

## ETHICS CASE

### How Should Medical Schools Respond to Students with Dyslexia?

Commentary by Frederick Romberg, MD, Bennett A. Shaywitz, MD, and Sally E. Shaywitz, MD

#### Abstract

We examine the dilemmas faced by a medical student with dyslexia who wonders whether he should “out” himself to faculty to receive the accommodations entitled by federal law. We first discuss scientific evidence on dyslexia’s prevalence, unexpected nature, and neurobiology. We then examine the experiences of medical students who have revealed their dyslexia to illustrate the point that, far too often, attending physicians who know little about dyslexia can misperceive the motives or behavior of students with dyslexia. Because ignorance and misperception of dyslexia can result in bias against students with dyslexia, we strongly recommend a mandatory course for faculty that provides a basic scientific and clinical overview of dyslexia to facilitate greater understanding of dyslexia and support for students with dyslexia.

#### Case

Dr. Miller is a senior physician and an influential administrator at a medical school. She is meeting with James, an incoming first-year medical student. James has dyslexia and requested to meet with Dr. Miller when he heard of her past efforts to try to help students with disabilities. James informs Dr. Miller that he was diagnosed with dyslexia after his fourth grade teacher noted his difficulty with reading and his parents arranged for him to be assessed by an educational psychologist. In grade school, he attended special reading programs to improve his reading and spelling skills. He studied twice as hard as his peers, received accommodations for extra testing time from grade school through college, and performed well in school exams.

By his junior year of college, James had maintained a GPA of 3.8 and excelled in clinical research in the Department of Radiology at his school’s affiliated medical school, fueling his ambition to become a radiologist. He took the Medical College Admissions Test (MCAT) with accommodations and was accepted to his college’s affiliated medical school, where he enrolled. Now a first-year medical student, James is struggling with the fear that his dyslexia will negatively impact his education, performance, and reputation among faculty and fellow students. He explains to Dr. Miller that he is worried that requesting accommodations could lead faculty and classmates to perceive him as less

capable of becoming a qualified physician. However, he knows that he would struggle to perform well in medical school without accommodations.

Dr. Miller realizes that James will likely suffer either way that she advises him. That is, either James must “out” himself to faculty and administrators if he is to use accommodations and thus risk being stigmatized, or he must remain silent about his disability and take his exams without accommodations to which he is legally entitled and risk performing poorly in his medical school coursework. Dr. Miller feels dismayed about this dilemma and wonders how her medical school’s policies and culture can be reformed to advocate for students like James. Specifically, she has wanted to make her medical school’s environment more accepting of students with disabilities for a few years now, but she’s also aware that this might upset some influential faculty who are not supportive of this goal. Dr. Miller wonders what to do next.

### **Commentary**

In our experience, James’s history and current dilemma are quite common. Dyslexia was first reported in 1896 in the *British Medical Journal* by a physician, W. Pringle Morgan [1], and, since that initial report, major medical journals including *JAMA*, the *New England Journal of Medicine*, and the *Journal of Pediatrics* have continued to publish research furthering the scientific understanding of dyslexia [2-4]. Given the scientific progress in understanding the epidemiology, cognitive basis, and neurobiology of dyslexia, it is surprising that ignorance of the condition persists [5]; such ignorance continues to result in faculty misperceptions of dyslexia. For example, the very common and physiologically based symptom of slow reading in dyslexia can be misinterpreted as slow thinking; a resulting need for additional time on tests can then be misperceived as trying to game the system. Over time, accumulating misperceptions create a negative, though false, image that can marginalize and bring harm to the medical student with dyslexia, the medical school, and the medical school’s faculty. We suggest that knowledge of dyslexia’s scientific basis and resulting symptoms would improve the medical climate for students with dyslexia as well as the faculty and should be widely disseminated within and across the medical school community.

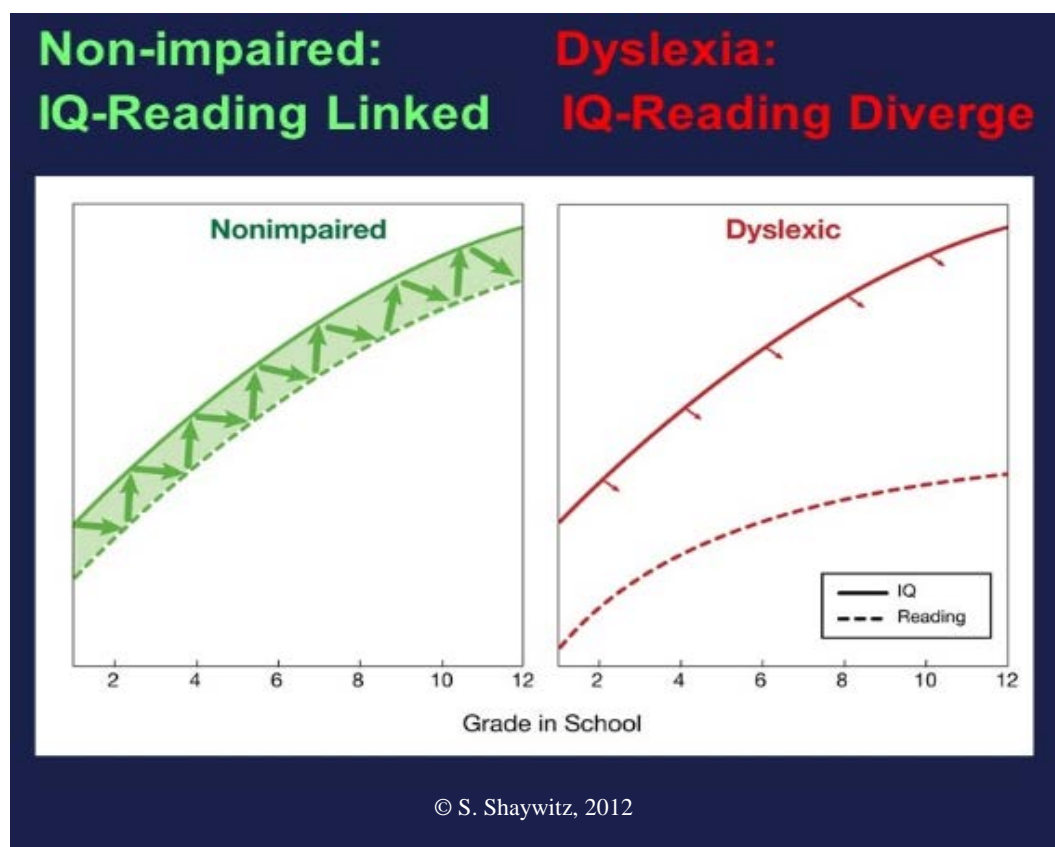
### **Understanding Dyslexia**

To begin with, it is important to understand the critical difference between dyslexia and [learning disabilities](#). In contrast to dyslexia, which is a highly specific condition, learning disabilities represent a more general, nonspecific category. To illustrate, the difference between learning disability and dyslexia parallels the difference between diagnosing a sore throat as an “infectious disease” which is nonspecific, or as “strep throat,” which is highly specific and amenable to a targeted, evidence-based treatment, penicillin.

*Prevalence.* Dyslexia affects 20 percent of the US population [2, 6, 7]. It occurs cross-culturally and knows no boundaries of language, geography, socioeconomic status, race,

ethnicity, or gender. To illustrate its cross-cultural nature, *Overcoming Dyslexia*, written by one of us (SES), has been translated into multiple languages, including not only alphabetic scripts but also logographic scripts such as Japanese, Korean, and Mandarin [8].

*Definition.* Although first described in the late nineteenth century, increasing scientific understanding of and interest in dyslexia has led to a twenty-first century definition of the condition, emphasizing that dyslexia is “an *unexpected* difficulty in reading for an individual who has the intelligence to be a much better reader” (italics added) [9]. Empirical evidence supports this definition. Ferrer et al.’s 2010 study [6] reports that, in typical readers, intelligence and reading are dynamically linked; over time, reading and IQ mutually influence one another. In other words, if someone is very bright, he or she can be expected to be a very good reader and, conversely, if someone is a very good reader, he or she is most often quite bright, (see figure 1, left panel). In contrast, in people who have dyslexia, IQ and reading are not linked and do not mutually influence one another (see right panel in figure 1). In other words, *a person with dyslexia can be quite intelligent and yet not read quickly.*



**Figure 1.** Scientific validation of “unexpected”—dynamic linkage between IQ and reading in typical readers and their divergence in dyslexia [6]. © 2012 by S. Shaywitz.

Awareness by faculty and students alike that in dyslexia there is a disparity between a person's often high intelligence (for example, as measured by the Wechsler Adult Intelligence Scale) and the same person's slow, effortful reading should be a powerful antidote to the mistaken belief that those who have dyslexia are not intelligent. Testifying before the US Senate Health, Education, Labor and Pensions Committee hearing on dyslexia on May 10, 2016, attorney David Boies, who is open about his dyslexia [10], commented on the disconnect between a person with dyslexia's ability to reason and analyze and that person's reading speed: "Success in life is not a function of how fast a person can read" [11].

*Deficit in decoding.* The first step in learning to read is mastering decoding, or breaking a word into its letter sounds. Decoding words is so hard for people with dyslexia because, at its core, dyslexia is a difficulty in phonology, i.e., appreciating the elemental sound structure of spoken language. In brief, the phonologic theory recognizes that speech is natural and inherent, but that reading is acquired and must be taught. 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; such awareness is largely deficient in children and adults with dyslexia [8]. As readers gain experience and continue to practice reading they develop reading fluency, the ability to read accurately, rapidly, and with good prosody. Reading fluency is of critical importance because it allows for the automatic, attention-free recognition of words.

Research has demonstrated that early interventions designed to improve the child's ability to decode words are helpful and will allow the child with dyslexia to become an accurate, *but not a fluent*, reader [12]. A person with dyslexia can be intelligent, even highly intelligent, and learn to read accurately and with good comprehension but, for physiological reasons, must read slowly and with some effort—that is, not automatically or efficiently. As a consequence, readers with dyslexia must focus their attention and concentrate very hard on the page in front of them. Assuming that medical school faculty members are aware that a student has dyslexia, understanding its impact should allow acceptance of the student's need for a separate, quiet room and extra time for test taking [8].

It is also well established that, when speaking, the person with dyslexia has difficulties in word retrieval—that is, the problem is not in conceptualizing what he or she wants to say *but in the act of retrieving the specific words he or she intends to say* [13]. The result is that a person with dyslexia may not be able to respond quickly to a question—even when he or she knows the answer. If attending physicians understood the symptoms and underlying neurobiological basis of dyslexia, they might be more supportive when

trainees who might have dyslexia are slow to retrieve the answer to a question. Unfortunately, in our experience, many physicians are not aware of scientific progress in dyslexia and know little about the condition. This, despite the fact that many extraordinarily accomplished physicians have—and are open about having—dyslexia [8, 14], including Delos “Toby” Cosgrove, cardiac surgeon and CEO of the Cleveland Clinic [15]; Beryl Benacerraf, professor of radiology at Harvard Medical School and international authority on prenatal ultrasonography [16]; Karen Santucci, professor of pediatrics at Yale Medical School and chief of the pediatric emergency department [17]; and Stuart C. Yudofsky, Distinguished Service Professor and chairman, Menninger Department of Psychiatry & Behavioral Sciences and the Drs. Beth K. and Stuart C. Yudofsky Presidential Chair in Neuropsychiatry at Baylor College of Medicine [18].

### **Misunderstanding Dyslexia**

As James’s situation demonstrates, the medical student with dyslexia is frequently faced with what seem to be two very poor choices: if the student self-identifies as having dyslexia and asks for what he physiologically requires—the [accommodation of extra time](#)—his instructors and other students might think he is not very smart or is trying to game the system. However, if the student does not self-identify, he will not receive accommodations to which he is entitled by law and will not be able to demonstrate his knowledge. In what follows, we draw anecdotally upon quotations from trainees we’ve met over the years at various medical schools. Below we quote one trainee’s reflections on what an attending physician in internal medicine wrote on his evaluation after he told the attending physician he had dyslexia, “Bob (a pseudonym) should really think before telling people he’s dyslexic. He shouldn’t expect to be treated any different from anybody else.”

My attending was thinking that I was trying to get around something, that if I knew the material I shouldn’t have to say I was dyslexic. She missed the point and was not understanding that sure, I could learn but had a different style of learning, for example, requiring more time to read the materials. Clearly, my attending did not understand anything about dyslexia.

Requests for accommodations often bring out such comments. Another student with dyslexia shared the following:

“Wait a minute, why is he getting extra time? Why is he getting to take the test in a separate room?” With the accommodations, there was a definite palpable and often voiced perception that I was trying to gain an advantage. In the first two years, I wished the professors understood more about dyslexia. For all the hard work just to be on a level playing

field and then to be kind of critiqued for that, that was a little bit frustrating.

Revealing one has dyslexia also affects one's relations with other students. As another physician with dyslexia recalled, "My medical school had student-based learning so once I revealed my dyslexia, the other students would shy away or try to—they didn't want it to be perceived that they were associating with me. They acted like somehow I was holding them back, not wanting the '*slow*' learner to hold them back."

Basic knowledge of dyslexia such as its negative impact on word retrieval would have made a major difference for another medical student with dyslexia who was traumatized by an attending physician who knew about her dyslexia. Here is how she described her experience to one of us (BAS):

One of the low points was being grilled by a surgeon who just did not give me any time to answer. If I didn't answer quickly enough, he assumed that I didn't know. I remember this surgeon asking me a question and before I could respond, he smiled in a kind of smirky way and said, "You just don't know that, do you?" A lot of the evaluation in this rotation is done on the fly. People who were more glib were thought of as knowing the content even if their knowledge was more superficial.

For a physician with dyslexia, in our experience, internship and residency can be better than medical school. As one physician with dyslexia recalled, "Residency is less an evaluative process and more doing the job. In residency you just focus on the patient—your evaluation depends on how well you took care of the patient and not how quickly you answered a question."

In a perfect world, a student who has dyslexia should not have any conflict or concern about sharing that he or she has dyslexia and, with it, requires certain accommodations. This perfect world depends on the [medical school culture](#), specifically whether those faculty physicians with whom the student will be interacting understand dyslexia, its neurobiological basis, and its impact on the student. In such an ideal world, the medical school environment would be accepting and supportive of dyslexia. However, as we have seen with the cases discussed here, each of the students told their attending faculty physician that he or she had dyslexia, and suffered negative consequences. Disappointingly, in each case, which involved the most common symptoms of dyslexia (i.e., slow reading, word retrieval difficulties), the attending faculty physicians reacted negatively, either indicating that the student was using dyslexia as an excuse to receive special treatment, showing resentment towards the student, or chastising the student for not responding quickly enough to questions. In addition, in this case and in the cases of the students quoted above, it was not only attending faculty physicians but also other students who misinterpreted the student with dyslexia's slow reading as reflecting low

intelligence. All of these reactions are expressions of a disappointing lack of awareness about dyslexia, the scientific progress made in understanding dyslexia, and the impact of the condition on the person with dyslexia—reactions all the more disappointing because they occurred in a medical school environment where science is highly valued and science and research are a major focus. Each of these students worked extremely hard and, even with the difficulties described, were unanimous in sharing that if they could do it all over again, without question, they would still not hesitate to disclose their having dyslexia.

The quoted medical students, who had all previously taken high stakes standardized tests with accommodations, were aware of their absolute requirement for accommodations, as, no doubt, is James. The students noted, too, the great positive difference made by the occasional attending faculty physician who had a deep understanding of dyslexia or who had dyslexia him- or herself. And although at times medical school was quite stressful, each of the quoted students did graduate. Two of the students are now in residency programs, while two others successfully completed their residencies, passed their specialty boards (with accommodations), and are engaged in successful medical practices.

Simply put, there is really no choice for a medical student with dyslexia but to disclose. Without accommodations, especially extra time for tests, the tests would be a reflection of the student's disability rather than his or her knowledge of the subject matter. Given this situation—the lack of understanding within a medical environment of what is, after all, a medical condition—there are possible solutions, discussed below.

### **Changing Medical Culture**

What should be done to change medical schools' policies and culture to be more accepting of students with dyslexia? Medical students with dyslexia we have known have suggested a mandatory, required short course for faculty that would provide a basic scientific and clinical overview of dyslexia, which could better enable faculty physicians who take the course to be supportive of students with dyslexia. A key emphasis of this course would be understanding that dyslexia is not slow learning and that a request by a student with dyslexia for extra time to complete a test is not an attempt to gain an advantage over other students but, instead, to ensure that the results of the examination reflect the student's ability rather than his or her disability. Students with dyslexia are legally entitled to, for example, the accommodation of extra time, which levels the playing field so that these students are able to demonstrate their knowledge.

Physicians with dyslexia, such as Karen Santucci who heads the pediatric emergency department at Yale School of Medicine, will tell you that, while she reads slowly, she thinks quickly and is able to provide immediate excellent care to a full range of her patients in her emergency medicine practice [17].

When one of us (SES) was applying to medical school, a dreaded question (addressed only to women) during an interview was, “What are you going to do about having a family?” Fortunately, for many years now, medical schools have been forbidden by law to ask this and other discriminatory questions. Specifically, for purposes of admission, medical schools cannot inquire whether an applicant has a disability, including dyslexia, and cannot ask whether he or she received testing accommodations for a disability, including dyslexia, during college or medical school [19]. Once an applicant has been admitted, then medical schools may inquire whether admitted students require any modifications to policies, practices, or procedures to accommodate a disability [20-22]. “Flagging policies that impede individuals with disabilities from fairly competing for and pursuing educational and employment opportunities are prohibited by the ADA” [23]. The revised final regulations for implementing Titles II and III of the ADA recognize explicitly that flagging test scores to indicate that an exam was taken with a testing accommodation is prohibited by the ADA and can lead to bias and unjust discrimination against applicants, who may choose to forgo the accommodations to which they are entitled by law out of fear of these negative consequences [23]. It should be up to an individual applicant or student to decide whether to disclose such information. According to the law, medical schools and residency programs cannot refuse to offer accommodations to students with dyslexia [24]. If a person has been diagnosed with dyslexia, he or she is entitled to accommodations. A student can be successful—he or she does not have to fail—to be eligible for and receive accommodations, a point emphasized by Congress in passing the ADA Amendments Act in 2008 [24, 25].

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### **Acknowledgements**

We thank Nancy Angoff, MD, MPH, MEd, associate dean for student affairs at Yale University School of Medicine, Sheree Carter-Galvan, JD, senior associate general counsel at Yale University, and Judy York, director of the Yale University Resource Office on Disabilities for their help in preparing this article.

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ISSN 2376-6980**