June 14, 2011

DSM-5 Task Force
American Psychiatric Association
1000 Wilson Boulevard
Suite 1825
Arlington, VA 22209

Members of the DSM-5 Task Force,

In response to the most recent request for input on proposed changes to the fifth revision of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), the CFIDS Association of America submits the following statement and urgent recommendation.

Consistent with our comments submitted April 1, 2010, the CFIDS Association strongly questions the utility of the proposed rubric of Somatic Symptom Disorders (SSD) and the subtypes of Complex Somatic Symptom Disorder (J00), Illness Anxiety Disorder (J02) and Functional Neurological Disorder (J03). Rather than improving upon the designation of CSSD after the close of the 2010 comment period, it appears that the working group has made this category even more problematic in the latest revision.

It is again noted that the updated proposal for DSM-5 revision correctly does not identify chronic fatigue syndrome (CFS) as a condition within the domain of mental disorders and the DSM. However, past discussions of the Somatic Symptoms Disorder Work Group have included such physiological disorders as chronic fatigue syndrome, irritable bowel syndrome and fibromyalgia (http://www.dsm5.org/Research/Pages/SomaticPresentationsofMentalDisorders%28September6-8,2006%29.aspx, accessed June 13, 2011) as "somatic presentations of mental disorders." None of the research and/or clinical criteria for chronic fatigue syndrome published since 1988 has established CFS as a mental disorder and a continuously growing body of literature demonstrates CFS to be a physiological disorder marked by abnormalities in the central and autonomic nervous systems, the immune system and the endocrine system. Research published in the last year has provided strong evidence of molecular and cellular markers that may make definitive diagnostic testing possible. Summaries of recent findings are regularly updated here: http://www.research1st.com/promising-cfs-research-findings/.

Based on the rationale statement (http://www.dsm5.org/Documents/Somatic/DSM%20Validity%20Propositions%204-18-11.pdf, draft dated April 18, 2011, accessed June 13, 2011), the proposed construct of SSD and its subtypes appears to serve a single purpose – to increase demand for cognitive behavioral therapies – the treatment identified in the statement as having the most promise for treating conditions that may fall under the new descriptor. It's as if the Work Group is suggesting a "Don't worry – be happy" approach to individuals who appear more concerned about their health than this particular group of professionals

thinks they should be, without regard to what focus on health may be warranted by diminished function and quality of life, or what attention may be essential to obtaining appropriate care in today's fractured and disconnected medical delivery system.

According to the DSM-5 website (http://www.dsm5.org/ProposedRevision/Pages/SomaticSymptomDisorders.aspx) accessed June 13, 2011):

To meet criteria for CSSD, criteria A, B, and C are necessary.

A. **Somatic symptoms**:

One or more somatic symptoms that are distressing and/or result in significant disruption in daily life.

B. **Excessive thoughts, feelings, and behaviors related to these somatic symptoms or associated health concerns**: At least two of the following are required to meet this criterion:

(1) High level of health-related anxiety.

(2) Disproportionate and persistent concerns about the medical seriousness of one's symptoms.

*(3) Excessive time and energy devoted to these symptoms or health concerns.**

C. **Chronicity:** Although any one symptom may not be continuously present, the state of being symptomatic is chronic (at least 6 months).

For patients who fulfill the CSSD criteria, the following optional specifiers may be applied to a diagnosis of CSSD where one of the following dominates the clinical presentation:

XXX.1 Predominant somatic complaints (previously, somatization disorder)

XXX.2 Predominant health anxiety (previously, hypochondriasis). If patients present solely with health-related anxiety with minimal somatic symptoms, they may be more appropriately diagnosed as having Illness Anxiety Disorder.

XXX.3 Predominant Pain (previously pain disorder). This classification is reserved for individuals presenting predominantly with pain complaints who also have many of the features described under criterion B. Patients with other presentations of pain may better fit other psychiatric diagnoses such as adjustment disorder or psychological factors affecting a medical condition

The creation of SSD and its subtypes violates the charges to DSM-5 Work Groups to clarify boundaries between mental disorders, other disorders and normal psychological functioning (http://www.dsm5.org/about/Pages/faq.aspx, accessed June 13, 2011). This is especially true with regard to patients coping with medical conditions that presently lack a mature clinical testing regimen that provides the evidence required to substantiate the medical seriousness of their symptoms. For instance, all of the case definitions for CFS published since 1988 have required that in order to be classified/diagnosed as CFS, symptoms must produce substantial impact on the patient's ability to engage in previous levels of occupational, educational, personal, social or leisure activity. All of the case definitions (for adults) require six months of illness and rely on patient report as evidence of the disabling nature of symptoms,

rather than results of specific medical tests. So by definition, CFS patients will meet the CSSD criteria A and C for somatic symptoms and chronicity.

As drafted, the criteria in b. “Excessive thoughts…” for CSSD establish a “Catch-22” paradox in which six months or more of a single or multiple somatic symptoms – surely a distressing situation for a previously active individual – is classified as a mental disorder if the individual becomes “excessively” concerned about his or her health. Without establishing what “normal” behavior in response to the sustained loss of physical health and function would be and in the absence of an objective measure of what would constitute excessiveness, the creation of this category poses almost certain risk to patients without providing any offsetting improvement in diagnostic clarity or targeted treatment, with the exception of a blanket recommendation for cognitive behavioral therapy.

The rationale document refers to the Whiteley Index for grading severity of these behaviors, but the document does not contain any data from study of the prevalence, duration or severity of the attributions in conditions that may possibly be subject to differential diagnosis with subtypes of SSD. It fails to establish “normal” levels or meaningful cutoffs for interpreting what should be considered “excessive” or “disproportionate” or “persistent.” There are blanks left in the current version of the document for the “impact of different thresholds for criteria B- from Francis” but it is unclear what type of survey or study is linked to this vague reference. It is also unclear whether Francis will be able to provide data about these thresholds specific to known medical conditions that still lack definitive diagnostic tests, those which have a positive prognosis or those uncertain long-term outcomes (because of the lack of longitudinal studies). Making any judgments on the basis of a single classification of all known medical conditions is certainly problematic, if not detrimental to the stated purposes for revising the DSM criteria.

The Somatic Symptoms Disorder Work Group states that patients fitting these criteria are generally encountered in general medical settings, rather than mental health settings (http://www.dsm5.org/Documents/Somatic/DSM%20Validity%20Propositions%204-18-11.pdf, accessed June 13, 2011), further limiting the usefulness of this classification in a manual written primarily for the benefit of mental health professionals.

In its latest draft of the rationale for these changes, the Somatic Symptoms Disorders Work Group has provided confusing language and recommendations regarding evaluation of SSD in the context of conditions that are characterized by “medically unexplained symptoms”:

> “Medically unexplained symptoms are 3 times as common in patients with general medical illnesses, including cancer, cardiovascular and respiratory disease compared to the general population (OR=3.0 [95%CI: 2.1 to 4.2] (Harter et al 2007). This de-emphasis of medically unexplained symptoms would pertain to somatization disorder, hypochondriasis, undifferentiated somatoform disorder, and pain disorder. We now focus on the extent to which such symptoms result in subjective distress, disturbance, diminished quality of life, and impaired role functioning.”

The recommendations go on to state that:

> "This is a major change in the diagnostic nomenclature, and it will likely have a major impact on diagnosis. It clarifies that a diagnosis of CSSD is inappropriate in the presence of only unexplained medical symptoms. Similarly, in conditions such as irritable bowel syndrome, CSSD should not be coded unless the other criterion (criterion B—attributions, etc.) is present."

However, given the lack of appropriate training to professionals in medical and mental health settings about the diagnosis of conditions that rely on patient report and subjective measures (rather than well-recognized signs and uniform objective measurements) and the lack of effective treatments, the degree to which criteria b. behaviors might be evaluated and warranted has not been reported by the Work Group.

For the reasons stated above and the general failure of the proposed creation of the SSD and its subtypes to satisfy the stated objectives of the DSM-5 without risking increased harm to patients through confusion with other conditions or attaching further stigma, the CFIDS Association strongly urges the DSM-5 Task Force to abandon the proposed creation of SSD and its subtypes.

Sincerely,

K. Kimberly McCleary
President & CEO
The CFIDS Association of America