

**Testimony Before the
Committee on Science, Space, and Technology
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Statement of

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Good morning Chairman Smith, Ranking member Johnson, and other committee members. Thank you for the opportunity to speak with you about the science of dyslexia and share with you the tremendous scientific progress that has been made in dyslexia.

My name is Sally Shaywitz and I am a physician-scientist, The Audrey G. Ratner Professor in Learning Development, and Co-Director of the Yale Center for Dyslexia & Creativity at the Yale University School of Medicine. I am a member of the National Academy of Medicine of the National Academy of Sciences, and have served on the Advisory Council of the National Institute of Neurological Diseases and Stroke (NINDS), the National Research Council Committee on Women in Science and Engineering, co-chaired the National Research Council Committee on Gender Differences in the Careers of Science, Engineering and Mathematics Faculty and have served on the Congressionally-mandated National Reading Panel and the Committee to Prevent Reading Difficulties in Young Children of the National Research Council. I am also the recipient of an Honorary Doctor of Science degree from Williams College. I am presenting these research data on behalf of myself and Bennett Shaywitz, MD, the Charles and Helen Schwab Professor in Dyslexia and Learning Development and Co-Director of the Yale Center for Dyslexia & Creativity who leads the Center's research program.

I speak to you as a physician-scientist. As a physician, I have all too many memories of sitting by an ailing child's bedside, wishing so desperately that we had the knowledge to help that child. As a physician I know the power of science and how once new knowledge becomes available we act quickly, indeed, race to put that knowledge to good use. We want to close that knowledge gap and improve the lives of the affected children. When I sat on the Advisory Council of the National Institute of Neurological

Disorders and Stroke, we constantly asked ourselves: how have we benefited mankind, how has our research improved the well-being of children and adults.

As you will hear, in dyslexia, science has moved forward at a rapid pace so that we now possess the data to reliably define dyslexia, to know its prevalence, its cognitive basis, its symptoms and remarkably, where it lives in the brain and evidence-based interventions which can turn a sad, struggling child into not only a good reader, but one who sees herself as a student with self-esteem and a fulfilling future.

In dyslexia: an action gap

So what's the problem? The good news is that our problem is a solvable one. Of course, we are always seeking new knowledge. In dyslexia there is sufficient high quality scientific knowledge to help and to turn around the lives of so many struggling children. In dyslexia, remarkably in America, in the year 2014, we have not a knowledge gap but an action gap. We have the knowledge but it is not being put into policy and practice and far too many children and adults, too, are suffering needlessly. There is an epidemic of reading failure that we have the scientific evidence to treat effectively and we are not acknowledging or implementing it. It is our hope that hearing the depth and extent of the scientific knowledge of dyslexia will alert policy makers to act and to act with a sense of urgency.

The really good news: Science is there for those who are dyslexic.

Science informing education

Resolution 456 submitted by Rep. Bill Cassidy, on behalf of the Bipartisan Dyslexia Caucus which he co-founded and currently Co-Chairs, provides the most up-to-date, universal, scientifically valid definition of dyslexia incorporating scientific advances in understanding dyslexia, especially, its unexpected nature, and represents a landmark in aligning science and education. Furthermore, Resolution 456 notes the “diagnosis of dyslexia is critical and must lead to focused, evidence-based interventions, and necessary accommodations...”

Dyslexia is specific; learning disabilities are general

Dyslexia is the most common and most carefully studied of the learning disabilities, affecting 80% to 90% of all individuals identified as learning disabled. Of the learning disabilities, dyslexia is also the best characterized and the oldest. In fact, the first description of dyslexia preceded the first mention of learning disability by over sixty years – dyslexia was first reported by British physician, Dr. Pringle Morgan, in 1896, describing Percy F., “He has always been a bright and intelligent boy, quick at games, and in no way inferior to others of his age. His great difficulty has been – and is now – his inability to learn to read.” – a description that characterizes the boys and girls, men and women, I continue to see to this day. In contrast, the term learning disabilities was first used only in 1962.

Dyslexia differs markedly from all other learning disabilities. Dyslexia is very specific and scientifically validated: we know its prevalence, cognitive and neurobiological origins, symptoms, and effective, evidence-based interventions. Learning disabilities is a general term referring to a range of difficulties which have not yet been delineated or scientifically validated. Learning disabilities are comparable to what in medicine are referred to as ‘infectious’ diseases, while dyslexia is akin to being diagnosed with a strep throat – a highly specific disorder in which the causative agent and evidence-based treatment are both known and validated.

Epidemiology of dyslexia: prevalence

Scientific studies in a range of disciplines provide epidemiologic, cognitive and neurobiological data to characterize dyslexia. Epidemiologic data from sample surveys in which *each* individual is assessed indicate that dyslexia is highly prevalent, affecting one in five, yes you read this correctly. It is not the stated prevalence often quoted. Why? The why is the reason we are here today – schools far too often fail to acknowledge, much less identify, students who are dyslexic. Consequently, schools will report low, but incorrect number of students affected. *If they are not identified, they cannot be counted.*

Many believe that even this 1 in 5 estimate may be too low. For example, data from the 2013 National Assessment of Educational Progress (NAEP, the Nation’s Report Card) indicate that 2 in 3 students in 4th or 8th grade are not proficient readers. Among some groups of students the numbers are far worse. The NAEP data show that 4 in 5 African-American, Latino and Native American students are not proficient readers. Many would consider this to be an out-of-control epidemic of reading failure, and considering its negative consequences, a national crisis demanding action. Longitudinal studies, prospective and retrospective, indicate dyslexia is a persistent, chronic condition; it does not represent a “developmental lag.”

Sample surveys in which every subject has been individually assessed show relatively equal numbers of males and females affected. Studies based on school-based identification show a high male prevalence with accompanying data indicating that the often disruptive behaviors of the boys in the classroom play a strong role in bringing them to the attention of their teacher with subsequent referral. Girls who may be struggling readers, but who are sitting quietly in their seats, far too often fail to be identified.

Dyslexia has no known boundaries, it is universal, affecting virtually all geographic areas, and both alphabetic and logographic languages. For example, my book, *Overcoming Dyslexia*, (Knopf) has been translated, as expected, into alphabetic languages (Portuguese, Dutch, Croatian, etc.) but also, a surprise to me, logographic scripts including Japanese and Korean, and most recently, Chinese. In addition, dyslexia occurs in every ethnic, race and socio-economic class.

Unexpected nature of dyslexia

Dr. Morgan's initial description of dyslexia over 100 years ago as an *unexpected* difficulty in reading has now been validated by empiric evidence. Our research group found that in typical readers, IQ and reading are dynamically linked, they track together over time and influence each other. In contrast, in dyslexic readers, reading and intelligence are not linked and develop more independently so that a child can have a very high IQ and, *unexpectedly*, read at a much lower level.

Cognitive basis of dyslexia

Dyslexia is a difficulty within the language system, more specifically, the phonological component of language – it is not seeing words backwards. Data from laboratories around the world now answer the question – why do otherwise bright and motivated children struggle or even fail to learn to read? Almost invariably, they have a phonologic deficit. To explain, converging evidence over the past several decades supports the phonological basis of dyslexia. Phonological refers to the smaller pieces of language that make up a spoken word. To understand the implications of this theory, we compare what we know about spoken compared to written language. Spoken language is natural and does not have to be taught - everyone speaks. Reading is artificial and must be taught. The key in learning to read is that the letters have to be linked to something that has inherent meaning – the sounds of spoken language. To read, the beginning reader must come to recognize that the letters and letter strings represent the sounds of spoken language. She has to develop the awareness that spoken words can be pulled apart into their basic elements, phonemes, and that the letters in a written word represent these sounds. Children and adults who are dyslexic struggle to pull apart the spoken word and, as a result, cannot isolate each sound and attach it to its letter. Results from large and well-studied populations of dyslexic children confirm that in young children as well as adolescents a deficit in phonology represents the most specific and robust correlate of dyslexia.

With the phonologic deficit recognized and validated, it is now possible to understand and to predict the symptoms emanating from this basic difficulty, which can be both observed and measured, resulting in an accurate diagnosis of dyslexia. Dyslexia is a language based difficulty and impacts spoken language, for example, word retrieval difficulties; reading, initially impacting reading accuracy and then reading fluency, the ability to read not only accurately, but also rapidly and automatically with good understanding. Not being able to read automatically, dyslexic readers must read what I refer to as 'manually,' requiring the output of large amounts of effort and consuming much of the individual's attention. A dyslexic reader lacks fluency meaning that he reads slowly and with great effort, although he may understand the content at a high level. Importantly, the dyslexic's vocabulary and comprehension may be quite high. Spelling is also problematic as is learning a foreign language.

The paradox of dyslexia

Dyslexia is a paradox, the same slow reader is often a very fast and able thinker – giving rise to our conceptual model of dyslexia as a weakness in getting to the sounds of spoken words surrounded by a sea of strengths in higher level thinking processes such as reasoning and problem solving. Reflecting this paradox are many eminent dyslexics - Charles Schwab, David Boies, and Dr. Toby Cosgrove. On the other side of the coin, are many who are not identified, do not receive evidence-based instruction, continue to struggle to read and see themselves as failures. Sadly, these boys and girls have no knowledge of what their difficulty is or that it even has a name, have no self-understanding, come to view themselves as dumb or stupid, see themselves as not meant for school, suffer low self-esteem, often drop out of school with a loss to themselves, to their families and to society.

Neurobiology of dyslexia

Converging evidence using functional magnetic resonance imaging (fMRI) from our own and laboratories around the world has identified three major neural systems for reading in the left hemisphere, one region, anterior, in Broca's area and two regions posterior, one in the parieto-temporal (or Wernicke's area), and another, in the occipito-temporal region, often referred to as the word form area. Furthermore, such fMRI studies indicate that in dyslexic readers, the posterior neural systems are functioning inefficiently, providing a *neural signature for dyslexia*. Critically, these posterior neural systems appear to be important in skilled, automatic reading and inefficient functioning in these neural systems suggest an explanation for the slow, effortful reading characterizing dyslexic readers. Recent studies of brain connectivity by us and others demonstrate that in dyslexic readers there is reduced connectivity to the posterior neural systems responsible for skilled, automatic reading.

Promising areas for research

In terms of promising areas for research, we believe it is important to better understand the relationship between reading and attention, the construct, and not ADHD, the disorder. Studies now in progress in our lab are examining the role of attention in reading, including probes of the relationship between those neural systems for attention and those for reading.

Reading gap already present by first grade and persists

Scientific knowledge, too, has delineated the progression of reading development. Reading growth is most rapid early on, during the first few years of school and then plateaus. Recent data from our laboratory indicate that the gap between typical and dyslexic readers is already present by first grade and persists. A very clear message: we have to get to these children very early and not wait.

National Reading Panel and teaching reading

Fortunately, thanks to Congressional action there is now strong evidence of what treatments are effective in teaching children to read. In 1998 Congress mandated the formation of a National Reading Panel to investigate the teaching of reading. I was proud to serve on the panel which produced the Report of the National Reading Panel. As a result, today it is no longer acceptable to use reading programs lacking scientific evidence of efficacy; instead it should be mandatory to use programs that are evidence-based, proven to be effective in the same way that medications must be tested and proven to be effective before they can be approved by the FDA. Our children deserve no less. And yet, today, this powerful information is not being used in schools, children are not learning to read and giving up, and not reaching their full potential. We have what amounts to an educational emergency in the US. Children are not learning to read with serious academic, economic and health consequences including, school drop-out, being half as likely to go on to college, significantly lower lifetime earning, significantly higher unemployment, higher rates of mental health issues such as often incapacitating anxiety, and, as reported in 2013, significantly higher mortality rates related to lack of a high school diploma. These harsh consequences harm not only the dyslexic individual but place our country at a competitive disadvantage.

Accommodations

Given that a student who is dyslexic has both a weakness and strengths, it is critical that for example, tests, both in school and on high stakes standardized examinations actually measure the student's ability and not his disability. The dyslexic student may learn to read fairly accurately but hardly ever with fluency; he remains a slow reader albeit a quick thinker. These dyslexic students may know the answer to a test question, but as a result of their slow reading never get to reach many questions or to finish the test, the student simply runs out of time. Or, she is so anxious about finishing the exam that she races through it and misses questions which, given the needed time, she would be able to answer correctly. Thus, it is critical that students who are dyslexic receive the accommodation of extra time; it is not a perk but a necessity if the result of the test is to reflect that student's knowledge. In adolescents and young adults applying for high-stakes standardized tests for college, graduate or professional schools, the Americans with Disability Amendment Act (ADAA) of 2008 is highly supportive of the need for accommodations for those with disabilities like dyslexia that impair a major life activity like reading. The ADAA regulations also state that students should receive accommodations even if they are doing well in school, it is not the outcome of their performance but rather what they have to do to achieve the outcome.

High school and college students with a history of childhood dyslexia often present a paradoxical picture; they may be similar to their unimpaired peers on measures of comprehension, but they continue to suffer from the phonologic deficit that makes reading less automatic, more effortful, and slow. Neurobiological data provide strong evidence for the necessity of extra time for readers with dyslexia. Functional MRI data demonstrate that in dyslexic readers the word-form area, the region supporting rapid

reading, functions inefficiently. Readers compensate by developing anterior systems bilaterally and the right homolog of the left word-form area. Such compensation allows for more accurate reading, but it does not support fluent or rapid reading. For these readers with dyslexia, the provision of extra time is an essential accommodation, particularly on high stakes tests such as SAT, ACT and tests for professional schools such as LSAT, MCAT and GRE. The accommodation of extra time allows the student time to decode each word and to apply his unimpaired higher-order cognitive and linguistic skills to the surrounding context to get at the meaning of words that he cannot entirely or rapidly decode. While readers who are dyslexic improve greatly with additional time, providing additional time to non-dyslexic readers results in very minimal or no improvement in scores.

Although providing extra time for reading is by far the most common accommodation for people with dyslexia, other helpful accommodations include allowing the use of computers for writing essay answers on tests, access to recorded books and text to voice software. Other helpful accommodations include providing access to syllabi and lecture notes, tutors to “talk through” and review the content of reading material, alternatives to multiple-choice tests (e.g., reports or projects), waivers of high stakes oral exams, a separate, quiet room for taking tests, and a partial waiver of the foreign language requirement. Dyslexic students who have difficulty accessing the sound system of their primary language will, almost invariably, have difficulties learning a foreign language. Students with dyslexia most often have no difficulty with the mastery of high level courses, the problem lies in their lack of fluent, rapid reading so that it is the time necessary for them, as dyslexics, to read through the materials that is problematic. Many rigorous schools allow these students to take one course less during the school year and take this course during the summer. With such accommodations, many students with dyslexia are successfully completing studies in a range of disciplines, including science, law, medicine and education. It is accommodations such as these that are encouraging, and allowing, more students who are dyslexic to enter and to succeed in STEM fields.

Summary and Implications of the science of dyslexia

Yes, dyslexic children can learn to read and must be taught to read. It is imperative that teachers and parents learn about the powerful science of dyslexia, know how to identify dyslexia early on and to provide evidence-based methods to teach dyslexic children to read. We must not give up on teaching reading and limit a child’s future options. Education must, and can be, aligned with science.

We must ensure that scientific knowledge is translated into policy and practice and that ignorance and injustice do not prevail. We know better, we must act better.

I cannot look into the face of one more child who has lost faith in himself and the world, I cannot look into the face of a child’s father who is desperately trying to hold back tears; I cannot hear once again about how a school told a mother, ‘we do not believe in dyslexia.’

As an iceberg is 90% underwater with only 10% visible; similarly, in dyslexia, we hear about the 10% like Max Brooks, who have made it. Let's not give up on the invisible 90% still underwater, asking, indeed, begging to be helped.

I am optimistic, once this committee is aware of the strong science of dyslexia, educators will want to align their practices and policies with 21st century science.

Recommendations

To bring education together with current scientific knowledge, the following are recommended:

1. First and foremost, schools must not be allowed to ignore, fail to recognize or deny the reality or diagnosis of dyslexia.
2. Schools, including teachers, principals and other administrators and parents should make every effort to use the word dyslexia since it has specific, highly relevant and explanatory meaning; science has provided its: definition; epidemiology; cognitive basis; neurobiological basis; developmental progression; long-term outcome. For dyslexia, knowledge of its cognitive basis indicates what symptoms to look for so that symptoms of dyslexia in the classroom (and at home) are noted and acknowledged rather than as currently happens, ignored or overlooked. This greater awareness and understanding of dyslexia and its impact will benefit both the teacher and student, both in the teaching of reading and in the climate and attitudes within the classroom.
3. Using the word dyslexia provides a common language facilitating communication among teachers, clinicians, scientists and parents.
4. For the student, the knowledge that he is dyslexic is empowering, providing the student with self-understanding and self-awareness of what he has and what he needs to do in order to succeed.
5. For students, knowledge that they are dyslexic also provides a community to join – they know they are not alone.
6. For the parent and teacher and importantly, the student, knowledge that he or she is dyslexic brings with it the information that the individual is not stupid or lazy.
7. Critically important is that schools must use evidence-based programs that have proven efficacy; research-based simply indicates that there are theoretical suggestions but does not provide evidence that the program is, indeed, effective. Evidence-based programs are akin to the level of evidence the FDA requires before a medication can be approved for use. Many, many theoretical, research based approaches, when tested in the field, prove to be ineffective. Our children's reading is too important to be left to theoretical, but unproven, practices and methods. We must replace anecdotal and common, but, non-

evidence-based practices, with those that are proven, that is, they are evidence-based.

8. Professional development programs targeted for teachers must provide evidence that the students of the teachers taking these programs actually improve in their reading performance. This is in contrast to some professional development programs which seem to improve teacher's understanding but not in a way that results in improvement in their student's reading performance.
9. Schools of education must ensure that aspiring teachers are taught evidence-based methods to teach reading and have monitored experience demonstrating that they are effective in implementing these methods.
10. Scientific evidence that reading growth is maximum in the very first few years of school and then plateaus together with new data indicating that the reading gap between typical and dyslexic readers is already present at first grade and persists means that students must receive evidence-based instruction at the start of their school experience and their progress carefully monitored. Waiting is harmful and not acceptable.
11. Given the rapid growth in reading in the very first years of school and the already present gap by first grade, it seems reasonable to encourage the creation of special charter schools for grades k-3 that focus solely on dyslexia. The goal is to reach children at-risk for dyslexia early on when reading intervention can be maximally effective and before the students fall further and further behind. At such specialized charter schools, such as the one, Louisiana Key Academy, attended by the children of a fellow panel member, the entire educational team from principal to classroom teacher to physical education instructor understand dyslexia, its impact on students in various situations and are on board to support the students throughout their day. Here, students learn and there is no bullying by students or frustration expressed by teachers who may not understand the impact of dyslexia. These schools can also serve as resources where teachers can come, spend time and learn about dyslexia, what it is and how it impacts a student and learn specific evidence-based methods for teaching reading to dyslexic students and how to best implement these methods.

There is so much more to tell; for those who have questions and want to know more, visit the Yale Center for Dyslexia & Creativity website: dyslexia.yale.edu or look at my book, "Overcoming Dyslexia," which discusses the scientific basis of dyslexia and how to translate this knowledge into practice.

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