Comments on Proposed DSM-5 Criteria for "Specific Learning Disorder" Submitted by the Co-chairs of the Congressional Dyslexia Caucus

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We write as co-chairs of the Congressional Dyslexia Caucus to share our concerns and comments on the proposed DSM-5 definition of "specific learning disorder." The Dyslexia Caucus was created to help educate Members of Congress and the public about dyslexia and identify policies that will support individuals as they overcome dyslexia and pursue educational and career opportunities. The caucus currently has 25 bipartisan Members representing all parts of the country.

We understand the American Psychiatric Association's (APA) desire to account for recent scientific advancements and update the definition of "specific learning disorder" for the DSM-5. However, the proposed definition, if adopted, would have negative impacts on children and adults with dyslexia and other learning disorders, causing many individuals to lose critical accommodations because they will no longer have a disability classification or will be misdiagnosed. In addition, the proposed definition is inconsistent with the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and Section 504 of the Rehabilitation Act of 1973 (Section 504) and would have the effect of undercutting the federal protections afforded by these statutes. Further, the proposed revision attempts to align the DSM with the IDEA, which only covers school-aged children and should not be the basis for a diagnostic classification that also covers adults. The revision also misinterprets IDEA in relation to the requirement for Response to Intervention (RTI) and the mandated use of the discrepancy model.

Dyslexia is the most common type of learning disability. A National Institutes of Health (NIH) study found the prevalence rate of dyslexia is nearly 20% (Shaywitz, S.E. Dyslexia. Current Concepts. New England Journal of Medicine. 338, 307-312, 1998). According to the Department of Education, nearly 2.5 million children between the ages of 3 and 21 were classified as having a learning disability, most commonly dyslexia, in the 2008-2009 school year. Millions of adults are also classified as having a learning disability and receive accommodations at work, in college, and on professional tests, such as the bar exam. Despite the high prevalence of dyslexia, the term is not used in the proposed DSM-5. Equally troubling though is that the proposed changes threaten continued progress in classifying and accommodating those with dyslexia and other learning disabilities. Our specific concerns are highlighted below. We trust that the APA will review these comments and others offered by individuals and organizations and make the needed revisions to the current proposed definition of "specific learning disorder" to ensure that individuals with dyslexia and other learning disabilities are properly diagnosed and provided with the accommodations afforded them under federal law.

I. The Proposed Revision "Specific Learning Disorder" is Inconsistent with the ADA and Undermines ADA Protections for Individuals with Learning Disabilities

Just four years ago, in 2008, Congress overwhelmingly voted to amend the ADA[1] and expand protections for those with learning disabilities. The primary test for disability under the ADA is whether an individual has "a physical or mental impairment that substantially limits one or more major life activities of such individual."[2] The changes to the law made in 2008 make it clear that Congress intends the definition of disability to be broadly construed. Congress specifically included language in the statute requiring that a "determination of whether an impairment substantially limits a major life activity shall be made without regard to the ameliorative effects of mitigating measures" and that "major life activities" shall include speaking, reading, and communicating.[3] Congress also concluded that determining whether an individual's impairment is a disability under the ADA should not demand "extensive analysis."[4] The intent of Congress is clear—the ADA should broadly protect those with learning disabilities and it should not be difficult for such individuals to show that their impairments cause substantial limitations in major life activities.

The proposed definition of "specific learning disorder" in the DSM-5 conflicts with ADA in important ways and could undermine protections under the ADA for individuals with learning disabilities.

The proposed definition states that the history or current presentation of difficulty in reading, writing, and other activities occur during the "formal years of schooling (i.e. during the developmental period.)" Many individuals with dyslexia and other learning disabilities are not diagnosed until well into adulthood. This is especially true for lower income students and students who are English Language Learners (ELL). These types of students may not have access to proper diagnostic services during the "developmental period" and it is not until they get to college that they are evaluated for dyslexia or other learning disabilities. Including a requirement that the individual exhibit learning difficulty during the developmental period could create unnecessary confusion for entities, such as colleges, that are working with dyslexic adults to provide appropriate accommodations under the ADA and other relevant laws and policies.

Additionally, the inclusion of response to intervention (RTI) in the proposed definition has troubling implications for un-diagnosed adults as RTI is not available for adults and could further complicate efforts to provide accommodations under the ADA to older individuals.
The proposed revision provides: "Current skills in one or more of these academic skills are well-below the average range for the individual's age or intelligence, cultural group or language group, gender, or level of education, as indicated by scores on individually-administered, standardized, culturally and linguistically appropriate tests of academic achievement in reading, writing, or mathematics."

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[1] ADA Amendments Act of 2008, P.L. 110-325.
[2] 42 U.S.C. § 12102(1).
[3] 42 U.S.C. § 12102(4)(E).
[4] 42 U.S.C. § 12101(b)(5).

This criteria is particularly troubling in light of the 2008 changes to the ADA and corresponding regulations[5] that make it clear that students with average and above average academic achievement and skills can still have a learning disability. This is especially true if accommodations, such as extra time, have been provided to the individual. The ADA recognizes that dyslexia and other learning disabilities are neurological disorders, not a deficiency in skills or academic success. By linking a diagnosis with a showing that the individual be "well-below the average range," the proposed definition has the potential to lead to confusion among those (such as college administrators or testing agencies) who make the initial determination of whether an individual is classified as disabled under the ADA and therefore entitled to reasonable accommodations. This would not only harm individuals with dyslexia and other learning disabilities who have managed to achieve academic success through either formal or self accommodations, it could also lead to increased litigation and higher costs for both individuals and entities such as colleges, universities, and testing companies. This is clearly contrary to both the letter and the spirit of the ADA.

Congress intended that the ADA be construed broadly. The Equal Employment Opportunity Commission (EEOC) regulations implementing the 2008 ADA changes state that the disability standard is "not meant to be a demanding standard,"[6] and that the determination of disability "will not usually require scientific, medical or statistical analysis."[7] The EEOC regulations are clear that determining coverage under the ADA is not meant to be an analysis focused solely on statistics or numbers and acknowledges that even individuals who score in the average or above average range could still be substantially limited in a major life activity.[8] Importantly, Congress emphasized that, "when considering the condition, manner, or duration in which an individual with a specific learning disability performs a major life activity, it is critical to reject the assumption that an individual who has performed well academically cannot be substantially limited in activities such as learning, reading, writing, thinking or speaking."[9]

The DSM-5 requirement for the diagnostic assessment to include "current skills" is at odds with the ADA requirements for documentation for diagnosis of a learning disability and the implementing regulations that seek to make the process less burdensome and unreasonable. This is especially true in the area of accommodations on high stakes tests. Department of Justice (DOJ) ADA regulations require that testing agencies give "considerable weight to

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[5] *See e.g.* 29 CF.R. § 1630.2(j)(4)(ii) clarifying that individuals with significant educational achievements can still be considered "disabled" under the law because they must spend additional time and/or effort to read, write, or learn when compared to the general population.

[6] 29 C.F.R. §1630.2(j)(1)(i)

[7] 29 C.F.R. §1630.2 (j)(1)(v)

[8] 29 C.F.R. §1630.2(j)(4)(i)

[9] 29C.F.R. §1630.2(j)(4)(i) (quoting 2008 Senate Statement of Managers at 8.).

documentation of past modifications, accommodations, or auxiliary aids or services received in similar testing situations, as well as such modifications, accommodations, or related aids and services provided in response to an Individualized Education Program (IEP) … or a plan describing services provided pursuant to Section 504 of the Rehabilitation Act ….”[10] In its Interpretive Guidance, DOJ further clarifies that: “If an applicant has been granted accommodations post-high school by a standardized testing agency there is no need for reassessment for a subsequent examination.”[11] These rules are particularly helpful to adults who were diagnosed at a young age and do not want -- and shouldn't need -- to undergo expensive evaluations as an adult to confirm the existence of a lifelong disability. The final DSM-5 revisions should not undermine these critical federal protections for individuals with learning disabilities.

II. The Proposed Revision Will Make it More Difficult, Time-Consuming, and Expensive for Individuals with Dyslexia and other Learning Disabilities to Request Accommodations on High Stakes Tests, Including Professional Exams.

As mentioned in the previous section, the ADA provides that determining whether an individual requesting accommodation is classified as disabled should not require an extensive analysis. Unfortunately, a 2011 Government Accountability Office (GAO) report makes it clear that it is currently burdensome and expensive for students with dyslexia and other disabilities to request and receive accommodations on high stakes tests, such as the LSAT, MCAT, bar exam, or medical boards.[12] GAO reported that students were being forced to provide updated medical assessments for conditions that had not changed. These new assessments ranged from $500 to $9000 and were paid for by the students themselves. Students reported needing to hire attorneys at their own expense to assist in obtaining accommodations. In addition, GAO found that testing companies did not dispose of accommodation requests in a timely manner and that some students reported waiting years for a final decision, putting their careers on hold and falling behind their peers. The proposed revision would worsen this already unacceptable situation for students with learning disabilities.

Specifically, the proposed revision's requirement that “[C]urrent skills in one or more of these academic skills are well-below the average range” and “[L]earning difficulties…significantly interfere with academic achievement” are likely to make the accommodations process for students even more burdensome.

Consider a hypothetical example of a talented and dyslexic medical student who reads slowly and with great effort. However, through an accommodation of extra time, during medical school, the student has achieved great success and is preparing to take the licensing exam. The student requests an accommodation

[10] 28 C.F.R. § 36.309(v).
[11] 28 C.F.R. § 36.309 (Interpretive Guidance).
[12] GAO-12-40, *Higher Education and Disability, Improved Federal Enforcement Needed to Better Protect Students' Rights to Testing Accommodations.*

for extra time on the exam. The testing company, relying on the proposed revision, initially denies the accommodation on the grounds that the student is academically well above average. The student is forced to pay (assuming they can even afford to do so) for a new diagnosis and must hope that the medical professional sees past parts B and D of the new DSM-5 definition of "specific learning disorder." The student is financially penalized and may even miss one or more testing dates, thus falling behind their peers in a competitive field.

As the GAO report demonstrates, the accommodations process is already a harrowing one for many students with disabilities. The APA should not make this problem worse by adopting the proposed revision.

III. The Alignment of the DSM with the Current IDEA Definition of Disability is Inconsistent

As stated earlier in these comments there are three major federal statues that protect individuals with learning disabilities- IDEA, ADA, Section 504. In the rationale for the proposed revision it states that the new diagnostic criteria are "consistent with the change in the USA's reauthorized IDEA regulations." It is unclear why the DSM-5 should attempt to align itself with the IDEA, but not the ADA or Section 504, statutes that cover not only children, but also adults and that are equally important to protecting individuals with disabilities. Attempting to align the DSM so closely with one particular disability statute that is restricted to eligibility for educational (specifically special education) services could have the effect of undermining both the ADA and Section 504. Because the IDEA pertains only to children, attempting to align the DSM with it will make it more difficult for adults with learning disabilities to be correctly diagnosed.

Although the proposed revision claims the new criteria are consistent with the IDEA, there are many inconsistencies. The IDEA's stated purpose is to guarantee a free, appropriate public education for all children with disabilities. The statute provides coverage to children who fall into one of ten disability categories, including "specific learning disabilities." This term is defined as: "a disorder in 1 or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations."[13]

Similar to the ADA's definition, the IDEA defines a learning disability as a problem with a process that impairs activities such as reading or writing. It is not a question of academic skills. The IDEA states that a child can be classified as having a disability even if they are obtaining grade level expectations. The proposed revision conflicts with the statute by including a provision that current skills be well-below average for the individual's age or intelligence. The IDEA explicitly rejects this requirement, yet the DSM-5 proposal includes it.

[13] 20 U.S.C. § 1401(30).

The proposed revision is also inconsistent with the IDEA's policy on intellectual ability achievement discrepancy. In the rationale for the proposed revision, it is implied that IDEA prohibits use of a discrepancy model- an approach that permits the identification of bright but struggling readers as learning disabled. In fact, Congress specifies in the law that use of the discrepancy approach is neither required nor is it prohibited; rather, the choice is left up to the states.

DSM-5 further conflicts with the IDEA statute by requiring that an individual's skills be "well-below average" for the individual's age or intelligence in order to be diagnosed with a learning disorder. The IDEA explicitly rejects this requirement, yet the DSM-5 proposal includes it.

Through the IDEA, Congress also provided local school districts with the option of using the RTI process to help in identifying students with disabilities.[14] There is no requirement that RTI be used. A January 2011 memo from the Department of Education's Office of Special Education and Rehabilitative Services to State Directors of Special Education clarified that RTI cannot be used to deny or delay an IDEA evaluation.[15] The memo was in response to incidents of school districts using the RTI process to place barriers in the way of children getting evaluated for a learning disability. This memo makes it clear that the fact that a child has not participated in an RTI framework cannot be the cause for delaying or denying a disability evaluation under IDEA. In contrast, the proposed revision states that a diagnosis of a "Specific Learning Disorder" is, "made by a clinical synthesis of the individual's history, psycho-educational reports of test scores and observations, **and** response to intervention [emphasis added]." The DSM-5's explicit endorsement of the RTI approach as a requirement of diagnosis will make the problem of un-founded delay and denials of disability evaluations worse. APA should seriously consider removing this requirement from the final revision.

<u>Conclusion and Recommendations</u>

Any revisions to the DSM involving dyslexia and learning disabilities should be undertaken with great care and awareness that such changes have the potential to undermine federal laws aimed at protecting those with disabilities and providing reasonable accommodations to them. As currently drafted, the proposed "Specific Learning Disorder" revision is inconsistent with both the ADA and IDEA, would make it more difficult for many individuals (particularly adults and those from lower income backgrounds) with learning disabilities to obtain needed accommodations under federal law, and would create confusion for those charged with evaluating individuals with learning disabilities.

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[14] 20 U.S.C. § 1414(b)(6)(B).

[15] Available at: http://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/osep11-07rtimemo.pdf

We hope that you will make the changes necessary to the final revision to ensure that all individuals with dyslexia and other learning disabilities are properly diagnosed and their rights under federal law are not undermined.

In light of these concerns, we recommend the following changes for the final revision:

1. Dyslexia is specifically noted in federal disability statutes and is the most common learning disability. It should be specifically included in the DSM-5.
2. The final revision should make it clear that a "current" assessment is not mandatory when the individual has a documented history of a learning disability. This change will ensure that the final revision does not undermine or contradict federal law.
3. The requirement that an individual's academic skills be well-below average should be removed from the final revision. Many students and individuals with dyslexia and other learning disabilities have achieved great academic and career success with the assistance of accommodations and federal law clearly protects these individuals with disabilities.
4. Requiring response to intervention (RTI) as part of a diagnostic assessment is contrary to federal law, including the IDEA, and should be removed from the final revision.
5. The final revision should align with all Federal disability statutes and regulations rather than solely IDEA-an education law restricted to children. Maintaining an explicit tie to the IDEA in the final revision will be harmful for adults with learning disabilities attempting to obtain a diagnosis or necessary accommodations.