

Comments on Proposed DSM-5 Criteria for Specific Learning Disorder from a Legal and
Medical/Scientific Perspective

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I. Overview

We are researchers and practitioners in the fields of law and medicine who have collaborated to comment on the proposed DSM-5 definition of “specific learning disorder (SLD).”

We congratulate the authors for incorporating SLD into the overarching meta-structure of the proposed DSM-5 document. We are pleased and highly support the movement of DSM-5 toward a “a neuroscience-based framework that can contribute to a nosology in which disorders are grouped by underlying pathophysiological similarities rather than phenomenological observations.”¹ We want to draw your attention to areas within SLD where the neurobiology, pathophysiology and clinical symptoms converge and may have inadvertently been overlooked in the development of criteria within the SLD category. As experts in neuroscience and learning disorders, we would be happy to contribute to this enterprise in any way that you may find helpful. You might also not be aware, and we bring to your attention, that specific components of the proposed criteria are at variance with important federal laws pertaining to civil rights. And here, too, we would look forward to contributing our expertise.

In this spirit, we make the following proposal: divide the category “specific learning disorder” into (1) Dyslexia, where much is known scientifically and clinically, and the criteria are based on science; and (2) the less well-defined Other Learning Disorders where the pathophysiology, neurobiology and mechanisms, which are less well understood, find a home. In the following pages we explain the rationale for these suggestions (Part IV Medical/Scientific Analysis). At the same time, there are a number of legal/civil rights concerns with the proposed DSM-5 criteria for SLD that are discussed in Part II (Legal Background), below. The legal issues identified apply to both groups, Dyslexia and Other Learning Disorders. We believe that our suggestions will result in much better alignment with the stated goals of DSM-5.

There are substantial reasons for considering dyslexia as a discrete entity within the SLD category. Specifically, dyslexia is a well-described and long-standing entity that adheres to a well-specified medical model including, known neurobiology, pathophysiology, symptoms and developmental manifestations, treatment, and long term outcome. In contrast to the other domains included under SLD, dyslexia is not a feature but a well described disorder. The primary mechanism for dyslexia, a difficulty getting to the sounds of spoken language affecting both spoken language and reading is strongly supported by hundreds of well-accepted scientific reports which converge with clinical experience (see below Part IV C). Converging and highly replicated fMRI brain data indicate how brain organization for reading in dyslexia differs from that reported for

¹ David Kupfer & Darrel Regier, *Neuroscience, Clinical Evidence, and the Future of Psychiatric Classification in DSM-5*, 168 AM. J. PSYCHIATRY 1, 1-2 (2011). It is important to note that the diagnoses of specific learning disorders are made by psychologist and neuropsychologists, and in some states, the vast majority of diagnoses are made by specialists trained in the assessment of learning disorders.

typical readers, importantly identifying the source of the lack of fluent reading (see below Part IV D). Consistent, too, with the goals of DSM-5, there is now a neurobiological signature for dyslexia based on converging findings from studies by a world-wide community of scientists.

Our suggested revisions for criteria for dyslexia incorporate and reflect coherent, neuroscientific and cognitively based pathophysiologic mechanisms rather than relying solely on phenomenological observations. The proposed classification of SLD with a list of “Descriptive Feature Specifiers” is perhaps reasonable in instances where there are less-well described entities, with scant reliable data available to provide criteria that reflect known neurobiology and pathophysiologic mechanisms. Dyslexia is not a feature but a well-described and validated disorder. We suggest maintaining the current format with a list of “Descriptive Feature Specifiers” for the less well delineated learning domains.

Given the advanced state of knowledge of its neurobiology and pathophysiology, dyslexia serves as a model for the identification of a learning disorder. From a clinical perspective, inclusion of dyslexia as a well-articulated learning disorder enhances DSM’s function as “first and foremost a tool for clinicians” (Kupfer & Regier, 2011). Dyslexia provides the practitioner with access to the large scientific knowledge base revealing the neurobiological and cognitive factors underlying the disorder, factors guiding the clinician to which specific symptoms to look for (word retrieval difficulties; poor phonemic awareness, difficulties with word reading and connected text reading, especially under time constraints, poor spelling and difficulties learning a foreign language) and appropriate evidence-based treatments. From a developmental perspective, the clinician’s diagnostic process is aided, too, by knowledge of the unfolding of the major symptoms of dyslexia over the course of childhood, adolescence and adulthood. Inexplicably, the proposed DSM-5 eliminates dyslexia and the accumulated scientific knowledge it provides for the clinician, negatively impacting the clinician’s ability to accurately and knowledgably diagnose this overwhelmingly most common LD.

We share our concerns that the proposed DSM-5 SLD criteria represent a major, even radical, departure from prior editions, a change unsupported by the evidence. Such a change appears at variance with the principle of avoiding change for change’s sake, that is, avoiding changes that lack substantial research evidence. This principle remains a goal of DSM-5: “we propose a highly conservative approach to the revision process and suggest that changes be made only when the empirical evidence or the need for change is compelling.”² Examples of major changes in the proposed new criteria include: elimination of dyslexia and its associated scientific and clinical implications; requiring “response to intervention;” and requiring academic skills to be “well-below the average range.” In addition to being unsupported by any credible evidence, such changes pose a serious problem arising from incompatibilities in the data sets obtained using criteria from one DSM version and its successor. The concern was recognized by the leaders of DSM-5: “that frequent changes in diagnostic criteria can potentially discredit the revision

² Bruce Rounsaville et al., *Basic Nomenclature Issues for DSM-V* in A RESEARCH AGENDA FOR DSM-V 1, 25-26 (2002).

process and increase the chances of the DSMs becoming the subject of ridicule.”³ But more than ridicule, there is the strong possibility of making DSM irrelevant if the change, (for example, elimination of a neurobiologically validated disorder, dyslexia), will be viewed by clinicians, scientists, policy makers and the public as foolish, harmful and a step backwards.

Physicians and clinicians are obligated to follow the long held ethic of their profession, *Prima non nocere* –First do no harm.

The proposed DSM-5 criteria for SLD have the potential to do considerable harm by:

- Doing away with the most prevalent, well-studied and scientifically informed LD, dyslexia,
- Preventing the development of a nosology based on neuroscience and cognitive science,
- Harming clinical practice by ignoring and hindering application of progress in neuroscience and cognitive science in the diagnosis of dyslexia,
- Harming patients by denial of a precise, accurate, coherent, scientifically informed diagnosis and the insights and self-empowerment gained from such a diagnosis, causing many to lose self-esteem and face growing anxiety,
- Harming and discriminating against patients by denying a diagnosis to individuals with dyslexia and related learning disorders who are bright, demonstrate an unexpected difficulty in reading and read slowly with great effort,⁴
- Negatively impacting the DSM process by basing criteria on misinterpreted, continually changing educational laws limited to children rather than on science,
- Damaging the DSM process by requiring for diagnosis a highly-criticized educational process (RTI) that few children and absolutely no adults have experienced, has not been scientifically validated, and is not and has not been made mandatory in the IDEA,⁵
- Misinterpreting the IDEA and incorrectly citing the IDEA as doing away with the discrepancy approach, which, in fact, is permitted under the IDEA,
- Overlooking the needs of older children and adults by citing the need to adhere to the IDEA, an education law limited to school age children, and, thus, limiting the application of the DSM criteria and diagnosis to children,
- Harming patients by limiting the diagnosis to only those fitting within a very narrow numerical range and ignoring those whose scores may be higher but who suffer from a lack of reading fluency and who do not read, write or spell in the same condition, manner or duration as most others,
- Harming patients by misunderstanding the functional impact of dyslexia. Thus, while dyslexia may significantly and negatively impact the affected *individual*, at the same time, there may be no or little noticeable negative impact on academics or occupational performance,
- Denying patients a diagnosis and potential access to the interventions and accommodations they require,

³ *Id.* at 11.

⁴ 28 C.F.R. §1630(j)(4) (i), (ii)

⁵ RTI is neither widely used nor implemented with fidelity to its theoretical framework.

- Hindering patients’ ability to take advantage of their rights under the ADA Amendments Act (ADAAA) of 2008 and related civil rights protections,
- Harming patients by requiring measurement of “current” skills” at any age, even in those adults whose diagnosis is well established,
- By requiring “current” measurement of skills, overlooking the persistence of both dyslexia and the associated lack of fluency and word retrieval difficulties, and thereby imposing a burdensome requirement that is not necessary scientifically or clinically, and
- Limiting access to diagnosis and potential accommodations for adults who have dyslexia and seek further education, licensing or certification by the requirement for providing evidence of “current” skills, thus imposing a requirement for retesting that is inconsistent with the Department of Justice regulations and guidance under the ADA.

II. Legal Background

The term “disability” is used in many federal and state statutes but these comments will focus on three federal statutes: The Americans with Disabilities Act, Section 504 of the Rehabilitation Act and the Individuals with Disabilities Education Act.

A. The Americans with Disabilities Act and Section 504

1. Statutory Overview

The Americans with Disabilities Act (“ADA”) prohibits discrimination against individuals with disabilities in the areas of employment (Title I), public-sector programs and activities (Title II) and “public accommodations” – private entities that are open to the public (Title III) including testing and licenses entities. Section 504 of the Rehabilitation Act of 1973 prohibits such discrimination with regard to any recipient of Federal financial assistance including every public elementary school and nearly every public or private university in the United States. The term “individuals with disabilities” is defined in Title I of the ADA and that term applies to all three ADA titles as well as Section 504. Hence, an individual with a disability, such as an individual with dyslexia, could be covered with respect to discrimination in employment (Title I and Section 504), at a public university (Title II and Section 504) or at a private university (Title III and Section 504). A different definition of disability (which is centered around a need for special education, not the existence of disability, per se) exists under the Individuals with Disabilities Education Act (“IDEA”), a funding statute, which covers students from ages 3 to 21 when they attend public school or a private school pursuant to their rights to a free, appropriate publicly funded education (FAPE), although there is some overlap in these definitions.

One particularly important provision of the ADA, which especially impacts individuals with dyslexia and related learning disorders, is the provision entitled “Examinations and Courses.” This section provides that “any person that offers examinations or courses related to applications, licensing, certification, or credentialing for secondary or

postsecondary education, professional, or trade purposes shall offer such examination or courses in a place and manner accessible to persons with disabilities or offer alternative accessible arrangements for such individuals.”⁶ This provision is not simply about the physical accessibility of test sites. Under this provision, and a similar, pre-cursor provision of Section 504, individuals often receive accommodations, such as extra time, for examinations at school, on admissions testing (such as the SAT and ACT tests)⁷ as well as professional examinations like the law or medical boards. Courts often rely on the DSM to help them conclude that a student has a disability that substantially limits his or her ability to read and write that entitles the student to extra time on a professional exam.⁸

2. Definition of Disability

In order to secure the civil rights protections of the ADA (and Section 504), one must be an “individual with a disability,” as defined by the statute. The ADA was amended in 2008 to have the following definition of disability:

- The term “disability” means, with respect to an individual
- (A) a physical or mental impairment that substantially limits one or more major life activities of such individual;
 - (B) a record of such an impairment; or
 - (C) being regarded as having such an impairment (as described in paragraph (3)).⁹

For our purposes, prong “A” is the most relevant with its three components: impairment, substantial limitation and major life activity.

Congress amended this provision by directly rejecting several Supreme Court cases that had narrowly construed the term “substantially limits” and “major life activities.” Thus, the statute also provides that:

The determination of whether an impairment substantially limits a major life activity shall be made without regard to the ameliorative effects of mitigating measures such as

⁶ 42 U.S.C. § 12189.

⁷ While serving high school students, these testing organizations are subject to the ADA rather than the IDEA, permitting the anomalous results that a student could be classified as learning disabled under the IDEA, but denied disability accommodations under the proposed DSM-5 criteria that are likely to affect disability status under the ADA.

⁸ See, e.g., *Rush v. National Board of Medical Examiners*, 268 F. Supp.2d 673, 677 (N.D. Tex. 2003) (“Following the testing and clinical assessment of Plaintiff, Dr. Egerton made a DSM-IV clinical diagnosis of a reading disorder, that is, that Plaintiff is substantially limited in his ability to read and comprehend. *It is undisputed that such a diagnosis means that such an individual requires extra time to read and comprehend written examinations and that an appropriate accommodation for a person with this reading disorder is to afford him extra time on written examinations requiring reading.*”)(emphasis added).

⁹ 42 U.S.C. § 12102(1).

- (I) medication, medical supplies, equipment, or appliances, low-vision devices (which do not include ordinary eyeglasses or contact lenses), prosthetics including limbs and devices, hearing aids and cochlear implants or other implantable hearing devices, mobility devices, or oxygen therapy equipment and supplies;
- (II) use of assistive technology;
- (III) reasonable accommodations or auxiliary aids or services; or
- (IV) learning behavioral or adaptive neurological modifications.¹⁰

Similarly, the statute provides a broad definition of “major life activities” that includes “speaking ... learning, reading, concentrating, thinking, [and] communicating.”¹¹

These changes reflected Congress’ intention “to convey that the question of whether an individual’s impairment is a disability under the ADA should not demand extensive analysis.”¹² In other words, “impairment,” “substantial limitation,” and “major life activities” should be broadly construed.¹³

The Equal Employment Opportunity Commission (“EEOC”) was charged with the responsibility to promulgate regulations to implement these statutory requirements. The EEOC’s interpretations have subsequently been applied to all areas of potential coverage under the ADA and Section 504, not just employment. The EEOC was aware that scientific standards can be useful in interpreting these rules but also did not want to make plaintiffs overly dependent on expert testimony. Thus, it promulgated a regulation that states:

The comparison of an individual’s performance of a major life activity to the performance of the same major life activity by most people in the general population usually will not require scientific, medical, or statistical analysis. Nothing in this paragraph is intended, however, to prohibit the presentation of scientific, medical, or statistical evidence to make such a comparison where appropriate.¹⁴

The purpose of that regulation was to keep down the expenses and increase access to the courts for plaintiffs in ADA and Section 504 cases because many courts had insisted on medical and other expert testimony to demonstrate that the plaintiff was disabled raising a high bar to overcome even when the fact that the individual had a disability was a matter of simple commonsense.

¹⁰ 42 U.S.C. § 12102(4)(E).

¹¹ 42 U.S.C. § 12102(2)(A).

¹² 42 U.S.C. § 12101(b)(5).

¹³ 42 U.S.C. § 12102(4)(A).

¹⁴ 29 C.F.R. § 1630.2(j)(v).

Nonetheless, the EEOC recognized that medical or other expert testimony is often helpful for individual with disabilities such as learning disabilities, which for the layperson may seem counterintuitive. Lay notions, grounded in common, but erroneous, beliefs are among those Congress sought to eradicate when it enacted the ADA. Thus, in its Interpretive Guidance, the EEOC explained:

This does not mean that disability cannot be shown where an impairment, such as a learning disability, is clinically diagnosed based in part on a disparity between an individual's aptitude and that individual's actual versus expected achievement, taking into account the person's chronological age, measured intelligence, and age-appropriate education. Individuals diagnosed with dyslexia or other learning disabilities will typically be substantially limited in performing activities such as learning, reading, and thinking when compared to most people in the general population, particularly when the ameliorative effects of mitigating measures, including therapies, learned behavioral or adaptive neurological modifications, assistive devices (e.g., audio recordings, screen reading devices, voice activated software), studying longer, or receiving more time to take a test, are disregarded as required under the ADA Amendments Act.¹⁵

This Guidance presumes that dyslexia and other learning disabilities are readily considered "impairments" and that it should not be difficult to demonstrate that these impairments cause "substantial limitations" in major life activities such as reading that can be demonstrated on the basis of clinical evidence. In particular, this Guidance presumes the continued use of the "discrepancy" model in demonstrating the existence of dyslexia and related learning disorders. It does not require the application of specific formulae or level of severity.

The 2008 Amendments to the ADA provide that the term "disability" "shall be construed broadly in favor of broad coverage of individuals under this chapter, to the maximum extent permitted by the terms of this chapter."¹⁶ The EEOC regulations clarify that these results are "not meant to be a demanding standard,"¹⁷ going on to indicate this "will not usually require scientific, medical or statistical analysis."¹⁸ The intent is not a "cut off score" but rather to use clinical judgment to determine if the individual is "substantially limited" in a major life activity by considering, "as compared with most people in the general population, the condition under which the individual performs the major life activity; the manner in which the individual performs the major life activity; and/or the duration of time it takes the individual to perform the major life activity."¹⁹ As Congress emphasized in passing the ADA 2008 Amendments, "when considering the condition, manner, or duration in which an individual with a specific learning disability performs a

¹⁵ 29 C.F.R. § 1630.2(j)(1)(v)(Interpretive Guidance).

¹⁶ 42 U.S.C. § 12102(4)(A).

¹⁷ 29 C.F.R. § 1630.2(j)(1)(i).

¹⁸ 29 C.F.R. § 1630.2(j)(1)(v).

¹⁹ 29 C.F.R. § 1630.2(j)(4)(i)(emphasis added).

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.”²⁰

Further, the EEOC regulations clarify that individuals who attain high level outcomes, such as good grades or degrees obtained, with respect to education or work can still be legally protected on the basis of a learning disability “because of the additional time or effort he or she must spend to read, write, or learn compared to most people in the general population.”²¹ “[T]he focus is on how a major life activity is substantially limited, and not on what outcomes an individual can achieve.”²² Fundamental to the purpose of disability-based civil rights protections is an acknowledgement that disability and competence are not mutually exclusive, a bias that is deeply engrained, but erroneous. The proposed criteria virtually preclude a diagnosis in the absence of significant failure. Surely, that cannot have been the DSM-5 neurodevelopmental committee’s intent.

As the district court said in *Bartlett v New York State Board of Law Examiners*, “Reading is a complex process composed of numerous cognitive functions. A deficit in one or more of these underlying processes can seriously affect an individual’s ability to read. The Board (like many others in the public) wants the comfort of a test score to measure this complex process. While research about learning disabilities continues to advance and diagnostic tools are being improved, no test exists today whose scores alone can diagnose learning disabilities.”²³ The limitations of psychometric testing remain. The percentile cut-off score indicated in the proposed criteria (“well below the average range”) serves to summarily eliminate and prevent large numbers of individuals who do not read in the same manner, condition and duration as others from receiving a diagnosis, precisely in the way that the *Bartlett* court rejected as “seriously infirm”²⁴ and which Congress unanimously rejected in the ADA 2008 Amendments. Having such a statistically determined cut off is totally contrary to the law and scientific findings in dyslexia and functions to deny bright, accomplished individuals who nevertheless struggle to read fluently access to their rightful diagnosis, reading support and accommodations.

Today, there are many students with dyslexia and other learning disabilities attending rigorous colleges who have, and continue to work incredibly hard, as well as

²⁰ Id. (quoting 2008 Senate Statement of Managers at 8).

²¹ 29 C.F.R. § 1630.2(j)(4)(ii).

²² Id.

²³ 2001 WL 930792 at *41 (S.D. NY 2001).

²⁴ Id. (“In practical terms, Dr. Flanagan is attempting to do the same thing that I found ‘seriously infirm’ in the first trial--setting a cut-off for the existence of disability. *Bartlett I*, 970 F.Supp. at 1113. In fact, Dr. Flanagan’s suggested cut-off-- below the 16th percentile--is even more conservative than Dr. Vellutino’s cut- off--below the 30th percentile. To the extent that I found a cut-off of the 30th percentile . . . to be under-inclusive based on research showing that one-third of dyslexics score above the 30th percentile on those tests, I find a 16th percentile cut-off to be even more problematic.”)

distinguished physicians, scientists, writers and attorneys, among others, who struggled, worked exceptionally hard in school and now at work, who are dyslexic and with great effort and often, accommodations, have succeeded. Such flawed diagnostic criteria will harm children who are working extremely hard in school and struggling but not failing, but who with appropriate diagnosis would receive the instruction and accommodations they require to succeed. Thus, while dyslexia may significantly and negatively impact the affected individual, at the same time, the EEOC recognizes that there may be no or little noticeable negative impact on academics or occupational performance due to self-mitigation or accommodations.

An underlying cognitive processing impairment may significantly interfere with academic or occupational performance. However, if the individual with dyslexia or a related learning disorder is provided with the instruction, tutoring or accommodations he or she requires, that individual is capable of good and often, high performance in academic skills and in the work place. To relegate the diagnosis of dyslexia or related learning disorders to only those who have failed shows a serious lack of understanding of both the scientific and clinical aspects of learning disorders, including dyslexia, about which more is known. Most importantly, such a seemingly “must fail” approach to diagnosis of dyslexia or related learning disorders gives the appearance of a bias and failure to understand the unexpected nature of the reading difficulties presenting in individuals of high intelligence. This approach is misguided and serves to deprive those extremely hardworking, bright children and adults with dyslexia or other learning disorders who do succeed in part because an accurate and informative diagnosis brought them needed attention, assistance and development of compensatory strategies.

In its Interpretive Guidance, the EEOC quoted with approval the statement from the House Education and Labor Committee Report that explained how the 2008 revisions to the ADA would apply to individuals with specific learning disabilities who it understood had a life-long impairment:

For the majority of the population, the mechanics of reading and writing do not pose extraordinary lifelong challenges; rather, recognizing and forming letters and words are effortless, unconscious, automatic processes. Because specific learning disabilities are neurologically-based impairments, the process of reading for an individual with a reading disability (e.g., dyslexia) is a word-by-word, and otherwise cumbersome, painful, deliberate and slow – throughout life. The Committee expects that individuals with specific learning disabilities that substantially limit a major life activity will be better protected under the amended Act.²⁵

Thus, based on expert medical testimony, Congress understood that dyslexia is a life-long condition and that individuals with dyslexia, with appropriate accommodations, can attain academic and occupational success.

²⁵ 29 C.F.R. § 1630.2(j)(4)(Interpretive Guidance).

In other words, Congress amended the ADA in 2008 to overturn Supreme Court decisions that had narrowly interpreted the term “disability” by amending the rules for construing the meaning of “substantially limits” and “major life activities” in ways that would clearly increase coverage for individuals with learning disabilities. Congress had individuals with learning disabilities in mind when it specifically listed, for example, “reading” on the list of major life activities. By contrast, Congress did not amend the term “physical or mental impairment” because courts had not narrowly construed those terms to disallow coverage. Congress expected that individuals with dyslexia would have this condition throughout their lives, whether or not they received accommodations that allowed them to be successful, and would readily meet the definition of disability.

One problem that Congress recognized often impacted students with disabilities who sought testing accommodations was onerous documentation requirements, particularly requirements that students take recent diagnostic examinations to demonstrate the existence of a specific learning disability. In the language quoted above, the House Committee recognized that dyslexia is a life-long, brain-based impairment that is not “cured” with therapy or educational interventions. In the regulations governing the testing section, the Department of Justice (“DOJ”), the entity charged with writing Title III regulations, added language stating: “Any request for documentation, if such documentation is required, is reasonable and limited to the need for the modification, accommodation, or auxiliary aid or service requested.”²⁶ Further, rather than require new clinical evaluations, the DOJ regulations state that entities should give “considerable weight to 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”²⁷ 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.*”²⁸ 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.

Longitudinal studies have confirmed that dyslexia is neither out-grown nor transient; dyslexia is a persistent, life-long condition. By requiring “current” diagnoses, it appears that DSM is not aware of the persistence of dyslexia and the persistence of the associated lack of fluency and word retrieval difficulties. Such a burdensome and unnecessary requirement is not necessary scientifically, clinically and legally. While less has been done in connection with researching the chronicity and characteristics of other learning disorders, there is no reason or support for the proposition that they go away with age or intervention.

²⁶ 28 C.F.R. § 36.309(iv).

²⁷ 28 C.F.R. § 36.309(v).

²⁸ 28 C.F.R. § 36.309 (Interpretive Guidance).

3. Problems with Proposed DSM-5 Criteria

The proposed DSM-5 diagnostic criteria for “Specific Learning Disorder” could undermine many of the important statutory changes enacted by Congress in 2008. These are some of the major problems:

1. The proposed criteria state, “A diagnosis of Specific Learning Disorder is made by a clinical synthesis of the individual’s history (development, medical, family, education), psycho-educational reports of test scores and observations, and response to intervention, using the following diagnostic criteria.”

- This statement suggests more testing than was contemplated by Congress and inappropriately ties the hands of clinicians. The hallmark of disability classification under the ADA, Section 504 and IDEA, as well as sound clinical practice, is individualized assessment²⁹ of various factors, including the individual’s experiences in using reading, writing, and spelling in their lives.
- The reference to “response to intervention” is troubling for three reasons. First, RTI is not available for older children and adults. These proposed diagnostic criteria seem to presume a school-age population but the ADA and Section 504 apply throughout an individual’s life. Second, the ADA regulations presume that the discrepancy model will still be available for establishing a learning disability yet the proposed DSM-5 eliminates that method for classification, imposing what amounts to a low achievement cut-off score. Third, as we will see when we discuss the IDEA, Congress has not required the RTI model be used for all children covered by the IDEA yet the proposed DSM-5 mistakenly seeks to align the IDEA and DSM by imposing such a requirement.

2. “History or current presentation of persistent difficulties in the acquisition of reading, writing, arithmetic, or mathematical reasoning skills during the formal years of schooling (i.e., during the developmental period).”

- The requirement that a diagnosis be made during the “developmental period” would be difficult for many, and especially difficult for low-income and limited-English proficient individuals who may not have benefited from clinical evaluation at a young age. Low-income, minority status and other factors can preclude a diagnosis during the developmental period. Moreover, the failure of

²⁹ 28 C.F.R. Part 36, Appendix A. Federal regulatory guidance recognizes that an individualized assessment by a qualified professional who has “individually and personally evaluated [a] candidate as opposed to simply considering scores from a review of documents” is key to getting it right. “This is particularly important in the learning disabilities context, where proper diagnosis requires face-to-face evaluation.” Guidance further indicates that “[r]eports from experts who have personal familiarity with the candidate should take precedence over those from . . . reviewers . . . who have never personally met the candidate or conducted the requisite assessments for diagnosis and treatment.”

school officials to recognize the symptoms of learning disabilities leads to delays in referrals for special education classification across the full socioeconomic, racial and ethnic spectrum. Still others go unrecognized because they are intelligent enough to find ways to compensate or self-accommodate their difficulties, often unconsciously. This problem is more acute, however, among low-income communities of color.

- This statement is ambiguous for three reasons. First, it states that one should have a “history or current presentation ... during the formal years of schooling” even though the case law is littered with individuals who first learned of their learning disability in college. An adult, who did not have the benefit of an individualized clinical evaluation or who self-accommodated during his or her schooling, would not appear to be able to qualify under this criterion. The phrase “during the formal years of schooling” should be deleted to avoid that ambiguity. Second, the criteria do not state whether these persistent difficulties exist with or without reasonable accommodations or mitigating measures. Criteria should explicitly state that those difficulties exist when the individual has not been provided with reasonable accommodations or mitigating measures (including self-managed mitigating measures such as assistance from other adults or students in the individual’s life). Third, the statement specifies that the individual would have difficulties with the “acquisition” of reading or writing. It is not clear what is meant by “acquisition.” Individuals with dyslexia, if given enough time to read material and allowed to use accommodating strategies, can “acquire” reading with normal rates of comprehension. This ambiguity is arguably resolved with the first criteria: “Inaccurate or slow and effortful word reading.” But reading is a much more complex process than “word” reading. The word “acquire” is not consistent with even that overly narrow example, and fails to recognize that individuals with learning disabilities experience difficulty using these skills in their lives, not just in acquiring them.

3. “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 tests of academic achievement in reading, writing, or mathematics.”

- This statement reduces dyslexia to a problem with “skills” rather than as a difficulty reflecting underlying primarily phonologic but other related processes as well.
- By referencing the word “current” throughout the criteria, it also embeds one commonly misunderstood expectation that reassessment on a regular basis is either needed or of substantive value with another serious misconception – that children can “outgrow” their learning disabilities. Both stereotypes are without foundation in science and assume a level of neuro-plasticity that does not exist. . Therefore, this statement reflects a re-evaluation mechanism instituted by

Congress under the IDEA to address school districts' concerns that school children who are classified as eligible for special education would never return to general education, costing the states significant resources on the one hand, and fearing the loss of federal funding on the other. Whatever the motivation and value within special education circles of re-evaluation as a condition of IDEA funding, the neurobiological functioning of individuals with dyslexia and related learning disorders do not permit this continual re-evaluation process to be the case for other civil rights protections, and there is no scientific basis for what has been well established as a chronic disability across the life span.

- Referencing “current” serves to discourage adults who are dyslexic from pursuing further education or required licensure or certification for professions or trades although this requirement for “current” is contrary to the Department of Justice Interpretive Guidance for the ADA regarding testing accommodations which state: “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.”³⁰ In such a situation an applicant for accommodations could be told by the testing agency that according to the DSM-5 criteria, current testing is required.
- This statement treats both dyslexia and other learning disorders as merely a problem with academic achievement, ignoring the individual’s aptitude and ignoring that dyslexia, for example, can exist in students with average (or even above average) reading levels. It ignores the research into basic cognitive processes underlying reading, especially phonologic processes but other cognitive processes as well. In addition, there is no provision for people who do not speak. It is contrary to the ADA regulation that recognizes that students with high academic achievement can also have dyslexia, especially if they have had accommodations. The ADA regulations do not allow academic success to be a factor that excludes one from coverage. In addition, it all but reduces a diagnosis best accomplished through a comprehensive clinical evaluation to an arbitrary low cut-off score (“well below the average range”), virtually excluding the other factors the proposed criteria appear to acknowledge as meaningful. The use of cut-off scores has been demonstrated to be the least reliable and valid approach to diagnosis, primarily because it increases the likelihood of both Type 1 and Type 2 error – both over- and under-including.
- This statement ignores that the EEOC regulations that permit a diagnosis of dyslexia to be made upon consideration of “the condition [or] manner in which the individual performs the major life activity” rather than by purely a reference to academic skills.

4. “Learning difficulties identified in Criterion A (in the absence of tools, supports, or services that have been provided to enable the individual [to] compensate for these

³⁰ 28 C.F.R. § 36.309 (Interpretive Guidance).

difficulties) significantly interfere with academic achievement, occupational performance or activities of daily living that require these academic skills, alone or in any combination.”

- This statement assumes that individuals with dyslexia or other learning disorders experience academic or occupational failure.
- This statement equates dyslexia with a “learning difficulty” although individuals with dyslexia often learn quite well.

These problems are extremely important because they appear to go against rights granted to individuals with disabilities where the statutes and regulations recognize that individuals who are disabled can, with accommodations, achieve at a high level in school and at work. When Congress enacted the ADA 2008 Amendments, it presumed that dyslexia was a “neurologically-based impairment,” which involved using a “word-by-word, and otherwise cumbersome, painful, deliberate and slow [process] – their brains in other words, trade speed for accuracy – throughout life.”³¹ Congress expected that such individuals, including those with learning disorders other than dyslexia, would be readily protected by the ADA and be able to receive accommodations in school and at work so they can perform at a high level.³² If the proposed DSM-5 criteria go into effect, that likelihood will be significantly diminished as schools and others will have a new tool to argue that such individuals are not “impaired” and therefore not “disabled” under the ADA and Section 504. The DSM-5 needs to specifically embrace dyslexia as a recognized impairment, with cognizable symptoms, to avoid that possibility.

B. Individuals with Disabilities Education Act

1. Statutory Overview

The purpose of the Individuals with Disabilities Education Act is to “ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for future education, employment, and independent living.”³³ In order

³¹ 29 C.F.R. § 1630.2(j)(4)(Interpretive Guidance).

³² U.S. Department of Education and State hearing officers repeatedly find that school districts have failed in their responsibilities to properly identify and evaluate such students or that, students with multiple disabilities, students whose first language is other than English, students of color for whom standardized diagnostic tools are invalid, and poor students whose parents are simply uninformed as to what is a learning disability are quite unlikely to be diagnosed at the elementary or secondary level of school. Moreover, a large number of individuals who because of their high IQs and strong work ethic, will not face the consequences of being dysfluent readers until the academic challenges overtake the number of hours in the day, as may happen in law school or medical school. Yet, it is precisely this latter group of students who Congress intended to cover in the 2008 ADA Amendments.

³³ 20 U.S.C. § 1400(d)(1)(A).

to be covered by the statute, a child must fit into one of the specifically listed disability categories. One of those categories is “specific learning disabilities.”

2. Definition of Disability

The IDEA defines “specific learning disability” as “a disorder in one or more of the basic psychological processes involved in understanding or using language, spoken written, which disorder may manifest itself in the imperfect ability to listen, think, speak, read, write, spell or do mathematical calculations.”³⁴ Thus, like the ADA and Section 504, it defines a specific learning disability as an impairment in a “process” that leads to the “imperfect ability” to engage in activities like reading.

Based on concerns about the way the discrepancy model was often implemented by school districts as an arbitrary calculation, Congress also specified the range of methods that states needed to make available to identify students with learning disabilities. Congress stated a school district “shall not be required to take into consideration whether a child has a severe discrepancy between achievement and intellectual ability in oral expression, listening comprehension, written expression, basic reading skill, reading comprehension, mathematical calculation, or mathematical reasoning.”³⁵ Further, Congress specified that a school district “may use a process that determines if the child responds to scientific, research-based intervention as a part of the evaluation procedures described in paragraphs (2) and (3).”³⁶ In other words, school districts can no longer be required to exclusively rely on particular discrepancy formulae (not the same as the concept of the discrepancy model); further, school districts must be permitted to use RTI. It is not accurate to say that the IDEA precludes school districts from using the discrepancy model although states are permitted to make that choice if they so desire.

Although Congress gave school districts the option of using the RTI process to identify students with learning disabilities, many parents and teachers complained that the RTI process was actually delaying disability identification for special educational services and accommodations, even in later grades where the RTI research is virtually non-existent and no actual evidence-based, effective reading interventions were being implemented. Thus, on January 21, 2011, the Office of Special Education and Rehabilitative Services issued a memo clarifying that the RTI process should not be “delaying or denying timely initial evaluations to children suspected of having a disability.”³⁷ It would be very troubling if adoption of the DSM-5 specific learning disorder criteria exacerbated this problem, and legitimized the already widespread pattern of illegal practices by school districts, by strongly endorsing the RTI approach as part of the diagnostic process.

³⁴ 20 U.S.C. § 1401(30).

³⁵ 20 U.S.C. § 1414(b)(6)(A).

³⁶ 20 U.S.C. § 1414(b)(6)(B).

³⁷ See <http://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/osep11-07rtimemo.pdf>.

The IDEA also does not limit coverage to those who are not attaining grade level expectations. Children can be classified as disabled and therefore entitled to a free appropriate public education “even though they are advancing from grade to grade.”³⁸

3. Problems with Proposed DSM-5 Rationale

The stated rationale for some of the language in the proposed DSM-5 is to align it with the current version of the IDEA. In fact, the proposed DSM-5 is not consistent with the IDEA. Unlike the IDEA, it requires the RTI approach and presumes that children who are classified as disabled are not meeting grade-level expectations. Also, the proposed DSM-5 does not describe a learning disorder as a “processing” disorder; instead, it describes a learning disorder as an achievement disorder. Moreover, IDEA is a statute that is reauthorized regularly and thus is subject to change in a manner inconsistent with the currently proposed DSM criteria, quickly making the DSM out of date.

“Learning disability” is, by far, the most common category of disability under the IDEA, yet it is still under-identified by schools. If the proposed DSM-5 criteria went into effect, it is possible that tens of thousands of children, who are currently classified under the discrepancy model or who are attaining grade level expectations though their reading lacks fluency, that is, it is effortful and slow, would no longer be considered disabled under the proposed DSM-5. The costs are too great. Data from juvenile and adult correctional facilities confirm that roughly 75% of inmate populations have childhood diagnoses or symptoms of dyslexia and related learning disabilities that have gone unaddressed. By contrast, those who have been identified as learning disabled and have received accommodations, whether formally or informally, have often gone on to great achievements.³⁹

III. Legal Summary

The proposed DSM-5 definition of “specific learning disorder”:

(1) requires more frequent clinical evaluations than contemplated by ADA, as recently amended by Congress and interpreted by the EEOC, Section 504 or the IDEA,

(2) presumes the availability of clinical evaluation during the “developmental years,” which will have a disproportionate impact against low-income and minority students who often do not have access to developmental testing,

(3) presumes the validity of RTI for all individuals with learning disabilities even though RTI does not emerge from well-respected research-based evidence and neither ADA, Section 504 nor IDEA require use of it; RTI is not applicable for and would therefore exclude older children and adults from diagnosis,

³⁸ 34 C.F.R. § 300.111(c)(2).

³⁹ See Betsy Morris, *Overcoming Dyslexia*, FORTUNE MAGAZINE (May 13, 2002) (available at http://money.cnn.com/magazines/fortune/fortune_archive/2002/05/13/322876/index.htm).

(4) presumes that RTI has been implemented on a large scale basis with the theoretical and practical fidelity necessary to underpin the DSM's reliance on it,

(4) defines learning disorders, including dyslexia, as if they were the same as academic or occupational failure rather than as a discrete life-long neuropsychological processing impairments, as contemplated by the ADA, Section 504 and IDEA,

(5) largely ignores the impact of accommodations on individuals' achievements even though ADA, Section 504 and IDEA require accommodations,

(6) presumes that individuals with learning disabilities have not been able to attain at least average performance even though both ADA, Section 504 and IDEA recognize the possibility of high-achieving individuals with disabilities, and

(7) does not recognize the discrepancy model for diagnosis (i.e., the unexpectedness of weaknesses where they would not normally exist) even though that model is recognized by ADA, Section 504 and IDEA and is fundamental to the category of learning disorders as it separates learning disorders from other disorders.

IV. Medical/Scientific Analysis

A. Dyslexia represents a specific disorder within the category of Specific Learning Disorders.

Dyslexia is the most prevalent, and, as noted earlier, the most carefully studied disorder in Specific Learning Disorders. In developing a scientifically-based nosology, dyslexia would seem to represent the exemplar of the goal of DSM, as stated in A Research Agenda for DSM-V, to lead to a more "etiologically-based diagnostic system" that would help psychiatry move... "into the mainstream of modern medicine where etiology and pathophysiology have replaced descriptive symptomatology as the fundamental basis for making diagnostic distinctions."⁴⁰ In fact, dyslexia represents the prototype of how a mental disorder is defined as "a clinically recognizable set of symptoms or behavior..."⁴¹

The proposed DSM criteria appear to ignore scientific advances in dyslexia, lumping a well-defined learning disorder, dyslexia, with other, not nearly as well understood learning difficulties. Such a major change is not supported by the evidence and does not appear to be warranted. To suddenly remove dyslexia, a disorder, supported by over a century of scientific evidence goes against science and the aims of DSM to allow researchers and clinicians to arrive at consistent, reliable scientifically-defensible diagnoses.

⁴⁰ Dennis Charney et al., *Neuroscience Research Agenda to Guide Development of a Pathophysiologically Based Classification System* in A RESEARCH AGENDA FOR DSM-V 31, 33(2002).

⁴¹ *Id.* at 2-3.

Experts have documented the significant disadvantages of changing criteria under previous versions of DSM for researchers, clinicians and policy makers.⁴² Thus, for research, proposed new criteria (e.g., requiring “response to intervention,” and requiring academic skills to be “well-below the average range”) pose a serious problem arising from incompatibilities in the data sets obtained using criteria from one DSM version and its successor. These changes in diagnostic criteria pose particular problems for longitudinal research projects that are “often the source of our best information about the causes and consequences of psychiatric illness.”⁴³ For research, questions arise about differences between the criteria in one DSM compared to the older version. Do these different criteria define same/different populations? Do the different criteria function differently as predictors of outcome or even mechanism? The changing criteria in different versions of DSM are very confusing and the new set of criteria may take a generation of doctors/practitioners to learn them. The problems for policy makers are discussed above in Part II (Legal Background section).

B. Dyslexia represents an unexpected difficulty in reading.

The clinical picture of dyslexia has been known for over a century. Since its first descriptions, (Morgan, 1896; Hinshelwood, 1917; Orton, 1937) dyslexia has been recognized as unexpected difficulties with reading and speaking in children and adults in comparison to their intelligence. The proposed DSM-5 criteria appear to be biased against and deny diagnosis and associated necessary interventions and accommodations to bright students with dyslexia such as Percy who was described by Dr. Morgan in 1896 and are more currently exemplified by Charles Schwab, Dr. Delos Cosgrove, Dr. Beryl Benacerraf, and Dr. Carol Greider, 2009 Nobel laureate in medicine. These individuals with dyslexia compellingly describe their struggles with their unexpected difficulties in reading and speaking.

The proposed DSM-5 criteria appear to deny the unexpected nature of dyslexia, contrary to converging scientific evidence (see below) and the law (see Part II (Legal Background), above), by making it imperative that diagnosis can only be made if the reading is well below average, regardless of the individual’s ability and the slow, effortful manner in which he or she must read. In the current schema, bright students with dyslexia who are discrepant, nonfluent, effortful readers and often, speakers, would find themselves no longer diagnosed as having a learning disorder and would be excluded from necessary interventions and accommodations on high stakes tests.

Recent evidence provides empiric validation for defining dyslexia as an unexpected difficulty in reading.⁴⁴ In typical readers, reading and IQ development are dynamically linked over time. Not only do reading and IQ track together over time, they also influence

⁴² Bruce Rounsaville et al., *Basic Nomenclature Issues for DSM-V* in A RESEARCH AGENDA FOR DSM-V 1, 10-11 (2002).

⁴³ *Id.* at 10.

⁴⁴ Emilio Ferrer et al., *Uncoupling of Reading and IQ Over Time: Empirical Evidence for a Definition of Dyslexia*, 21 PSYCHOL SCI 93 (2010).

one another. Such mutual interrelationships are not perceptible in readers with dyslexia, suggesting that reading and cognition develop more independently in these individuals.

These new data provide the first empirical demonstration of a coupling between cognition and reading in typical readers and a developmental uncoupling between cognition and reading in readers with dyslexia. Findings of an uncoupling between IQ and reading in dyslexia provide evidence to support the conceptual basis of dyslexia as an unexpected difficulty in reading in children who otherwise have the intelligence to learn to read but struggle to read fluently. Furthermore, the data indicate that, in the special case of dyslexia, a child or adult can be both bright and accomplished along with a much lower level of reading than expected for a person of their level of intelligence, level of education, or professional status. The implication is that, for individuals who are dyslexic, the appropriate comparison is between a person's ability and his or her reading. In dyslexia, a highly intelligent person may read at a level above average but below that expected, based on his/her intelligence, education, or accomplishments. In addition, children and adults who are dyslexic read in a different manner, condition and/or duration compared to typical readers (see Part II, Legal Analysis).

The reading difficulties experienced by readers whose reading is discrepant from their level of intelligence are at their core, no different from those experienced by low achieving readers, except that they are unexpected. Not surprisingly, studies find overlap between the two groups on reading-related constructs, including phonologic processing, but not on IQ-related measures.⁴⁵ In addition, both low-achieving and discrepant readers demonstrate comparable growth rates in word reading during the school years; discrepant were the lowest achievers at any given level of IQ, *i.e.*, the reading deficit in the discrepant was often more severe than in the low achieving group.⁴⁶ Not only do poor readers identified by either discrepancy or low-achievement criteria resemble one another on measures of reading and growth rates of reading, but each group also differs along multiple dimensions from groups of typically achieving boys and girls.

Together, these data indicate that discrepant readers have a relatively circumscribed deficit in phonological processing, the core deficit implicated in the reading difficulties experienced by readers with dyslexia, while low achieving readers have, in addition to a phonological weakness, a more global set of weaknesses related to those measured on tests of intelligence. Thus, converging cognitive and neurobiological evidence together with studies of discrepant compared to low achieving individuals with dyslexia describe an entity, dyslexia, encompassing struggling readers identified either by unexpected reading difficulties, compared either to their intelligence or to their age.

The authors of the proposed criteria seem to ignore and/or misinterpret the overwhelming evidence of the similarities between struggling readers identified by discrepant compared

⁴⁵ See Karla Stuebing et al., *Validity of IQ-Discrepancy Classification of Reading Disabilities: A Meta-Analysis*, 39 AMERICAN EDUCATIONAL RESEARCH JOURNAL 469 (2002).

⁴⁶ See David Francis et al., *Developmental Lag Versus Deficit Models of Reading Disability: A Longitudinal, Individual Growth Curves Analysis*, 88 JOURNAL OF EDUCATIONAL PSYCHOLOGY 100 (1996).

to simply low-achieving poor readers who score below a certain cut point. Findings that there is overlap, and indeed similarities in critical reading-related variables between low achieving and discrepant readers with dyslexia are good evidence that when it comes to reading, both groups are impaired and struggle.

There is no rationale, then, to diagnose one group and to deny diagnosis to the other group. That the discrepant group who have strong reasoning and other cognitive skills should struggle to read, similar to the low achievement group who have a range of cognitive difficulties, is a powerful testament to the unexpected nature and reality of the discrepant group's reading difficulties. This accumulating evidence supports identification criteria for dyslexia that include both low-achieving children and those struggling readers who are discrepant but who do not satisfy an arbitrary cut point for designation as low achieving. There is no scientific or logical reason to exclude either group.

The DSM-5 proposed criteria narrowing the diagnoses to only those who score "well below the average range" (well below the 16th percentile) are contrary not only to scientific findings but to the explicitly stated intent of the ADA and EEOC regulations, as discussed in Part II (Legal Background). The determination is correctly made on the basis of not the percentile of a reading score, but on the basis of the condition, manner or duration of how a person reads which should not and does not require statistical analysis. The very narrow statistical approach proposed in DSM-5 prevents the clinician from applying all that is known scientifically about dyslexia including its neurobiology, phonologic basis, symptoms arising from the phonological weakness, evidence-based interventions, developmental course and outcome (see below).

The proposed criteria represent a great disservice to clinicians who are denied access to the most up-to-date scientific knowledge of dyslexia which, in turn, empowers him or her to use scientific understanding of dyslexia to assess a potential patient with dyslexia based on the known neurobiological and cognitive basis of the patient's symptoms rather than have the clinician memorize a list of "features" that reflect nothing of the known pathophysiology of the disorder. In addition, once aware of the underlying pathophysiology, the diagnostician can effectively provide the patient not only the diagnosis, but explain the impact and implications of what is known of the disorder. The proposed DSM-5 criteria deny both clinician and patient this valuable knowledge.

By insisting that a mandatory criterion for diagnosis is "well below average," the proposed DSM criteria for SLD make a statistical and not a clinical diagnosis. If the patient scores above this mandatory statistical cut-off, the clinician is prevented from synthesizing and utilizing the full range of clinical information obtained in order to diagnose the patient.

C. Pathophysiology of Dyslexia: the Phonologic Basis of Speaking and Reading.

The clinical picture of dyslexia been known for over a century, and now, evidence accumulated over the last three decades has unequivocally demonstrated that dyslexia

involves a difficulty within the language system, and even more specifically, a particular component of the language system, phonology. Individuals with dyslexia have difficulty accessing the basic sounds of spoken language impacting both spoken language and reading. Knowledge of the pathophysiology of dyslexia leads directly to an understanding of the resulting symptoms.

Spoken language difficulties in dyslexia may present early in development as delayed language or as a tendency to mispronunciations. As the child develops, problems in word retrieval become noticeable and last through adulthood.⁴⁷ In fact, this fundamental difficulty with word retrieval has been noted in dyslexia for over four decades.⁴⁸ These problems in spoken language are best accounted for by Levelt's 2 step model of word retrieval.⁴⁹ As readers with dyslexia mature, they continue to experience phonological processing difficulties that continue to interfere with, and make it difficult to retrieve phonological codes. As a result of this fundamental difficulty in word retrieval, individuals with dyslexia are not glib – particularly when put on the spot or under stress, and instead manifest word-finding difficulties. Consequently, there are lots of um's and pauses, circumlocutions and mispronunciations, or the person talks around the word or he or she utters a word that seems similar to the intended word – and anxiety compounds this inherent difficulty experienced by individuals with dyslexia even more. A recent study emphasizes that spoken language problems persist even in high-functioning young adults with dyslexia.⁵⁰

“In the course of 30 years or so, the idea that reading words requires phonology has ascended from a minority view to one with such a substantial majority that it now amounts to a conventional wisdom.”⁵¹ Evidence is overwhelming that to read, the beginning reader must connect the letters and letter strings (i.e., the orthography) to something that already has inherent meaning - the sounds of spoken language. In the process, a child has to develop the insight that spoken words can be pulled apart into the elemental particles of speech (i.e., phonemes) and that the letters in a written word represent these sounds;⁵² such awareness is largely deficient in children and adults with

⁴⁷ Miriam Faust et al., *Naming Difficulties in Children with Dyslexia; Application of the Tip-of-the Tongue Paradigm*, 40 JOURNAL OF LEARNING DISABILITIES 1026 (2003).

⁴⁸ See Julie Dockrell et al., *Children with Word-Finding Difficulties – Prevalence, Presentation and Naming Problems*, 33 INTERNATIONAL JOURNAL OF LANGUAGE & COMMUNICATION DISORDERS 445 (1998); Diane German & Elaine Simon, *Analysis of Children's Word-Finding Skills in Discourse*, 34 JOURNAL OF SPEECH, LANGUAGE, AND HEARING RESEARCH 309 (1991); Perfetti & Hogaboam, *Relationship Between Single Word Decoding and Reading Comprehension Skill*, 67 JOURNAL OF EDUCATIONAL PSYCHOLOGY 461 (1975).

⁴⁹ See Willem Levelt et al., *A Theory of Lexical Access in Speech Production*, 22 BEHAVIORAL AND BRAIN SCIENCES 1 (1999).

⁵⁰ Tyler Perrachione et al., *Human Voice Recognition Depends on Language Ability*, 333 SCIENCE 595 (2011).

⁵¹ Charles Perfetti, *Phonology is Critical in Reading: But phonological deficit is not the only source of low reading skill* in EXPLAINING INDIVIDUAL DIFFERENCES IN READING (Brady et al eds. 2011).

⁵² See Sally Shaywitz, *OVERCOMING DYSLEXIA: A NEW AND COMPLETE SCIENCE-BASED PROGRAM FOR READING PROBLEMS AT ANY LEVEL* (2003).

dyslexia.⁵³ Results from large and well-studied populations with reading disability encompassing the full developmental spectrum confirm that in young school-age children⁵⁴ and in adolescents,⁵⁵ a deficit in phonology represents the most robust and specific correlate of reading disability⁵⁶ Such findings form the basis for the most successful and evidence-based interventions designed to improve reading.⁵⁷ Longitudinal data indicate that with effective interventions reading accuracy may improve; however, the reader with dyslexia remains nonfluent, reading effortfully and slowly throughout life.⁵⁸

D. Neurobiology of dyslexia.

To a large degree, advances in our understanding the neurobiological underpinnings of dyslexia have been made possible because of the significant advances in understanding dyslexia, its: historical roots, symptoms, unexpected nature, and phonologic basis. Thus, the well-developed and well-studied knowledge of the phonologic underpinnings of dyslexia allowed neuroscientists to focus neurobiological studies within a specified theoretical framework, rather than simply a non-theoretical fishing expedition using the tools of neurobiology. For example, understanding the phonological basis of reading led neuroscientists to develop neuroimaging methods for the study of dyslexia based on the phonological theory. In contrast, in other learning domains, the theoretical framework is far less developed and not surprisingly, neurobiological studies have not advanced as far as in dyslexia.

Converging evidence from many laboratories around the world has demonstrated what has been termed “a neural signature for dyslexia,” that is, inefficient functioning of left posterior reading systems during reading real words and pseudowords, and often what has been considered as compensatory overactivation in other parts of the reading system, but not in the neural system required for fluent, automatic reading. This evidence from functional brain imaging has, for the first time, made visible what previously was a hidden disability.⁵⁹ Other studies report similar findings in readers with dyslexia speaking German,⁶⁰ Italian,⁶¹ French⁶² and Chinese.⁶³

⁵³ See Isabelle Liberman & Donald Shankweiler, *On Phonology and Beginning Reading* in LEARNING TO READ: BASIC RESEARCH AND ITS IMPLICATIONS (Rieben & Perfetti eds. 1991); Donald Shankweiler et al., *The Speech Code and Learning to Read*, 5 JOURNAL OF EXPERIMENTAL PSYCHOLOGY: HUMAN LEARNING AND MEMORY 531 (1979).

⁵⁴ See Keith Stanovich & L.S. Siegel, *The Phenotypic Performance Profile of Reading-Disabled Children: A Regression-Based Test of the Phonological-Core Variable-Difference Model*, 86 JOURNAL OF EDUCATIONAL PSYCHOLOGY 24 (1994).

⁵⁵ See Sally Shaywitz et al., *Persistence of Dyslexia: The Connecticut Longitudinal Study at Adolescence*, 104 PEDIATRICS 1351 (1999).

⁵⁶ See Robin Morris et al., *Subtypes of Reading Disability: Variability Around a Phonological Core*, 90 J. EDUC. PSYCHOL. 347 (1999).

⁵⁷ See National Reading Panel, *TEACHING CHILDREN TO READ* (2000).

⁵⁸ See Emilio Ferrer et al., *Uncoupling of Reading and IQ Over Time: Empirical Evidence for a Definition of Dyslexia*, 21 PSYCHOL SCI 93 (2010).

⁵⁹ See Fabio Richlan et al., *Meta-Analyzing Brain Dysfunctions in Dyslexic Children and Adults*, 56 NEUROIMAGE 1735 (2011); Sally Shaywitz & Bennett Shaywitz, *Dyslexia (specific reading*

Critical for reading fluency, (reading automatically and rapidly), is the reading system localized in the left ventral occipito-temporal area which Cohen and Dehaene have termed the visual word-form area⁶⁴ and Price and her colleagues refer to as the ventral occipitotemporal cortex.⁶⁵ Recent studies have also examined the development of this fluency system⁶⁶ as well as the connectivity of the ventral occipitotemporal system to other major language areas.⁶⁷

Summary:

- Dyslexia represents the prototype of how a mental disorder is defined: “a clinically recognizable set of symptoms or behavior...” whose pathophysiology is explained by findings emerging from neuroscience and cognitive science.
- Proposed SLD criteria are at variance with the stated goals of DSM-5 to develop “a neuroscience-based framework that can contribute to a nosology in which disorders are grouped by underlying pathophysiological similarities rather than phenomenological observations.”⁶⁸

disability), 57 *BIOLOGICAL PSYCHIATRY* 1301 (2005); Cathy Price & Andrea Mechelli, *Reading and Reading Disturbance*, 15 *CURRENT OPINION IN NEUROBIOLOGY* 231 (2005)(reviewing studies)

⁶⁰ See Martin Kronbichler et al., *Evidence for a Dysfunction of Left Posterior Reading Areas in German Dyslexic Readers*, 44 *NEUROPSYCHOLOGIA* 1823 (2006).

⁶¹ See Simona Brambati et al., *Neuropsychological Deficits and Neural Dysfunction in Familial Dyslexia*, 1113 *BRAIN RES.* 174 (2006).

⁶² See Eraldo Paulesu et al., *Dyslexia: Cultural Diversity and Biological Unity*, 291 *SCIENCE* 2165 (2001).

⁶³ See Wei Hu et al., *Developmental Dyslexia in Chinese and English Populations: Dissociating the Effect of Dyslexia from Language Differences*, 133 *BRAIN* 1694 (2010).

⁶⁴ See Laurent Cohen et al., *The Visual Word Form Area: Spatial and Temporal Characterization of an Initial Stage of Reading in Normal Subjects and Posterior Split-Brian Patients*, 123 *BRAIN* 291 (2000); Stanislas Dehaene et al., *The Neural Code for Written Words: A Proposal*, 9 *TRENDS COGN. SCI.* 335 (2005); Fabien Vinckier et al., *Hierarchical Coding of Letter Strings in the Ventral Stream: Dissecting the Inner Organization of the Visual Word-Form System*, 55 *NEURON* 143 (2007).

⁶⁵ See Cathy Price & Joseph Devlin, *The Interactive Account of Ventral Occipito-temporal Contributions to Reading*, 15 *Trends in Cognitive Neuroscience* 246 (2011) (reviewing studies).

⁶⁶ See Michal Ben-Shachar et al., *Contrast Responsivity in MT+ Correlates with Phonological Awareness and Reading Measures in Children*, 37 *NEUROIMAGE* 1396 (2007); Sanne van der Mark et al., *Children with Dyslexia Lack Multiple Specializations Along the Visual Word-Form (VWF) System*, 47 *NEUROIMAGE* 1940 (2007).

⁶⁷ See Sanne vanderMark et al., *The Left Occipitotemporal System in Reading: Disruption of Focal fMRI Connectivity to Left Inferior Frontal and Inferior Parietal Language Areas in Children with Dyslexia*, 54 *NEUROIMAGE* 2426 (2011).

⁶⁸ David Kupfer & Darrel Regier, *Neuroscience, Clinical Evidence, and the Future of Psychiatric Classification in DSM-5*, 168 *AM. J. PSYCHIATRY* 1, 2 (2011).

- Well-established neuroscientific and cognitive-based pathophysiologic criteria exist to provide a neuroscience-based framework for dyslexia and yet, are entirely absent from the criteria proposed for DSM-5 Learning Disorders. As if totally unaware of the progress in neuroscience and cognitive science in dyslexia, the proposed criteria continue to resort to phenomenology.
- Inexplicably, the authors of the current criteria have ignored converging findings demonstrating the neurobiological signature for dyslexia.
- The Specific Learning Disorder criteria fail to take advantage of all that is known about dyslexia. Instead of holding dyslexia up as a model, scientifically-informed disorder to which other learning domains could eventually aspire to emulate, the proposed criteria eliminate dyslexia, treating dyslexia as if it is a poorly understood difficulty rather than a disorder understood at a neurobiologic and cognitive level.
- If DSM-5 is intended as “first and foremost a tool for clinicians,”⁶⁹ elimination of dyslexia will negatively impact the clinician’s ability to accurately and knowledgeably diagnose this overwhelmingly most common LD.
- The proposed criteria represent a great disservice to clinicians who are denied access to the most up-to-date scientific knowledge of dyslexia. Rather than have the clinician memorize a list of “features” which reflect nothing of the known pathophysiology of the disorder, awareness of the neurobiological and cognitive underpinnings of dyslexia empower the clinician to use scientific understanding of dyslexia to assess and accurately diagnose the patient.
- This major change appears to violate the admonition noted in the Research Agenda for DSM-V “that frequent changes in diagnostic criteria can potentially discredit the revision process and increase the chances of the DSM becoming the subject of ridicule.”⁷⁰ But more than ridicule, there is the strong possibility of making DSM irrelevant if the change (in this case, elimination of a neurobiologically validated disorder, dyslexia), will be viewed by clinicians, scientists, policy makers and the public as foolish, harmful and regressive.
- Contrary to converging scientific evidence and the law, the proposed DSM-5 criteria appear to deny the unexpected nature of dyslexia. Proposed criteria appear to make it imperative that diagnosis can be made only if the reading is well below average, regardless of the individual’s ability and the slow, effortful manner in which he or she must read. In the current schema, bright students with dyslexia who are discrepant, nonfluent, effortful readers and often, speakers, would be greatly harmed, finding themselves no longer diagnosed as having a

⁶⁹ *Id.* at 2.

⁷⁰ Bruce Rounsaville et al., *Basic Nomenclature Issues for DSM-V* in A RESEARCH AGENDA FOR DSM-V 1, 7 (2002).

learning disorder and excluded from necessary interventions and accommodations on high stakes tests.

- DSM-5 proposed criteria restricting the diagnoses to only those who score well below the average range are not only contrary to scientific findings, but also the ADA Amendments Act of 2008 and its regulations which state that the condition, manner or duration of how a person reads must be considered and this should not require statistical analysis. Individuals with dyslexia scoring at higher levels may still not read in the same manner as others. The criteria of a “well below the average range” in the proposed criteria serve to summarily eliminate and prevent large numbers of individuals who do not read in the same manner, condition and duration as others from receiving a diagnosis.
- This very narrow proposed “statistical” approach prevents the clinician from applying all that is known scientifically about dyslexia including its neurobiology, phonologic basis, symptoms (lack of reading fluency; word retrieval difficulties) arising from the phonological weakness, developmental manifestations and course, evidence-based interventions, and outcome.
- Once aware of the underlying pathophysiology, the diagnostician can effectively provide the patient not only the diagnosis, but explain the impact and implications of what is known of the disorder. The proposed DSM-5 criteria deny both clinician and patient this valuable knowledge.
- Recommendation: Recognize that the scientific knowledge of dyslexia conforms to a neuroscience-based framework. Utilize the neurobiological, cognitive and developmental data to develop criteria for dyslexia. Divide the category of “specific learning disorder” into (1) Dyslexia, where much is known scientifically and clinically, and the criteria are based on science; and (2) Other Learning Disorders, less well characterized, whose neurobiology, pathophysiology, and developmental course are not as clearly delineated at this time.

V. Proposed Criteria

A 08 Specific Learning Disorder

A diagnosis of Specific Learning Disorder is made by a clinical synthesis of the individual’s history (development, medical, family, education), psycho-educational reports of test scores and observations. Two categories of Specific Learning Disorder are recognized: 1. Dyslexia/Specific Reading Disorder and 2. Other Learning Disorders.

A 08.1 Dyslexia/Specific Reading Disorder

- A. History or current presentation of persistent difficulties in the acquisition and/or proficiency of accurate and fluent reading of individual words and/or connected text, often, but not necessarily, noted during the school years (i.e., during the developmental period). In adults who may not have been formally diagnosed during the developmental period, a history of the above difficulties will be elicited. Reading comprehension may be unimpaired, provided the individual has received the accommodation of extra time, formally or informally, to compensate for the continued persistence of the lack of fluency (slow reading). Individuals with dyslexia often possess strengths in higher level cognitive function such as thinking, reasoning and analytic abilities. The symptoms of dyslexia are best explained as emanating from a difficulty within the phonologic component of the language system. Other cognitive processes may be involved as well, for example, slow processing speed, but have not as yet been as well delineated. The symptoms noted below will have different manifestations depending on the developmental trajectory; for example, reading accuracy may improve significantly during development while difficulties in word retrieval, spelling and reading fluency, manifest as slow, effortful reading, persist through adulthood.

Spoken Language - at least one of the following:

1. Slow learning to talk (early childhood)
2. Trouble recognizing words that rhyme (e.g., cat, bat, hat) (early childhood)
3. Mispronounces and/or confuses words that sound alike (e.g., *tornado* for *volcano*) (school-age through adult)
4. Struggle to retrieve words: "It was on the tip of my tongue" (school-age through adult)

Reading - at least two of the following:

1. Trouble learning letters, letter-sounds, and/or sounding out words (early childhood -school-age)
2. Inaccurate reading of words (school age-adult, with good instruction improves over development)
3. Reading slow and effortful, need to reread (school age through adult, persistent across development)
4. Avoids reading aloud (school age through adult)
5. Poor spelling (e.g., may add, omit, or substitute vowels or consonants, prefixes or suffixes) (school-age through adult)
6. Difficulty learning a foreign language (school-age through adult)
7. Inability to complete timed tests (school-age through adult)

- B. Performance in reading is unexpected 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.

- C. The reading difficulties are not better explained by Intellectual Developmental Disorder, Global Developmental Delay, neurological, sensory (vision, hearing), or motor disorders.
- D. Reading difficulties identified in Criterion A without accommodations (i.e., in the absence of the tools, supports, services that have been provided to enable the individual to compensate or internally developed compensatory strategies), significantly interfere with academic achievement, performance on examinations or activities of daily living that require these language and/or reading skills, alone or in any combination. Individuals who have been provided with the instruction and/or accommodations are often capable of high performance in academic skills and in the workplace.

A 08.2 Other Learning Disorders

- A. History or current presentation of persistent difficulties in the acquisition and/or proficiency in reading comprehension, written expression, arithmetic, or mathematical reasoning, often, but not necessarily noted during the school years (i.e., during the developmental period). The individual must have at least one of the following:
 - 1. Difficulty understanding the meaning of what is read (e.g., may read text accurately but not understand the sequence, relationships, inferences, or deeper meanings of what is read)
 - 2. Poor written expression (e.g., makes multiple grammatical or punctuation errors within sentences, written expression of ideas lack clarity, poor paragraph organization, or excessively poor handwriting)
 - 3. Difficulties remembering number facts
 - 4. Inaccurate or slow arithmetic calculation
 - 5. Ineffective or inaccurate mathematical reasoning
 - 6. Avoidance of activities requiring reading comprehension, writing or arithmetic
- B. Performance in one or more of these skills or their underlying cognitive processes is unexpected 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 comprehension, writing, or mathematics, and/or underlying processes, such as oral language or processing speed.
- C. Learning difficulties identified in Criterion A without accommodations (i.e., in the absence of the tools, supports, or services that have been provided, formally or informally, to enable the individual to compensate for these difficulties),

significantly interfere with academic achievement, performance on examinations or activities of daily living that require these skills, alone or in any combination.

Individuals who have been provided with the instruction and/or accommodations are often capable of high performance in academic skills and in the workplace.

- D. The learning difficulties are not better explained by Intellectual Developmental Disorder, Global Developmental Delay, neurological, sensory (vision, hearing), or motor disorders.

Descriptive Feature Specifiers

For individuals in the Other Learning Disorders category, specify which of the following domains of academic difficulties and their subskills are impaired, at the time of assessment:

1. Reading comprehension
2. Written expression
 - a) Spelling accuracy (including spontaneous spelling)
 - b) Grammar and punctuation accuracy
 - c) Legible or fluent handwriting
 - d) Clarity and organization of written expression
3. Mathematics
 - a) Memorizing and automaticity of arithmetic facts
 - b) Accurate or fluent calculations
 - c) Effective and efficient math reasoning

Rationale for changes in Dyslexia/Reading Disorder in DSM-5

Dyslexia/Reading disorder was included in DSM-IV and the criteria proposed here (in these comments) for DSM-5 now elaborate on and update the description in DSM-IV based on recent clinical, pathophysiologic and neurobiological data.

While the clinical picture of dyslexia has been known for over a century, recent evidence provides empiric validation for defining dyslexia as an unexpected difficulty in reading. Evidence accumulated over the last three decades has unequivocally demonstrated that dyslexia involves a difficulty within the language system, and even more specifically, a particular component of the language system, phonology. Individuals with dyslexia have difficulty accessing the basic sounds of spoken language impacting both spoken language and reading.

Advances in neuroimaging have provided converging evidence from many laboratories around the world of what has been termed “a neural signature for dyslexia,” that is, inefficient functioning of left posterior reading systems during reading real words and pseudowords, and often what has been considered as compensatory overactivation in other parts of the reading system. This evidence from functional brain imaging has, for the first time, made visible what previously was a hidden disability and further, provides

a neurobiological explanation for the clinical symptoms in dyslexia, including the lack of reading fluency. These findings have been reported in English speaking dyslexic readers and similar findings have been reported in dyslexic readers speaking German, Italian, French and Chinese.

Critical for reading fluency, (reading automatically and rapidly), is the reading system localized in the left ventral occipito-temporal area which Cohen and Dehaene have termed the visual word-form area and Price and her colleagues refer to as the ventral occipitotemporal cortex. Recent studies have also examined the development of this fluency system as well as the connectivity of the ventral occipitotemporal system to other major reading and language areas.

Thus, in the interim between DSM-IV and currently, evidence from a number of lines of investigation now provides a pathophysiologic and neuroscience-based framework for dyslexia that did not exist when DSM-IV was written. In fact, this evidence is so compelling that dyslexia represents the prototype of how a mental disorder should be defined, “a neuroscience-based framework that can contribute to a nosology in which disorders are grouped by underlying pathophysiological similarities rather than phenomenological observations.”⁷¹

Specific Gender Features

Occurs slightly more often in males

Prevalence

Epidemiologic studies in which a population is tested indicate 15%-20% affected.

Developmental Course

Persistent, life long. Important to be aware that accuracy may improve over the course of development. However, difficulties with reading fluency persist, resulting in accurate but not automatic and slow reading. Word retrieval difficulties typically persist throughout life. For fear of misspeaking or mispronouncing a word, many individuals who are dyslexic, will exhibit a spoken language vocabulary that appears to be much smaller than their listening vocabulary.

Familial Pattern

Both genetic and environmental factors implicated.

Cultural

Dyslexia is reported in all parts of the world and in both alphabetic and logographic languages. An important difference exists between onset of symptoms in different languages. For example, in so-called shallow orthographies (e.g., Finnish, Italian, Spanish, German) there is a good correlation between the way a letter looks and the way it sounds. As a result children who are dyslexic may learn to read accurately with little difficulty early on, but experience increasing difficulty as they mature which is typically

⁷¹ David Kupfer & Darrel Regier, *Neuroscience, Clinical Evidence, and the Future of Psychiatric Classification in DSM-5*, 168 AM. J. PSYCHIATRY 1, 2 (2011).

manifest by a lack of fluency. In contrast, in deep orthographies such as English or French, a single letter may have several different pronunciations so that there is a much lower correlation between the letter and its sounds, for example, the letter “a” may have several sounds, for example, “apple” versus “arm” versus “gate.” In English, difficulties may impact reading accuracy and may, though not invariably, be observed early on. In some cases, children are able to memorize words and/or use their good vocabularies and contextual information to guess at words; in these cases their difficulties in reading may not be noticed until later childhood or when they are adults.

Rationale for changes in Other Learning Disorders in DSM-5

No previous general criteria for learning disorders.

- Learning disorders interfere with the acquisition and use of one or more of the following skills: oral language, reading, written language, mathematics. These disorders affect individuals who otherwise demonstrate at least average abilities essential for thinking or reasoning. As such, Learning Disorders are distinct from Intellectual Developmental Disorder.
- The Learning Disorder Not Otherwise Specified category may be coded under this super-ordinate category of Learning Disorder.

Severity

Recommendations for severity criteria for this disorder are forthcoming. We encourage you to check our Web site regularly for updates.