

The CFIDS Association of America

Working to make CFS widely understood, diagnosable, curable and preventable

April 1, 2010

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 an open 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.

The CFIDS Association strongly questions the utility of the proposed rubric of complex somatic symptom disorder (CSSD). According to the DSM-5 website (<http://www.dsm5.org/Documents/Somatic/APA%20Somatic%20Symptom%20Disorders%20description%20January29%202010.pdf>, accessed March 28, 2010):

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

A. Somatic symptoms:

Multiple somatic symptoms that are distressing, or one severe symptom

B. Misattributions, excessive concern or preoccupation with symptoms and illness: At least two of the following are required to meet this criterion:

(1) High level of health-related anxiety.

(2) Normal bodily symptoms are viewed as threatening and harmful

(3) A tendency to assume the worst about their health (catastrophizing).

(4) Belief in the medical seriousness of their symptoms despite evidence to the contrary.

(5) Health concerns assume a central role in their lives

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

The creation of CSSD appears to violate 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 March 28, 2010). This is especially true with regard to patients coping with conditions characterized by unexplained medical symptoms, or individuals 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. Yet, all of the case definitions 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, and by virtue of the lack of widely available objective clinical tests sensitive and specific to its characteristic symptoms, CFS patients may also meet criterion B-4.

As drafted, the criteria 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.

To provide another common example, back pain that is debilitating and severe, with negative MRIs, is still debilitating and severe back pain. A patient in this situation might be concerned about this back pain, might view it as detrimental to his quality of life and livelihood, and might direct time and resources to seeking care from multiple specialists (e.g., neurology, rheumatology, orthopedics, rehabilitation) to relieve it. Each of these specialists is likely to recommend slightly different therapies, compounding the patient's focus on alternative explanations for and long-term impact of decreased function and diminished health. Such a patient could be diagnosed with CSSD, yet no empiric evidence has been provided by the Somatic Symptoms Disorders Work Group that applying the label of CSSD will facilitate communication with the patient, add clinical value to the patient's experience, or improve the care any of these various specialists might provide.

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/ProposedRevisions/Pages/proposedrevision.aspx?rid=368#>, accessed March 28, 2010), further limiting the usefulness of this classification in a manual written primarily for the benefit of mental health professionals.

The Somatic Symptoms Disorders Work Group conveys considerable uncertainty about the impact of this new label, in spite of the charge to all DSM-5 work groups to demonstrate the strength of research for the recommendations on as many evidence levels as possible. The Somatic Symptoms Disorders Work Group states:

"It is unclear how these changes would affect the base rate of disorders now recognized as somatoform disorders. One might conclude that the rate of diagnosis of CSSD would fall, particularly if some disorders previously diagnosed as somatoform were now diagnosed elsewhere (such as adjustment

disorder). On the other hand, there are also considerable data to suggest that physicians actively avoid using the older diagnoses because they find them confusing or pejorative. So, with the CSSD classification, there may be an increase in diagnosis.”

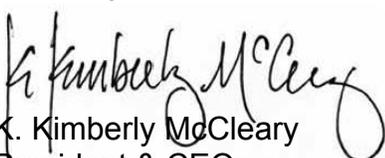
(<http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=368#>, accessed March 28, 2010)

The proposed 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>) as “somatic presentations of mental disorders.” None of the research and/or clinical criteria for chronic fatigue syndrome published since 1988 have 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. The role of infectious agents in the onset and/or persistence of CFS has received renewed attention since the DSM-5 revision process began in 1999. Most recently, the October 2009 report of evidence of a human retrovirus, xenotropic murine leukemia-related retrovirus (XMRV), in CFS patients in *Science* (Lombardi, 2009) has generated new investigations into this and other infectious agents in CFS.

The conceptual framework for CFS detailed in the “Clinical Working Case Definition, Diagnostic and Treatment Protocols” (Carruthers, 2003) serves as a useful tool for professionals to establish a diagnosis of CFS, address comorbidities that may complicate the clinical presentation and distinguish CFS from conditions with overlapping symptomatology. Research on CFS continues to explore and document important biomarkers. Lack of known causation does not make CFS – or the CFS patient’s illness experience – psychopathological any more than multiple sclerosis, diabetes, or other chronic illnesses with objective diagnostic measures, would be so considered.

For the reasons stated above and the general failure of the proposed creation of the CSSD 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 CSSD.

Sincerely,



K. Kimberly McCleary
President & CEO

The CFIDS Association of America