

Psychiatrists Revise Diagnostic Manual – In Secret

Robert L. Spitzer, M.D.

Professor of Psychiatry, Columbia University

Former Chair of Work Group to Develop DSM-III and DSM-III-R

Email address: Spitzer8@verizon.net

There is great interest in the development of DSM-V. Perhaps the best-kept-secret about DSM-V is that rather than being “an open and transparent process” as has been claimed by the American Psychiatric Association leadership (Rabinowitz, Psychiatric News, June 6, 2008) it will essentially be developed in secret. This became apparent when Darrel Regier, Vice Chair and David Kupfer, Chair of the DSM-V revision, informed me that they would not let me have the minutes of DSM-V Task Force meetings, as I had repeatedly requested (Email Regier to Spitzer, February 23, 2008). They said this was because the Board of Trustees of the American Psychiatric Association believed it was “important to maintain DSM-V confidentiality.” All DSM-V Task Force and Work Group members are therefore required to sign a “confidentiality agreement” which prohibits members from disclosing anything about DSM-V to anyone. The only exceptions are if the Task Force or Work Group member believes that the disclosure is “necessary for the development of DSM-V”, the material has already been published by the APA or the DSM-V leadership has given permission for the disclosure.. Although the actual confidentiality agreement that members sign does not mention minutes of Task Force and Work Group meetings, the refusal of the DSM-V leadership to let me (or anyone else) have access to the minutes of DSM-V meetings is a logical consequence of the confidentiality agreements that all DSM-V members sign.

It should be noted that in contrast to this new APA confidentiality policy, which discourages DSM-V members from providing information about the ongoing revision process, the World Health Organization has adopted the opposite policy with regard to its development of ICD-11. Minutes of all ICD-11 meetings are posted on the WHO website without any restrictions on who can have access http://www.who.int/mental_health/evidence/en/.

Ever since I became aware of this new DSM-V policy, I have tried to understand its justification and purpose by exchanging email letters with the APA and DSM-V leadership, and by an exchange of letters in Psychiatric News (Quotes in *italics* are from these letters which are all available on a web site generously developed by Mike Miller http://taxa.epi.umn.edu/~mbmiller/sscpnet/20080909_Spitzer/

According to the APA and DSM-V leadership, an important benefit of the confidentiality agreements is that it... “allows Task Force and Work Group members to...freely discuss and candidly exchange their views with others in their Work Group or the DSM-V Task Force without concern that those initial and perhaps tentative views will be made public.” This is ludicrous. It has never been seen with previous DSM revisions. It is hard to imagine a distinguished DSM-V researcher or clinician being reluctant to speak candidly because of such concerns. I have seen Task Force and Work Group members in previous revisions concerned that their contribution to the revision was not made public but never that is was.

The DSM-V confidentiality agreements "...protect APA rights." This is puzzling. APA owns the copyright to all DSM publications. What rights might be in jeopardy??"

"The current confidentiality agreements are narrow and ensure the integrity of the process used to develop DSM-V" Narrow? Here is what it covers: I will not, during the term of this appointment or after, divulge, furnish or make accessible to anyone or use in any way ...any Confidential Information. I understand that "Confidential Information" includes all Work Product, unpublished manuscripts and drafts and other pre-publication materials, group discussions, internal correspondence, information about the development process and any other written or unwritten information, in any form, that emanates from or relates to my work with the APA task force or work group.

Another benefit of the confidentiality agreements...avoids incomplete and inaccurate information from being disseminated and misused. Sure – but that can happen with the final official DSM-V. The solution is not secrecy but an effective public affairs committee that quickly responds to inaccurate or unfair accounts of DSM drafts..

Why minutes of the work group are not being distributed outside the work groups ...for a number of reasons that were recommended by our attorney. No response to a request for one of the reasons.

It should be noted that I never received an answer when I asked for examples of problems with the development of DSM-III, DSM-III-R and DSM-V that the Confidentiality Agreements are designed to avoid.

I return to the beginning claim by the APA that the development of DSM-V is "transparent and open." The Merriam Webster's dictionary defines transparent as "characterized by visibility or accessibility of information" and this is how the term is commonly used. The APA has provided the names of all of the DSM-V committee members, as well as information about each member's financial relationships with the pharmaceutical industry. This information is available to anyone interested. Thus, it is accurate to characterize the "who are the members of the DSM-V committees" aspect of the DSM-V revision as being transparent. However, by not making minutes of meetings available to all but a relatively few DSM-V insiders, the DSM-V revision process – what is discussed, what options were considered, who supported a particular viewpoint - is largely opaque.

The DSM-V revision process could easily become transparent by simply putting the minutes of all meetings and conference calls on the DSM-V Website. Dr. Regier claims that posting minutes on the DSM-V Website would require APA to spend "an inordinate amount of time and energy dealing with every spontaneous response that someone might make to even considering certain diagnostic issues." Making the DSM-V process transparent by posting the minutes on a public web site, as the WHO does for the ICD-11 revision groups, does not obligate the APA to respond to "every spontaneous response"? How much time does it take to ignore a crackpot blog posting? If in fact there is an increased need for staff support to deal with the consequences of transparency, that is money well spent. Another precedent here is the President's Council for Bioethics, which posts transcriptions of its meetings online:

<http://www.bioethics.gov/transcripts/>

Outside review of DSM-V should be ongoing and begin early in the revision process, not after all the decisions have been made. It is clear that the confidentiality agreements are limiting critical review of the DSM-V revision – and perhaps this is the true motivation for instituting this unprecedented new policy. Unfettered critical review by colleagues – a foundation of science - should be encouraged – not discouraged. A Task Force or Work Group meeting that properly has a scientific discussion that is focused on methodological, empirical and practical issues should have nothing to hide from the public.

It is ironic that one of the most widespread (and in my view unfair) criticisms of DSM-III and progeny has been the process of decision-making by committee. This silly new “confidentiality” policy plays right into the hands of these critics and fuels cynicism about the decision-making process - except that in this case, in contrast to decision making for the revision of prior DSMs, the cynicism may be well justified.

The Board of Trustees of the APA will only reconsider this new policy if large numbers of mental health professionals protest the new policy and demand that the minutes of regular conference calls and meeting be made available to anyone interested.

With the help of Scott Lilienfeld and Jerry Rosen (psychologists), John Sadler (psychiatrist) and Jerome Wakefield (social worker) an online petition will be developed (with Mike Miller’s help) that will call on the American Psychiatric Association’s Board of Trustees to open the DSM-V revision process by placing minutes of Task Force and Work Group conference calls and meetings on the DSM-V website.