME is to identify diagnostic tests for it, even before its cause is clarified. Of course you can research the effects of treatment of cancer without knowing its cause. The same does not apply to an illness were the diagnosis has not been positively confirmed".*

Benefit entitlement: The Report notes: "*At present ME/CFS (sic) is defined as a psychosocial illness by the Department for Work and Pensions (DWP) and medical insurance companies. We recognise that if ME/CFS (sic) remains defined as psychosocial, then it would be in the financial interests of both the DWP and the medical insurance companies. The Group feels that patients with CFS/ME, which is often an extremely long-term condition, should be entitled to the higher rate of DLA (Disabled Living Allowance). The sooner there is a biomedical model of assessment for this illness, the better*". The Report then reproduces an extract from Hansard of 18th December 2002 (column 853W) about DLA: "*It is clear that, until a biomedical cause is researched and identified, ME patients will continue to find it difficult…they are at a massive disadvantage because of the controversy surrounding the cause of their illness and suggestion that it may be psychosomatic".* The Report is clear: "*Until medical opinion is better informed as to the nature of this illness, ME sufferers will have to live with the double burden of fighting for their health and their benefits".*

Formulation of Policy: The Report states about the problems for patients arising from DWP policy on CFS/ME: "*Government looks like adopting a new benefits policy which may still leave it discriminating against claimants with ME/CFS (sic)".*

Vested interests: The Group is particularly troubled about this issue: "*There have been numerous cases where advisors to the DWP have also had consultancy roles in medical insurance companies, particularly UNUMProvident. Given the vested interest private medical insurance companies have in ensuring CFS/ME remains classified as a psychosocial illness, there is blatant conflict of interest here. The Group finds this to be an area for serious concern and recommends a full investigation by the appropriate standards body".*

The Group's Conclusions

The Report states:

"*The Group was very interested in the international evidence submitted and concerned as to why this evidence has not been seriously examined in the UK".*

"*The opposing opinions about the nature of the disease are very problematic".*

*"The lack of easy confirmation of the organic nature of the illness lends itself to occasional invasion by those who are not genuine sufferers (and) the inability of some in the medical profession to separate them from genuine patients with CFS/ME enhances the view that all patients with CFS/ME are neurotic and / or not genuinely ill".*

*"Severe cases of CFS/ME do not respond well to psychological treatment".*

*"ME and CFS have been defined as neurological illnesses by the WHO. Various clinical and research studies around the world have suggested CFS/ME to have a biomedical cause".*

*"The UK has not been a major player in the global progress of biomedical research into CFS/ME. In the UK, precedence has been given to psychological research and definitions".*

*"There is a great deal of frustration amongst the CFS/ME community that the progress made in the late 1980s and early 1990s toward regarding CFS/ME as a physical illness has been marginalized by the psychological school of thought. It is clear that the CFS/ME community is extremely hostile to the psychiatrists involved".*

*"The Group does not intend to criticise motivations or actions of any one group. Our aim is to build consensus from this point forward".*

*"The principal actuality remains that there exists a serious disease, which causes much suffering for patients, which may be severe and incapacitating and which causes a multitude of symptoms. This is the baseline from which all else should follow".*

Areas for further examination

*"Is this one disease or two – CFS/ME, or CFS and authentic ME?"*

*"Why does the DoH not keep or collect data pertaining to the number of CFS/ME sufferers in the UK?"*

*"No representative who appeared at the Oral Hearings proposed CFS/ME was entirely psychosocial, so why has this model taken such a prominent role in the UK?"*

*"The research areas defined by the CMO Report in 2002 have not been addressed. Further research is the single most important area in this field".*

*"The evidence for a toxin aetiology requires critical and controlled studies".*

*"All current treatments are symptomatic".*

*"The MRC should call for research into this field, recognising the need for a wide-ranging profile of research".*

*"An independent scientific committee must examine the wealth of international research data. To exclude it from the debate is a great injustice to patients".*

*"We recommend that this condition be recognised as one which requires an approach as important as heart disease or cancer".*

*"There is no compelling evidence that it is purely psychosocial".*

*"The Group believes that the MRC should be more open-minded in their evaluation of proposals for biomedical research into CFS/ME and that, in order to overcome the perception of bias in their decisions, they should assign at least an equivalent amount of funding (£11 million) to biomedical research as they have done to psychosocial research".*

"*It can no longer be left in a state of flux and these patients should expect a resolution of the problems which only an intense research programme can help resolve".*

Whilst there will be some people who may be disappointed that more weight was not given to the wealth of existing biomedical evidence, the UK ME/CFS community owes a debt of gratitude to Dr Ian Gibson MP and to most of his committee members for agreeing to tackle such an immensely complicated issue. It is a remarkable achievement that, considering the difficulties under which they laboured (especially the total lack of funding) and the opposition that they faced, they have produced such a valuable Report that must surely help to move matters forwards in the direction that will best support and help -- and not damage – patients who have been so abused for so long.