Submission No 26

THE PROMOTION OF FALSE OR MISLEADING HEALTH-RELATED INFORMATION OR PRACTICES

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Committee on the Health Care Complaints Commission

Parliament House , Macquarie St Sydney NSW 2000

I have reasons to be concerned about this inquiry and its intentions as it may well affect me personally and professionally.

At the moment I am a registered health service provider as a psychologist. I am also Vice-President of the Medical Consumers Association (MCA), a position I have held since my earlier role as a lecturer in Health Services Management UNSW. I was also authorised under the Public Hospitals Act to look into medical/surgical practices, including deaths. And finally, like most people, I am occasionally in the role of medical/dental patient.

- In my role as a psychologist I may have some exemptions under the claimed focus only "on individuals who are not recognised health practitioners". But it would seem illogical to extend this exemption beyond my areas of expertise and experience. So where would we draw the line? Could I comment on Psychiatry or Surgery?
- In my role as a lecturer it was my job to research and review medical practice. My employment in the Medical Faculty gave me some exemption, but I was employed as a researcher and health economist, not as a provider of health services.
- To fulfil my voluntary role with MCA it becomes necessary to make submissions such as this one. In some cases the information I present is likely to be related to "general community mistrust of, or anxiety toward, accepted medical practice".
- As a NSW government investigator it was my duty to report on things that had already generated "community mistrust of, or anxiety toward, accepted medical practice". The statutory NSW Psychosurgery Review Board that employed me was not a provider of health services.
- And as a patient I clearly fall into none of the above categories. I have never studied dentistry. But I have spent time in a dental chair. If something went wrong or if I read that some practice I had undergone had been reviewed internationally as unsafe it would seem a public duty to warn so the next patient is not affected. The same applies to any other treatment or remedy. And as a patient, dead or alive, I might be the last to know anything went wrong. It might be my family or one of the staff who becomes the whistleblower.

These are not abstract considerations for me. I have concerns because of the way I had been dealt with in the past in these roles. I was threatened and it became the subject of NSW Parliamentary speech and news commentary.

If I retire as a psychologist or even merely quit the profession for other pastures I could lose my exemptions and fall afoul of extended investigatory powers merely for continuing to ask the same questions that any other member of the public would be eligible to do. The current federal registration of psychologists specifically forbids those who retire or deregister from having any voice*: "For the purposes of this registration standard, practice is not restricted to the provision of direct clinical care. It also includes using professional knowledge in a direct nonclinical relationship with clients, working in management, administration, education, research, advisory, regulatory or policy development roles, and any other roles that impact on safe, effective delivery of services in the profession"*. Psychology Board of Australia).

People within the science and medical community commonly deter people from “accepted” treatments when they make new findings. That is their job.

The United States courts have long recognised this. The landmark decision, Daubert v. Merrill Dow Pharmaceuticals, 509 U.S., 113 S.Ct. 2786 (U.S. Supreme Court, 1993), forced the US courts to significantly revise the earlier Freye concept of " general acceptance in the field” and force the courts go back to basics and examine the claims of scientific credibility in the following terms:

- technique "can be (and has been) tested … can be falsified”;
- "subjected to peer review and publication“
- "known or potential rate of error . . . existence and maintenance of standards controlling the technique's operation“
- per Frye " general acceptance in the field”

This was a clear concession that relying on peer networks reflecting accepted practice of the day is inadequate.

As an example fundamental to psychology in recent years there has been renewed focus on the relative merits of “talk therapies” versus “drug therapies”. Publication bias can create what is taken as the accepted practice at the time. Yet there is evidence and now controversy over whether there has been extensive publication bias in favour of pharmaceutical industry-funded research. Those who question the medication treatments might be made more vulnerable to exclusion as part of the science and medical community.

So these so-called ‘protections’ are extremely selective. And they have been used in precisely these ways in the past to stifle criticism of medical excesses such as lobotomies, narcosis and deep sleep therapy.

In my official role as a government investigator a central issue was the “accepted practice” of the day as currently stated by the RANZCP

- *“There is no evidence to suggest that patients will demonstrate any decline in intellectual functioning following such surgery using modern techniques ”* [1]

This is an official statement from what could be regarded as the voice of the Australian science and medical community. Yet it is directly in opposition to the foundations of neuropsychology in Australia, much of which arose from studies of psychosurgery patients[2].

Any group that cautioned against having a lobotomy might be at risk for raising concerns. It would be cold comfort for neuropsychologists to be able to claim exemption on the grounds of being members of the science and medical community if these protections did not extend to others who chose to cite and prefer their neuropsychology position over that of psychiatry. It might deter people from having the “accepted” treatment of lobotomy which Australian doctors sometimes claimed raised IQ.

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[1] RANZCP Position Statement #29 Neurosurgery for mental disorders October 2009 https://www.ranzcp.org/Files/ranzcp-attachments/Resources/College_Statements/Position_Statements/ps29-pdf.aspx

[2] Hohne HH,; Walsh KW. (1970) Surgical modification of the personality. Melbourne: Mental Health Authority; Turner, E.H., Matthews, A.M., Linardatos,B.S., Tell, R.A. & Rosenthal, R. (2008). Selective publication of antidepressant trials and its influence on apparent efficacy. New England Journal of Medicine. 358 (3): 252-260

This is no exaggeration as that is precisely what happened to the Chelmsford victims who complained publicly about their psychosurgery experiences. They were frequently mentioned in the same sentence as Scientologists and aspersions were cast on researchers probing these allegations during the Mental Health Royal Commission.

The exemptions for what is regarded as “legitimate discussions and studies” needs to be broad so that it does not infringe free speech. Lay groups have been prevented from access to the Mental Health Royal Commission archives, which are only available upon endorsement by a 'recognised ethics committee'. This wording even excludes access to the patients themselves and researchers who provided the information to the Royal Commission. Indeed, I had to use FOI to access the very report I had written! Successive NSW Ministers for Health subsequently described this as a “cover-up”.

So it is quite common policy in Australia to selectively use exclusions to stifle criticism and review. Based on many such experiences I am concerned that any new powers might be used in such ways rather than in actually protecting the public.

The provisions are ambiguous and open to abuse as to which persons or organisations are given free speech rights as accepted members of the 'science and medical community'. Good examples of borderline cases are the Australian Broadcasting Corporation and the National Heart Foundation of Australia. Neither are health service providers.

The ABC science program Catalyst aired a two-part documentary, The Heart of the Matter, 24th October, with an audience in millions. The ABC review show, Media Watch, was then sceptical of the programme, as was the National Heart Foundation of Australia. None of these is specifically an official science or medical organisation.

If such organisations are to run afoul of future changes in information laws who would decide which of them, if any, would be protected by exemption? Would it be only those who followed the most orthodox of the orthodox line? In the cholesterol example, there is clearly some debate within the medical community so one could be critical while still accepting some medical opinions.

The same logic applies to the several allegations of medical scientific fraud raised by Dr Norman Swan in earlier ABC Science shows and countless other medical controversies such as psychiatric labelling of behavioural conditions such as dyslexia and attention deficit disorder. These diagnoses are sometimes accompanied with drug treatments and the stakes run into many millions of dollars and thousands of careers, not to mention the issues of prescribing drugs to young children. There are many critics from within the medical profession. Will protections and exemptions only be extended to those who follow the most orthodox of the orthodox line at the time? And what if the orthodox line changes, as it did with stomach ulcer? Will there be redress and reinstatement?

Patients and those directly affected by it should have some right to publicly question their treatments and outcomes. If this brings the treatment or methods of diagnosis into disrepute so be it. The practitioner defamed has remedies in law.

Term of Reference (c) the promotion of health-related activities and/or provision of treatment that departs from accepted medical practice which may be harmful to individual or public health;

The issue presumably being considered in this term is that rival practitioners or groups with non-scientific motives might broadcast false information to discredit orthodox competitors with a motive of promoting their own treatment or service. There is a long history of such concerns since the beginnings of modern registered medicine. It works both ways. Some supposed 'medical foundations' have strong commercial sponsorship links.

And some ardent critics of medicine have traditionally been religious organisations that are clearly not official science or medicine. Does implied freedom of religion imply freedom to criticize medicine? The interchange between Medicine and the Christian Scientists has been [3] ongoing for over 100 years. Some of these concerns might already be covered by Common law and Criminal Law if the usual factors such as motive and reckless indifference to evidence and harm could be provable. Prosecutions have been mounted in Christian Science cases[4].

Regarding the assurance that *"Nor will it inquire into the many legitimate discussions and studies taking place within the science and medical community"*

There is ample historical reason for concerns that such wording could be used to silence those outside this orthodoxy. The word "community" would be preferable. We have numerous current examples of how the local science and medical communities have abused such distinctions in the recent past. The Psychologists Registration provisions show how easy it is to banish someone from these supposed communities with a stroke of a pen.

Many of medicine's greatest critics have themselves been doctors. Medicine changes frequently. Stomach ulcers were once regarded as psychosomatic disorders. An Australian patient had a lobotomy on the basis of this supposed link, now disregarded by subsequent research.

The benefits of assumed protections against presumed -guilty medical misinformation however well-intended might be outweighed by the restrictions on free speech. Lord Hewart put the issues very well in 1928: *"..the decision of a Court is in every important respect sharply contrasted with the edict, however benevolent, of some hidden authority, however capable, depending upon a process of reasoning which is not stated and the enforcement of a scheme which is not explained. The administration of the law of the land in the ordinary Courts presupposes, at least, personal responsibility, publicity, uniformity, and the hearing of the parties."*

Sincerely

[redacted]

T Benjamin

[3] http://www.nytimes.com/2010/03/24/nyregion/24heal html?_r=0
[4] Commonwealth v. Twitchell, 416 Mass. 114 (1993) USA