AIRA Inc

Allergies & Intolerant Reactions Association
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ABN 52 493 877 325

15 April 2010

MCS Report,
NICNAS,
GPO Box 58,
Sydney NSW 2001

AIRA Inc (AIRA) was formed in Canberra in the early 1980s to provide individual support and advocacy as well as systemic advocacy for people with allergies and intolerant reactions, including to small amounts of substances which do not appear to bother others. This includes those people now identified as suffering from multiple chemical sensitivities (MCS).

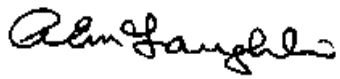
AIRA members recognise that the final draft released in February 2010 is much improved from the previous one. We find it less biased towards the psychological position and support it including reference to management strategies such as avoidance. However, we consider that further work is needed for it to be a rigorous and useful scientific review.

We value and support the detailed submissions which identify and provide evidence regarding errors and omissions relating to evidence and deductions in the final draft. These include those from Dr. Martin Pall, MCS Australia, ASEHA and ACTA.

Our AIRA's objectives with this submission are to draw attention to the context of the review, to explore the barriers to its effectiveness and to suggest ways to improve the effectiveness of its communication. We make a number of recommendations which are discussed in detail below:

We would be happy to clarify any aspect of this submission.

Regards



President

Context of the review

We recognise that undertaking this review is courageous in the politically "risky" sense. It gives the Australian government the opportunity to do what is right and to give justice to those who need it.

We believe that MCS is a physiological condition which can include some psychological impacts directly and indirectly: as part of the symptomatology in some cases and as a consequence of having the condition.

There are two opposing positions relating to initiation and continuation of MCS and other conditions such as myalgic encephalomyelitis/chronic fatigue syndrome ME/CFS, irritable bowel syndrome (IBS), Gulf War syndrome (GWS). We welcome the fact that this review considers these positions in detail. However, we don't believe that the evidence for MCS being a psychological condition is as strong as it is portrayed in the draft report.

The position of those supporting a physiological basis to MCS and other conditions is often misrepresented as rejecting any acknowledgement of psychological impacts. What we reject is that the condition is always caused and maintained by psychological mechanisms; for example, conditioning, phobias or faulty illness beliefs. What we recognise is that psychological symptoms can be a part of the symptomatology or as a consequence of the condition.

There are powerful individuals and organisations with financial vested interests in the outcome of this review. These include the pharmaceutical, chemical and polluting industries, as well as insurers carrying liability for injuries or treatments generally. In particular, in some cases, the liability can be higher for mental than for physical conditions. Such individuals and organisations can impact on the review directly by their submissions (anonymous or otherwise) and indirectly by funding published research.

What may be less obvious is the effect of people and organisations without such financial vested interests who nevertheless do not reflect impartially on the situation. This can occur whether they are part of the input to the process or those deliberating in the review. The history of science and medicine has many examples of good quality evidence which is ignored by others for short or long periods. There may be many reasons such as not looking for the evidence, not willing to believe it because it doesn't fit with preconceived ideas or disdain for proponents. Those doing that may in fact be people of good will, be caring and dedicated practitioners, be respected and influential professionals. Nevertheless, peer-reviewed published literature and "generally accepted wisdom" are not immune from their influence.

The report of the review will be read and acted on by non-scientists and non-bureaucrats. This includes individual citizens, administrators and policymakers on all the areas on which MCS impacts. It is therefore very important that the language and style be comprehensible by a wide range of readers.

Barriers to the effectiveness of the review

There has been ongoing discussion in prestigious medical journals questioning selection of articles and the effectiveness of peer review, as we raised in our previous submission.

1. Please be aware that publication in a prestigious Journal does not make the article unable to be challenged.

The impact of the current body of work by those holding the psychological position is apparently enhanced by their repeated citations of their own and each other's work as well as by failure to address positions which conflict with theirs.

2. Please ensure that all citations/references which are relied upon for the final report's recommendations and conclusions be tested for ongoing validity by identifying and, if necessary, examining subsequent documents, especially peer-reviewed Journal articles, which cite them.

In our experience, reports written about our situations are rarely totally accurate, unless we get to edit them before completion. We sometimes wonder if this is caused by inadequate attention to detail or unjustified reliance on memory by report writers. In any case, this may apply to both those who are acting with goodwill towards us and those who appear not to be doing so. Presumably the processes used for scientific reviews would reduce such inaccuracies but the tendency should always be watched for.

3. Please ensure that the report is exhaustively checked for accuracy.

We are concerned that there may be unrecognised conflating and confounding of factors and logical progressions.

4. Please ensure that all deductions and recommendations are logically and evidentially supported.

The draft report refers to unpublished consultations with unnamed practitioners. We find it difficult to believe that at least some elements of the summary of consensus findings would reflect involvement of the range of views known to be held about this condition. This raises the possibility that the consultations were either not with an appropriately wide group or were not properly reported. In any case, we believe that a rigorous scientific review should only be influenced by published materials which can be scrutinised.

5. Either all references to the consultations should be deleted from the review OR the consultation report, including the names of the participants, should be published and the citation should be included in the review report.

We are concerned that there is inadequate discussion of environmental medicine units, such as that of Dr. William Rea in Dallas, Texas. We doubt that Australian units were shut down because "the treatments provided by the facility were not effective" (page 58) even if that is what some

people thought. There was no general physician listed as a consultation participant on page 65. We would be concerned if Dr. Colin Little (a general physician with extensive knowledge and experience in MCS) has not been involved.

6. We urge the review to consider the published materials by Dr. William Rea from Dallas Texas including four published volumes and Journal articles.

Effectiveness of the review's communication

It is difficult for some readers to usefully access PDF files, for example, due to vision impairment or to the difficulty of using comparison and commenting tools, especially when changes can only be accessed by hovering over markers.

7. Please provide the current draft as well as the final version in RTF format.

There are a number of terms which are surprising (such as the use of the term "chemical species" on page 10). Others are Not clear (such as the use of the terms "naive" on page 28, "behavioural state" on page 30, "multifactorial model of disease" on page 59 and "interplay" on page 62). Another is not yet acceptable terminology (the term biological to incorporate psychological).

We suspect that there are significant aspects of the expression "mode of action" which are not addressed in the brief description in the text. In particular, the text on page 8 " An understanding of mode of action and specifically how chemicals initially interact with organ systems would be assisted by more detailed identification of the chemical species and the exposure scenarios responsible for symptoms in MCS" appears to exclude reference to the actual interaction in the body.

8. Please provide a detailed explanatory glossary of terms, in plain English.

Some citations in the text are incorrect, for example groups Goudsmit and Howes should be 2008 on page 43. Not all citations in the text have accompanying reference details. This includes the reference on page 8 "An Australian clinical review", Randolph on page 10, "local lymph node assay" on page 45 and "An animal model of SBS" on page 46. We also question whether the use of "anonymous" for the reference on the Canadian clinical guidelines should be replaced by the actual authors.

9. Please ensure that all reference details are included correctly.

Judgements or conclusions may not be evidenced in the text. We cite the example on page 7: "Although non-specific neurological symptoms are common, overall there is no characteristic symptom profile that identifies MCS. Nevertheless, reported symptoms can, in some cases, be debilitating". The word "nevertheless" seems to be irrelevant and unnecessary and undermines the significance of the symptoms being debilitating.

10. Please ensure that the expressions used properly reflect the meaning and weight of the evidence on which they rely.

In some cases, proposals are not spelt out in enough detail. For example on page 9 "The development of a clinical education program should be investigated. Such a program should be based on evidence currently available, utilise any findings from clinical research in Australia (such as a longitudinal investigation) and consider the practical guidance on approaches to MCS clinical management agreed by participants in the recent clinical review of MCS." Does not include any anecdotal evidence currently available other than from the participants in the recent clinical review. It also seems to exclude further clinical research from overseas.

11. Please ensure that all sources of evidence and guidance for the proposals are included.