Society of Indian Psychologists

July 18, 2011

David J. Kupfer, M.D.
Chair, DSM 5 Task Force
3811 Ohara Street
Pittsburgh, PA 15213-2593

Dear Dr. Kupfer,

We are sending this letter on behalf of the **Society of Indian Psychologists**, a professional society of psychologists, medical professionals, social workers, drug & alcohol counselors, marriage and family therapists, and community counselors who work in areas related to American Indian Psychology. We are deeply concerned about the proposed changes in the *Diagnostic and Statistical Manual* that could contribute to an alarming artificial increase in mental health disorders in a population that already has the highest rates of mental health disorders in the United States, or that otherwise distorts our understanding of the problems and strengths that co-exist among these populations.

The **Society of Indian Psychologists** has a number of general and specific concerns, some of which are highlighted in this letter. We are highly dissatisfied by the frequent references to Field Trials as a substitute for clear standards, finalized before the field Trials, and based on a thorough review of all the relevant mental health literature. Indeed, the vast literature in reference to how identity and mental health are mutually co-informed and the role of cultural context in identifying mental illness has been ignored in the drafting of DSM-5.

1. Multicultural Validity and Utility

The Gender and Cross-Cultural Issues Study Group had one woman and no Native American members. It is not clear which cultural principles were considered, since socio-economic and cultural causes for behaviors were not included in any of the considerations for diagnosis. The absence of social, political and cultural contributors to symptoms in the diagnostic criteria ignores a huge literature on the importance of those factors in mental health. It is well established in the research literature that the failure to take these factors into account can result in an increase of false positives and outright mistakes in the accurate diagnosis of ethnic minorities. In this respect, the DSM-5 is many steps backwards from the DSM-IV. It is unfortunate and

unethical that the Task Force decided to ignore this literature, as the DSM-5 is a product that the insurance companies will likely insist that mental health professionals use for all ethnic groups in this country.

The world owes a debt of gratitude to the APA for its leadership in the development of the DSM. However, the DSM-5 is not an internal APA document. It is a service that psychiatry offers the world and is used by the full range of mental health professionals as well as primary care physicians.

There is a startling absence of mental health disciplines other than psychiatry within the groups that developed the DSM-5. The discipline of psychiatry represented 90% of the members across the Task Force, Study Groups, and Work Groups. Psychiatrists are among the smallest of the groups of mental health professionals who use the DSM. To treat the DSM as the privileged domain of predominantly White, predominantly male, U.S. psychiatrists is to abdicate responsibility for how the DSM is used in the U.S. and around the world. The DSM-5 illustrates a dangerously narrowed point of view in the continued evolution and development of the art and science of diagnosis, which could result in this DSM being considered parochial and of limited relevance. This is not a scientific path, nor one that speaks to advancing an understanding of the human mind, of mental health or of human well-being.

2. Concerns with Scientific Rigor – Diagnoses

The clinical validity of a number of the diagnoses is in question, even by the DSM-5 Work Groups (as stated on the web-site descriptions). For example, there have been no systematic studies to determine the clinical validity of: Attenuated Psychosis Syndrome, Substance-Induced Psychotic Disorder, Disruptive Mood Dysregulation Disorder, Complex Somatic Symptom Disorder, Autism Spectrum Disorder, Premenstrual Dysphoric Disorder, Gender Dysphoria, Gender Dysphoria in Children, Genito-Pelvic Pain/Penetration Disorder, Post-Traumatic Stress disorder in Preschool Children. *(List not comprehensive.)* Nonetheless, these diagnoses are being field tested for reliability before clinical validity has been established.

A brief summary of our concerns are as follows. This is not a comprehensive list of our concerns.

Attenuated Psychosis Syndrome – This category has an alarmingly low threshold with NO longitudinal research supporting its clinical validity or specificity to avoid false positives. There is a great risk of stigmatizing ethnic minority and recent immigrant populations, who may have culturally based ways of expressing distress and concern that are unfamiliar to psychiatrists, who are overwhelmingly White and middle-to-upper class.

Substance-Induced Psychotic Disorder – There is no description for this disorder. Yet, it is being field tested.

Substance-Induced Anxiety Disorder - There is no description for this disorder. Yet, it is being field tested.

Substance-Induced Obsessive-Compulsive or Related Disorders - There is no description for this disorder. Yet, it is being field tested.

Substance-Induced Dissociative Disorder - There is no description for this disorder. Yet, it is being field tested.

Substance-Induced Sexual Dysfunction - There is no description for this disorder. Yet, it is being field tested.

Disruptive Mood Dysregulation Disorder (Depressive Disorders) – There is no research showing the validity of distinguishing frequent temper outbursts from variable expressions of depression, personality disorders, epilepsy, dementia, or general lack of social and personal competence. This diagnosis could absolve people from taking responsibility for their subjective interpretations of events that others do not "dysregulate" around. It could also be used in forensic settings to excuse violent behavior stemming from those temper outbursts, such as hate crimes.

Complex Somatic Symptom Disorder - The definition of the pain element in this category is vague, with no guiding criteria. The symptoms that are listed are not well defined, leaving a lot of room for subject judgments that could mislabel cultural ways of dealing with pain.

Autism Spectrum Disorder – Prior discrete disorders have been collapsed into this new unified category, leaving less specificity for the group of these disorders in children. There is not a consensus on this among child clinicians and researchers. The Severity Scale for this category has not been tested for validity in identifying the children who might be excluded due to the collapse of the category. The Severity Scale ignores the sensory processing challenges exhibited by many children with these disorders. The different disorders require different interventions and different intensity of interventions. Autism 1, Autism 2, and Autism 3 can restrict services schools are willing to offer to children. The diagnosis of Autism 1 places a very serious label on children who previously would not have been identified as autistic.

Premenstrual Dysphoric Disorder – It has not been definitively established that this is a real and discrete disorder of the brain as opposed to a hormonal imbalance that may affect the brain, much like thyroid imbalances. Yet, hyper-thyroid and hypo-thyroid conditions are not in the DSM-5. Is the next inclusion to be Prostate Dysphoric Disorder, when men become frightened, depressed, and anxious (real disorders of the brain benefitting from treatment) when they find out they need surgical intervention to treat their prostates? Can the labeling of Menopause as a mental disorder be far behind?

Gender Dysphoria & Gender Dysphoria in Children – At one time, the APA considered homosexuality as a mental illness. It is not at all clear from the research that these diagnoses represent a real disorder of the brain as opposed to a subjective interpretation of the highly variable process of sexual identity development. The inclusion of children and adolescents in this possible diagnosis is of particular concern. The symptom lists and severity scales include variations in human sexuality development. This category has not been adequately researched for clinical validity.

Genito-Pelvic Pain/Penetration Disorder – This diagnosis confounds physical pain with mental pain in the same category. The description implies that physical pain upon intercourse indicates mental illness. Cultural and religious factors that could contribute to the expressions of pain are not included, thus running the risk of pathologizing groups of cultural and religious women, as well as women who have suffered vaginal mutilations.

Post-Traumatic Stress Disorder in Preschool Children - There is not consensus among the Work Group on the criteria. This diagnosis will have severity indicators but they are not there yet. Nonetheless, this is being field tested.

Posttraumatic Stress Disorder - For children, the inclusion of the loss of a parent or other attachment figure is being considered. How is the data for this going to be gathered? In the Field Trials that measure inter-rater reliability? Mixing criteria for adults and children in the same symptoms checklist, disregards developmental stages that influence how a person reacts to trauma and grief. The severity rubric focuses on the symptoms most likely to be seen in adults. The web-site states, *"The optimal number of required symptoms for both adults and children will be further examined with empirical data."* How? The Field Trials are testing inter-rater reliability, not clinical validity.

Grief – The treatment of grief in the DSM-5 is of particular concern. As has been pointed out by others, debilitating grief that lasts more than two months may be given the diagnosis of Major Depression. For a child, the loss of a parent may be diagnosed as Post Traumatic Stress Disorder. In previous responses to this, Dr. Regier has stated, "Watchful waiting is (an *sic*) important tool for all skilled clinicians. As a good internist might adopt a watch and wait attitude toward a diagnosable upper respiratory infection assuming that it is unlikely to progress to a pneumonia, so a good psychiatrist, on seeing an individual with major depression after bereavement, would start with a diagnostic evaluation." This response does not address our concern that the majority of distressed people never see a psychiatrist, particularly in Indian Country. Even for psychiatrists, the recognition of cultural variations in the expressions of grief is imperative. These cultural elements are unlikely to be recognized in the typical 15-20 minute psychiatry visit. Once again, the lack of consideration of cultural factors in the descriptions of diagnoses is likely to generate many false positives.

Other/Unspecified - Almost all the diagnostic families include non-specific diagnoses with no criteria. They are not in the Appendix, indicating a need for further research. Yet they are being field tested. For example:
Unspecified Anxiety Disorder
Unspecified Psychotic Disorder
Unspecified Catatonic Disorder
Other Specified Trauma- or Stressor- Induced Disorder
Unspecified Trauma- or Stressor- Related Disorder
Unspecified Gender Dysphoria
Unspecified Paraphilic Disorder
Other Specified Paraphilic Disorder
Unspecified Disruptive or Impulse Control Disorder

3. Concerns with Scientific Rigor – Severity Scales

Most of the proposed severity indicators and suggested "tests" have not been thoroughly vetted and do not have psychometric reliability, although they may someday. They have been introduced in the draft of DSM-5 for the first time. Although they do not have established clinical validity, they are already being tested for inter-rater reliability in the Field Trials.

Personality disorders – The Work Group reported on the web-site that the Levels of Personality Functioning Scale was validated through literature review. This statement is alarming, since even beginning researchers know that a literature review establishes theoretical consistency. Validity is only established through population studies that prove the psychometric qualities are congruent with the theoretical intent. The Levels of Personality Functioning Scale is being tested through the Field Trial process for inter-rater reliability before validity has been established although the *Work Group stated on the web-site that further research on validity, reliability and utility is needed*.

Anxiety Disorders - There is a proposed severity measure that cuts across all Anxiety Disorders, which will take the place of separate, already validated measures. This measure has not been validated for either generalizability or specificity. It is being tested through the Field Trial process for inter-rater reliability.

Schizophrenia Spectrum Disorders – Once again, the descriptions are not finalized and yet they are being field tested. For the Classification of Longitudinal Course for Schizophrenia, the course specifiers "are to be worked on"! There is a 9-dimension rubric to rate severity across the spectrum. The clinical validity and specificity of this rubric has not been established. It is being tested through the Field Trial process for inter-rater reliability.

Schizotypal Personality Disorder - The web-site indicates that this disorder will have severity indicators but they are not there.

4. Concerns with Scientific Rigor – Field Trials

The symptom lists have not been finalized. The wording of many options on the various symptom lists has not been finalized. Many of the severity scales have not been tested for clinical validity. Having skipped the establishment of clarity and validity in the new diagnostic categories, the Field Trials are focused on "feasibility, clinical utility, and sensitivity/ responsiveness to change." We are dissatisfied that the Field Trials are basically inter-rater reliability studies that reify incomplete and outdated cultural frameworks and do not take into account solid multicultural as well as epidimiological research that emphasizes the necessity to do otherwise.

As taken from the web-site:
All assessment tools that will be utilized in this study (i.e., patient- and clinician-rated forms) will be available only in electronic forms. These assessment tools will include the cross-cutting dimensional measures *(non-validated)*, the DSM-5 diagnostic checklist *(with the wording still in*

flux), the list of diagnostic-specific severity measures *(non-validated),* and the Clinical Utility Questionnaire. The feasibility of these assessment methods will be pilot tested prior to the start of the Field Trials. *(Italics ours.)* Even so, we are concerned that clinical utility has not been adequately explored for clinicians who are not psychiatrists, including family practice physicians, who treat the majority of ethnic minority members.

The Field Trials are designed to include 5,000 mental health professionals, 2,500 of them psychiatrists. This means the trials will be heavily weighted to large urban areas and middle to upper class populations who have access to psychiatrists. Clients must be able to use computers to be in the Field Trials. The methodology of the Field Trials has not been inclusive of rural ethnic minority populations, who have much higher percentages of poor and non-computer literate members. There is no outreach for rural and reservation settings.

The face-to-face unit of the Field Trials consists of structured interviews that ask direct questions. The previously mentioned large multicultural literature that the Task Force chose to ignore emphasizes that there are many people for whom interview-style questioning bares little cultural relevance. In these populations, the structured interview cannot ascertain the nature of human mental suffering.

5. Forensic Concerns

For a number of diagnoses, including Disruptive Mood Dysregulation Disorder mentioned above, it appears that the potential for forensic misuse has been over looked. This is of grave concern to us, as Native Americans are over represented as crime victims in this country. We are concerned that the following diagnoses could offer a spurious and unscientific defense to a perpetrator in a criminal trial.

Paraphilic Coercive Disorder (appendix) - Rape is a crime, not a disorder.

Frotteuristic Disorder – This diagnosis requires three crimes.

Pedohebephilic Disorder – Again, this diagnosis has the potential for excusing pedophilia under the guise of a mental illness.

6. Organization of the Multiaxial System

We are dissatisfied that cultural variation has not been given adequate permeation into the whole of the DSM-5. Cultural fit, cultural context, and a person's spiritual orientation should be given its own Axis every diagnosis. For many minority cultures, the fact of trans-generational transmission of trauma must be understood and considered in every diagnostic assessment.

We are not in favor of the proposed collapse of Axes I – III. The separation of state, trait and medical factors gives much better specificity of diagnoses. The separate axes encourage busy clinicians to look at each category. One combined axis is likely to result in a less complete picture of the patient.

The Society of Indian Psychologists strongly urges you to consider the issues we raise in this letter with regard to the diagnosis and treatment of indigenous populations including American Indian, Alaska Native, Native Hawaiian, Canadian First Nations, Mesoamerican and other indigenous groups. There is great concern that symptoms and behaviors of indigenous patients will be misinterpreted and not considered within their cultural context. We would be happy to provide consultation on these issues from licensed Native psychologists committed to culturally appropriate and competent work with indigenous populations.

Respectfully submitted,

Jacqueline S. Gray, Ph.D.
President
jacqueline.gray@med.und.edu

Melinda A. García, Ph.D.
DSM-5 Response Coordinator
drmagarcia@qwestoffice.net

By moving ahead with the current draft DSM-5 the APA will be bowing to the economic forces driving the current dismal health care picture.