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MEMORANDUM

DATE: September 29, 2014

TO: Ms. Sharon L. Summers, DMMA
Planning & Policy Development Unit

FROM: Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: 18 DE Reg. 186 [Proposed DSHP 1115 Waiver Amendment Covering PROMISE]

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Health and Social Services/Division of Medicaid and Medical Assistance's (DMMA's) proposal to submit an application to the Centers for Medicare and Medicaid Services (CMS) to amend the Diamond State Health Plan (DSHP) Section 1115 Demonstration Waiver. A link in the Register of Regulations (at p. 187) connects to a 38-page document dated August 22, 2014 entitled "1115 Demonstration Amendment for State of Delaware PROMISE (Promoting Optimal Mental Health for Individuals through Supports and Empowerment) Program Changes", hereinafter "Amendment". The proposal was published as 18 DE Reg. 186 in the September 1, 2014 issue of the Register of Regulations.

As background, the target population is described as "individuals meeting the Olmstead settlement BH target population as well as other Medicaid-eligible adults with serious mental illness and/or substance abuse disorder needs requiring HCBS to live and work in the most integrated setting." Amendment, p. 1. Specific eligibility standards are outlined at pp. 3-6.

The enhanced benefit package (pp. 7-8) includes the following fifteen (15) supports:

- care management
- benefits counseling
- community psychiatric support and treatment
- community-based residential supports, excluding assisted living
- financial coaching
- independent activities of daily living/chore
- individual employment supports

- non-medical transportation
- nursing
- peer support
- personal care
- psychosocial rehabilitation
- respite
- short-term small group supported employment
- community transition services

Individuals enrolled in the Pathways program would be categorically ineligible for enrollment in the PROMISE program. Amendment, p. 3. For individuals enrolled in the DSHP and DSHP+ program, case management and services would be coordinated. Amendment, p. 3.

SCPD endorses the initiative subject to consideration of the following.

First, SCPD highly recommends that Target Criteria A (pp. 3-5) be amended to include “Major Neurocognitive Disorder Due to TBI” (DSM-5), a/k/a Dementia Due to Head Trauma (294.1x) under DSM-IV. Consistent with Attachment “A”, characteristics associated with Dementia Due to Head Trauma are described as follows:

These symptoms include aphasia, attentional problems, irritability, anxiety, depression or affective liability, apathy, increased aggression, or other changes in personality. Alcohol or other Substance Intoxication is often present in individuals with acute head injuries, and concurrent Substance Abuse or Dependence may be present.

Concomitantly, Target Criteria B should be amended to include at least trauma-based “Major Neurocognitive Disorders”.

On a practical level, individuals with a diagnosis of “Major Neurocognitive Disorder Due to TBI” will generally present with an array of symptoms at least equivalent to the included PTSD, OCD, and anxiety-based disorders. The former individuals also frequently have co-occurring physical/spinal cord deficits which could be addressed with many of the supports in the services menu, including personal care, nursing, and respite. Moreover, the diagnosis of Major Neurocognitive Disorder Due to TBI requires persistent and significant impairments:

In DSM-5, not all brain injuries can be considered potentially causative of NCD (neurocognitive disorder). The diagnostic criteria for NCD due to TBI require that the TBI be associated with at least one of four features: loss of consciousness, posttraumatic amnesia, disorientation and confusion, or neurological signs, such as neuroimaging findings, seizures, visual field cuts, anosmia, or hemiparesis (Ref.5, p. 624). Furthermore, the NCD must have its onset either immediately after the TBI or after recovery of consciousness and must persist past the acute post-injury period. Thus, trauma that produced no cognitive or neurological changes at the time of the incident cannot produce an NCD under this scheme.

J. Simpson, M.D, Ph.D., DSM-5 and Neurocognitive Disorders, Journal of the American Academy of Psychiatry and the Law (June 1, 2014) (Attachment “B”).

Second, there is some inconsistency/tension in the descriptions of choice of providers. Compare the following:

All adults receiving PROMISE services will have a choice of practitioner among the contracted and qualified providers. At 8

If the individual is identified as a CRISP individual, the individual will be enrolled in the PROMISE program only and will receive all services necessary for community living from the PROMISE program through CRISP. At 3.

The Department may wish to conform the reference on p. 8 to acknowledge the “CRISP” exception described on p. 3.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our position or observations on the proposal.

cc: Mr. Stephen Groff
Ms. Kevin Huckshorn
Ms. Deborah Gottschalk
Mr. Glyne Williams
Mr. Brian Hartman, Esq.
Governor’s Advisory Council for Exceptional Citizens
Developmental Disabilities Council

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Information

Dementia Due to Head Trauma Symptoms and DSM-IV Diagnosis

Dementia Due to Head Trauma Symptoms and Diagnosis Overview:

Dementia Due to Head Trauma symptoms and diagnostic criteria follow below. While some of these Dementia Due to Head Trauma symptoms may be recognized by family, teachers, legal and medical professionals, and others, only properly trained mental health professionals (psychologists, psychiatrists, professional counselors etc.) can or should even attempt to make a mental health diagnosis. Many additional factors are considered in addition to the Dementia Due to Head Trauma symptoms in making proper diagnosis, including frequently medical and psychological testing considerations. This information on Dementia Due to Head Trauma symptoms and diagnostic criteria are for information purposes only and should never replace the judgment and comprehensive assessment of a trained mental health clinician.



[Mental Health Diagnosis - DSM-IV Diagnosis and Codes: Alphabetical](#)

[Diagnostic Codes beginning with:](#)

[A, B, C, D, E-H,](#)

[I-M, N-O, P-R,](#)

[S, T-V](#)

[Misc. Criteria](#)

[Psychiatric and Weight Loss Medication Information:](#)

[Antidepressants](#)

[Anxiety Medication](#)

[Depression Medication](#)

[Psychiatric Medications](#)

[Weight Loss Medications](#)

[Popular Anxiety Medications:](#)

[Ativan](#)

[Valium:](#)

[Xanax](#)

[Popular Depression Medications:](#)

[Effexor](#)

[Elavil](#)

[Lexapro](#)

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[Anger](#)

294.1 Dementia Due to Head Trauma

The essential feature of Dementia Due to Head Trauma is the presence of a dementia that is judged to be the direct pathophysiological consequence of head trauma. The degree and type of cognitive impairments or behavioral disturbances depend on the location and extent of the brain injury. Posttraumatic amnesia is frequently present, along with persisting memory impairment. A variety of other behavioral symptoms may be

Attachment "A"

Antidepressants	evident, with or without the presence of motor or sensory deficits. These symptoms include aphasia, attentional problems, irritability, anxiety, depression or affective lability, apathy, increased aggression, or other changes in personality. Alcohol or other Substance Intoxication is often present in individuals with acute head injuries, and concurrent Substance Abuse or Dependence may be present. Head injury occurs most often in young males and has been associated with risk-taking behaviors. When it occurs in the context of a single injury, Dementia Due to Head Trauma is usually nonprogressive, but repeated head injury (e.g., from boxing) may lead to a progressive dementia (so called dementia pugilistica). A single head trauma that is followed by a progressive decline in cognitive function should raise the possibility of another superimposed process such as hydrocephalus or a Major Depressive Episode.
Anorexia Nervosa	
Anorexia	
Treatment	
Anxiety Disorders	
Anxiety Disorder Symptoms	
Anxiety Information	
Anxiety Medication	
Bipolar	
Bulimia Nervosa	Information from Diagnostic and Statistical Manual of Mental Disorders DSM-IV
Clinician Articles and Websites	<u>Also, See other Diagnosis and Symptoms of Delirium, Dementia, and Amnesic and Other Cognitive Disorders</u>
Depression	<u>Other Mental Health Diagnostic Symptoms and Criteria</u>
Drug Treatment	
Eating Disorders	
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DSM-5 and Neurocognitive Disorders

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Abstract

The newest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) introduces several changes in the diagnostic criteria for dementia and other cognitive disorders. Some of these changes may prove helpful for clinical and forensic practitioners, particularly when evaluating less severe cognitive impairments. The most substantial change is that the cognitive disorder-not otherwise specified category found in prior editions has been eliminated. Those disorders that do not cause sufficient impairment to qualify for a diagnosis of dementia are now defined as neurocognitive disorders and placed on a spectrum with the more severe conditions. The concept of social cognition is also introduced as one of the core functional domains that can be affected by a neurocognitive disorder. This concept may be particularly significant in the evaluation of patients with non-Alzheimer's dementias, such as frontotemporal dementia. With the aging of the population and the increasing recognition of the possibility of long-lasting cognitive deficits after traumatic brain injury, the need for assessment of cognitive disorders in medicolegal contexts is certain to increase. Forensic psychiatrists who perform these evaluations should understand the conceptualization of Neurocognitive Disorders as presented in DSM-5 and how it differs from prior diagnostic systems.

The importance of dementia in the field of forensic psychiatry cannot be exaggerated. It affects numerous core areas of civil and criminal forensic practice, such as testamentary capacity, capacity to consent to medical treatment, competence to stand trial, and criminal responsibility, to name but a few. For many practicing forensic psychiatrists and psychologists, diagnosing dementia, determining its severity, and reaching a conclusion about its effect on the medicolegal capacity in question is a regular component of their work. As the average age of the population continues to increase in most industrialized countries, the demand for mental health professionals who have the expertise in dementia to address medicolegal concerns is certain to grow.

In addition to dementia, another type of acquired cognitive disorder, cognitive impairment after brain injury, is also becoming more and more relevant in the forensic arena. The population of people who have sustained brain trauma at some point in their lives is increasing. Part of the increase is related to 21st century military conflicts, where tactics such as placing improvised explosive devices under passing vehicles have produced a higher proportion of brain injuries than in previous wars. In addition, the survival rate for both military and civilian brain trauma has increased relative to earlier eras when medical technologies were less advanced.¹⁻³

Neurologists, neuropsychologists, and psychiatrists have also begun to examine the potential cumulative effects on cognition of less drastic but repeated brain injuries. Persistent cognitive impairment resulting from repeated concussions (i.e., mild traumatic brain injuries) has been linked to chronic traumatic encephalopathy (CTE), a neuropathological finding associated with a dementing condition long known in boxers (*dementia pugilistica*) and now thought to have affected some professional athletes.⁴

Changes Introduced by DSM-5

The Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition (DSM-5),⁵ contains revisions of the diagnostic criteria and nomenclature for dementia and other cognitive disorders. The name of the diagnostic category

Attachment "B"

has been changed; the section entitled delirium, dementia and amnestic and other cognitive disorders in the fourth edition and subsequent text revision (DSM-IV⁶ and DSM-IV-TR⁷) is now "neurocognitive disorders," or NCDs. The dementias, if the clinician prefers, can still be referred to by their traditional names (e.g., Alzheimer's dementia, vascular dementia, dementia due to Huntington's disease). All the diagnostic entities found in the prior section are subsumed under the new NCD rubric, and therefore cognitive impairments that are not severe enough to qualify for a diagnosis of dementia are now also defined as belonging to the category of NCDs. They are no longer referred to by the descriptor not otherwise specified (NOS) found in DSM-IV.

Under the previous classification system, cognitive impairments not meeting the criteria for dementia were labeled cognitive disorder NOS, or perhaps age-related cognitive decline. The non-DSM term mild cognitive impairment (MCI) has also been in widespread use in the elderly population, despite its limited clinical value. Patients identified as having MCI are known to progress to dementia at a higher rate than age-matched patients without MCI, but there are currently no therapeutic interventions to delay or prevent progression, nor are there any reliable predictors of which patients with MCI will develop dementia.⁸

In the new system, cognitive impairments that do not reach the threshold for a diagnosis of dementia are termed mild NCDs, whereas the dementias constitute nearly all of the major NCDs.

The diagnostic criteria for mild NCD include:

- A. Evidence of modest cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual motor, or social cognition) based on:
 1. Concern of the individual, a knowledgeable informant, or the clinician that there has been a mild decline in cognitive function; and
 2. A modest impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment.
- B. The cognitive deficits do not interfere with capacity for independence in everyday activities (i.e., complex instrumental activities of daily living such as paying bills or managing medications are preserved, but greater effort, compensatory strategies, or accommodation may be required [Ref. 5, p 605].

The concept of a continuum between mild and major NCDs is explicitly noted. "Major and mild NCDs exist on a spectrum of cognitive and functional impairment" (Ref. 5, p 607). "The distinction between major and mild NCD is inherently arbitrary, and the disorders exist along a continuum. Precise thresholds are therefore difficult to determine" (Ref. 5, p 608).

The use of standardized neuropsychological testing is specifically discussed in the context of distinguishing between major and mild NCDs. Evidence of impairment on standardized testing is Criterion A2 for both types of NCDs (substantial for major, modest for minor NCD), although other quantified clinical assessments can be used when standardized testing is not practical. It is noted that standardized testing is particularly important when evaluating patients with suspected mild NCD, and suggested cutoffs are provided: "For major NCD, performance is typically 2 or more standard deviations below appropriate norms (3rd percentile or below). For mild NCD, performance typically lies in the 1-2 standard deviation range (between the 3rd and 16th percentiles)" (Ref. 5, p 607).

The mild-major continuum will undoubtedly take some getting used to. Under the new schema, any cause of dementia can also produce mild NCD. Thus, both major and mild NCD due to Alzheimer's disease are diagnosable conditions. Clinicians may find it awkward to apply the Alzheimer's label to patients who do not meet criteria for dementia, as Alzheimer's has heretofore been essentially synonymous with senile dementia. This type of usage may be less confusing for mild NCD due to, for example, Parkinson's or Huntington's disease, in which other symptoms are often much more prominent than the cognitive impairments, particularly early in the course of illness.

Potentially adding to the confusion, the term mild has been retained as a specifier of severity for the major NCDs, along with moderate and severe. So, for example, in DSM-5 we find this sentence: "Apathy is common in mild and mild major NCD" (Ref. 5, p. 607). It seems unwieldy that the same adjective, mild, can be used either in reference to an NCD not severe enough to qualify as a dementia or when describing the severity of a particular clinical case of dementia (i.e., a major NCD). In other words, a patient can have mild NCD (not a dementia), mild major NCD, moderate major NCD, or severe major NCD (these latter three are all dementias). In theory, a patient might even progress through each of these stages over time. Granted, the mild major usage is not much different from the use of the mild specifier in major depressive disorder, but it seems to risk confusion among providers as well as consumers and their family members nonetheless.

Etiology of Neurocognitive Disorders

A further potential source of confusion or ambiguity of the NCD conceptualization is that for several of the most common dementia syndromes, the clinician is expected to qualify the diagnosis with the descriptor probable or possible. This is the case for those NCDs that lack a gold standard premortem diagnostic test: specifically, Alzheimer's disease, frontotemporal lobar degeneration (Pick's disease in DSM-IV and DSM-IV-TR), Lewy body disease, vascular disease, and Parkinson's disease. In cases of NCD due to traumatic brain injury (TBI), HIV infection, prion disease, or Huntington's disease, the probable and possible specifiers are not required, as the causative factor can be definitively identified during life.

There is no disputing the causative nature of TBI in some cases of major NCD. Although there is no close correlation between the severity of the TBI and the resultant cognitive impairment, the probability of developing a major NCD is undoubtedly greater with moderate and severe TBI than it is with mild TBI. On the other hand, the most common cause of mild NCD, and also the most likely to lead to eventual civil litigation in such cases, is TBI.

Head injuries are extremely common in society. Even though most of them either produce no brain injury at all or cause only transient impairment, the sheer number of events means that NCD due to TBI is far from rare. DSM-5 cites 1.7 million TBIs annually in the United States, with "1.4 million emergency department visits, 275,000 hospitalizations, and 52,000 deaths" (Ref. 5, p. 625). These numbers were taken from the U.S. Centers for Disease Control and Prevention's 2010 publication⁹ on TBI in the United States, which includes a wealth of information on the demographics of TBI victims and the causes of TBI.

In DSM-5, not all brain injuries can be considered potentially causative of NCD. The diagnostic criteria for NCD due to TBI require that the TBI be associated with at least one of four features: loss of consciousness, posttraumatic amnesia, disorientation and confusion, or neurological signs, such as neuroimaging findings, seizures, visual field cuts, anosmia, or hemiparesis (Ref. 5, p. 624). Furthermore, the NCD must have its onset either immediately after the TBI or after recovery of consciousness and must persist past the acute postinjury period. Thus, trauma that produced no cognitive or neurological changes at the time of the incident cannot produce an NCD under this scheme.

Diagnostic Criteria for Neurocognitive Disorders

There have also been some significant changes in the diagnostic criteria for the various NCDs. The criteria for delirium have been reworded to some degree, but overall, they are fairly similar to the previous criteria. One notable difference is the addition of attenuated delirium syndrome, an example of the diagnosis, other specified delirium. In this syndrome, "the severity of cognitive impairment falls short of that required for the diagnosis" (Ref. 5, p. 602) or only some of the criteria for delirium are met.

In DSM-5, the amnesic disorders, whose appearance in the title of the section in previous editions implied a certain importance, have all but disappeared. In fact the only reference to these disorders is on the introduction page, which states:

[T]he major NCD definition is somewhat broader than the term *dementia*, in that individuals with substantial decline in a single domain can receive this diagnosis, most notably the DSM-IV category of "Amnesic Disorder," which would now be diagnosed as major NCD due to another medical

condition and for which the term *dementia* would not be used [Ref. 5, p 591].

The diagnostic criteria for the major NCD category is where the substantial differences from the criteria for dementia in DSM-IV are found. In the new system, memory impairment is no longer a requirement in the diagnosis of a major NCD. Impairment in only one cognitive domain is enough to qualify for a diagnosis of a major NCD, except in the case of major NCD due to Alzheimer's disease, where two domains are still required, one of which must be memory impairment. This change may be useful, given the growing recognition that a significant percentage of people with NCDs, particularly those with conditions such as frontotemporal dementia, have a relatively intact memory, at least until later in the course of the illness.

New descriptions of the cognitive domains affected by NCDs are also introduced in DSM-5. In DSM-IV, the cognitive disturbances that could be seen in dementia (in addition to memory impairment) were all indeed cognitive: aphasia, apraxia, agnosia, and impaired executive functioning. DSM-5 includes these concepts in somewhat reworded form, and adds the domain of social cognition. Table 1 of the chapter (Ref. 5, pp 593-5) summarizes the six cognitive domains (complex attention, executive function, learning and memory, language, perceptual motor, and social cognition) and lists examples of signs and symptoms and possible methods of assessment.

Implications for Forensic Psychiatry

What effects might the new conceptualization of neurocognitive disorders have on the practice of forensic psychiatry? One potential change for the better is that the severe, disabling cognitive disorders (the dementias) may more clearly be viewed as lying on a continuum with the less severe disorders that do not reach the threshold for a diagnosis of dementia. Separating the universe of cognitive disorders into dementia and cognitive disorder NOS ran the risk of obscuring commonalities between the two. Cognitive disorder NOS, like all NOS diagnoses, also could carry the implication that the professional making the diagnosis in reality does not know very much about what is going on with the patient. From a medicolegal perspective, the new classification system may prove useful in emphasizing that mild NCDs differ from major NCDs only in degree, not in kind.

For patients with neurodegenerative diseases, meeting criteria for only mild NCD will in most cases unfortunately be nothing more than a transitional state on the inexorable path to a major NCD. However, in the case of cognitive disorders due to static insult(s), most commonly TBI, but possibly other events, such as stroke, anoxia due to cardiac arrest, acute toxic exposure, or medication overdose, the new diagnostic entity may have significant clinical and forensic implications. For example, the criteria for NCD due to TBI specified in DSM-5 could help researchers establish a more scientific ground for conditions that have been in some ways controversial, such as postconcussional syndrome and the aforementioned CTE, neither of which is mentioned in DSM-5.^{4,10,11}

From a medicolegal perspective, a diagnosis of mild NCD sounds more definitive and thus may carry more weight in the courtroom than the former cognitive disorder NOS. Only time will tell how widespread the use of the mild NCD diagnostic category in the courtroom will become and how persuasive testimony about the impact of mild NCD on the legal issue at hand will be.

The recognition that some patients with dementia have relatively intact memory is likely to be important in both civil and criminal forensic matters. Previously, normal-range memory performance on neuropsychological tests in a subject thought to have dementia might lead the evaluator to instead lean toward a diagnosis of mood disorder or personality disorder. Under the new criteria, a diagnosis of dementia can be made without overt memory impairment (except in cases of Alzheimer's), with potential implications for the forensic opinion on many legal questions, such as undue influence, competence to stand trial, and criminal responsibility. It can be anticipated that patients whose dementia manifests in impaired judgment and executive function, but whose memory is intact, will now be identified more easily, and the impact of their impaired condition on their legal capacities will be better appreciated, with the requirement for formal memory deficits removed.

In addition to the inclusion of social cognition as one of the six domains potentially impaired by an NCD, forensic practitioners will be encouraged to note that legal involvement is specifically mentioned as one of the potential sequelae of frontotemporal NCD (Ref. 5, p 617). Behavioral and personality changes, including criminal acts and violations of social norms, are not uncommon in frontotemporal dementia (FTD). For example, a recent article in *The Journal* described several examples of aberrant and criminal behavior in a series of subjects who were subsequently found to have FTD. These included repetitive shoplifting despite the ability to pay, attempted child molestation, and hit-and-run.¹² The relatively early age at onset and often, preserved memory and other abilities in FTD can make these types of cases challenging to explain to family members, victims, and courts as being due to organic disease rather than willful bad behavior. The new language concerning this diagnosis may help in explaining FTD and its effects to those involved.

For legal questions such as negligence, malpractice, personal injury, or workers' compensation, where the presence of a diagnosable impairment (and its causation) is the primary focus, a forensic expert applying DSM-5 to diagnose mild NCD should be straightforwardly helpful to the finder of fact. A diagnosis of mild NCD is likely to be more difficult to discount in a legal context than the more nebulous cognitive disorder NOS. On the other side of the coin, applying DSM-5 criteria for NCD due to TBI could prevent those who lack sufficient symptoms (e.g., who do not demonstrate impairments on objective testing), whose initial injury did not have any of the required clinical features necessary to produce an NCD, or whose symptoms developed after an interval of documented normal function, from successfully claiming that their current difficulties are the result of the alleged brain trauma.

The factors become more complicated when the question is the impact of mild NCD on other functional or legal capabilities. Can mild NCD render someone incompetent or incapacitated? Would someone with mild NCD be more susceptible to undue influence? By definition, mild NCD does not interfere with capacity for independence in everyday activities, but does this lack of interference extend to drawing up a will or to refusing a life-saving medical procedure?

One could envision an attorney making the argument that Criterion B for mild NCD ("the cognitive deficits do not interfere with capacity for independence in everyday activities ... such as paying bills or managing medications ...") (Ref. 5, p 605) extends to the cognitive capacities at issue: for example, testamentary capacity. After all, if the testator is still cognitively capable of paying his bills, how could he at the same time lack knowledge of his assets (or heirs and other aspects of his finances)?

A similar case could be made for competence to stand trial. Given the functional independence (by definition) of a defendant with mild NCD, it might be challenging to establish that the diagnosis prevents him from having "sufficient present ability to consult with his lawyer with a reasonable degree of rational understanding" or a "rational as well as factual understanding of the proceedings against him," the standard for competence to stand trial prescribed by the U.S. Supreme Court in *Dusky v. United States*.¹³ (A complex case involving, for example, sophisticated financial crimes, might be an exception, where mild NCD could be sufficient to render the defendant incompetent.)

Conclusion

With the aging of the population, and the aftermath of 12 years of combat for U.S. military personnel, a clear understanding of the spectrum of cognitive disorders and of their diagnosis and management has never been more important for health care professionals. Forensic experts will undoubtedly encounter more and more cases involving traumatic brain injury and neurodegenerative disease in the years ahead.

The conceptualization in DSM-5 of mild neurocognitive disorder, and the elimination of the diagnosis of cognitive disorder, not otherwise specified, may be helpful to the forensic practitioner tasked with examining a person who is in the early stages of a dementing illness, or who has experienced a traumatic brain injury, and may help in the explanation of his condition and impairments to a finder of fact. Other potential benefits of the new system include the removal of the requirement of memory loss for a diagnosis of dementia, and the introduction of social cognition as a specified functional domain. However,

the actual effect of these changes on fact finders who hear expert testimony in civil and criminal matters is not yet known, and it will undoubtedly take some time before the implications of the changes in DMS-5 that affect the forensic evaluation of neurocognitive disorders are fully appreciated.

Footnotes

Disclosures of financial or other potential conflicts of interest: None.

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