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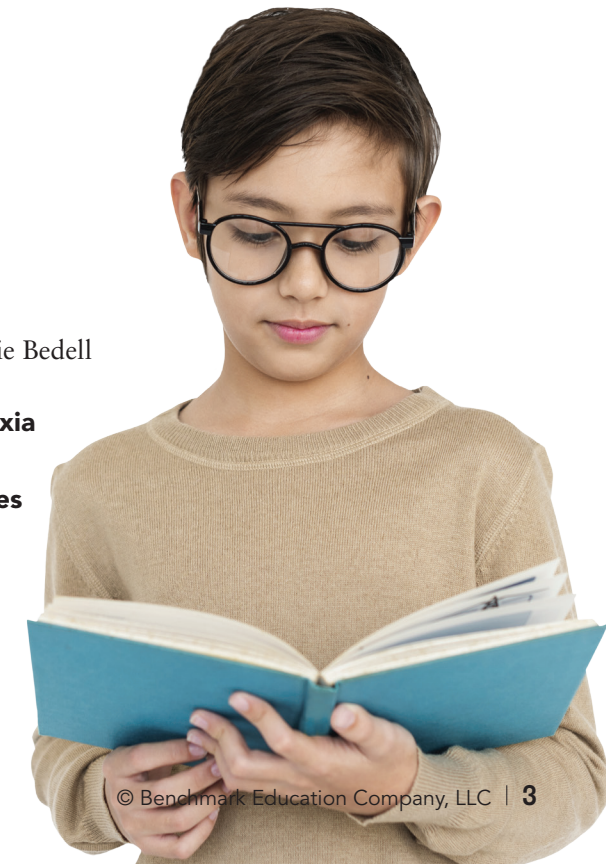
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What Is Dyslexia?

There are many different descriptions and definitions of dyslexia. For this book we will use the following definition, adopted by the Board of Directors of the International Dyslexia Association (IDA) in 2002 and recently validated by more than 30 international researchers on dyslexia (Dickman, 2017). Throughout this book, I will return to this definition and consider what it means for classroom practices and routines that children and parents can engage in.

Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge. dyslexiaida.org/definition-of-dyslexia

IN THIS CHAPTER

What We Know About
Dyslexia

10 Common Myths—
10 Facts to Debunk Them

An Adult's Perspective

Evolving Understandings

- **late 1800s:** Dyslexia first discussed in medical literature as “word blindness”
- **early 1900s:** Reading instruction first used to address “word blindness”
- **1920s-30s:** Orton and Gillingham and Spalding developed instruction specifically for dyslexia
- **1980s:** Theories about dyslexia being primarily an auditory, not visual, concern
- **1990s:** fMRI research expands the science of dyslexia

What We Know About Dyslexia

Since the end of the 19th century, researchers from around the world have attempted to describe and define dyslexia, which occurs to varying degrees in readers who speak different languages. The research on dyslexia has spanned many disciplines, including neuro-anatomy, pediatrics, ophthalmology, and optometry; cognitive and educational psychology; developmental cognitive neuroscience; and audiology and speech pathology. As a result of this systematic, multi-disciplinary, scientific study—especially the most recent studies conducted over the past 30 years—today we can state that the processes of reading and dyslexia are no longer mysteries. For one thing, we now understand how incredibly complex the process of learning to read is! The human brain has simply not yet evolved to “naturally” or organically “reorganize” itself from a brain that can process and generate language to one that can translate print to match our understanding of spoken words (Dehane, 2009; Wolf, 2007). Reading is not learned in the same way we learn to talk (Seidenberg, 2017).

Today we can state that the processes of reading and dyslexia are no longer mysteries.

Three Key Research Strands from Neurobiology

Early detection and effective instruction for children with dyslexia develop from a clear understanding of what causes it and how it tends to present. Fletcher et al. (2019) provide a comprehensive overview of the dyslexia research conducted in neurobiology that has addressed three primary areas: brain function, brain structure, and genetics.

THE BRAIN FUNCTION STUDIES have found that a specific set of neural network activation patterns, consistently present in the left hemisphere of the brains of proficient readers, are either dysfunctional or absent in less proficient readers.



All educators need to be well-versed in the dyslexia research of the last decade because its implications for instruction and intervention are profound.

THE BRAIN STRUCTURE STUDIES have provided less conclusive evidence but have identified some differences in the gray and white matter of skillful and less-skillful readers. It is difficult for researchers to attribute these differences to something “organic” in the brain because there is clear evidence that brains are significantly affected by environmental factors, including instruction, that can also make permanent, structural changes in the brain, even at very young ages (Gaab, 2019).

THE GENETIC STUDIES show a moderate-to-high heritability of dyslexia but the specific genes that might be involved have yet to be identified.

Findings from Instructional Research

Most important of all, we now know what to do to help students at all levels and at any age become skillful and confident readers and writers (Archer & Hughes, 2011; Carnine et al., 2010; Dehane, 2009; Fletcher et al., 2019; Kilpatrick, 2015; Seidenberg, 2009; Shaywitz, 2003), including those who have dyslexia. This will be discussed in Chapter 4: Reading: How to Teach, and Chapter 5: Reading: What to Teach.



Key Findings to Know

Findings from this extensive research base have allowed us to draw several firm conclusions about dyslexia, including:

- We now know where and how dyslexia manifests itself in the brain.
- We understand dyslexia involves unexpected struggles with reading, and spelling words accurately and automatically despite adequate effort and instruction.
- Readers with dyslexia will have difficulty reading isolated, individual words presented in lists but may have less difficulty reading text because of the support provided by context and vocabulary knowledge.
- If a student’s difficulties with reading words accurately and automatically are not adequately addressed with effective intensive instruction, most students with dyslexia will go on to have difficulties reading and understanding text.
- Dyslexia is one of several reading disabilities. For example, when students can read words and text accurately and fluently but struggle to understand or comprehend the meaning of the text, it is more accurately referred to as “text-level reading disabilities” or specific reading comprehension disability (Fletcher et al., 2019).
- Dyslexia, like all learning disabilities, is a **spectrum disorder** that varies in the level of impact, meaning that someone can have mild, moderate, or severe dyslexia.
- When students are learning to read in languages such as English where many of the sounds in words (**phonemes**) are often spelled using a variety of letters or letter combinations (**graphemes**) and which then results in many “**irregular words**” (such as “one”, “eight”, “have”, “enough”), dyslexia is more commonly manifested as word-level reading challenges (Brady, 2019).
- Word reading difficulties are more common in some languages than others, although the actual prevalence of dyslexia remains the same. This is because in some languages the spelling (**orthography**) that represents the speech sounds of the language is more regular or “transparent” (for example Spanish, Turkish, Serbo-Croatian, Finnish, and Korean), so more students learn to read words without extra **intervention**. In more **transparent languages**, students with dyslexia may initially learn to read words accurately but have difficulties later with reading text fluently.

Dyslexia, like all learning disabilities, is a spectrum disorder that varies in the level of impact.

SUPPORT SUCCESS



“Dyslexia is the most common learning disability, and it undermines more than the ability to read. **It undermines all the good things that come with reading: the confidence, hope, and knowledge that reading brings.** By understanding dyslexia so we can address it effectively, we are doing more than teaching reading. We are restoring the benefits of reading to the mind and spirit of a child who would otherwise be denied. In the final analysis, compared to the skill of reading itself, this restoration of confidence, hope, and opportunity may prove to be the greater thing.”

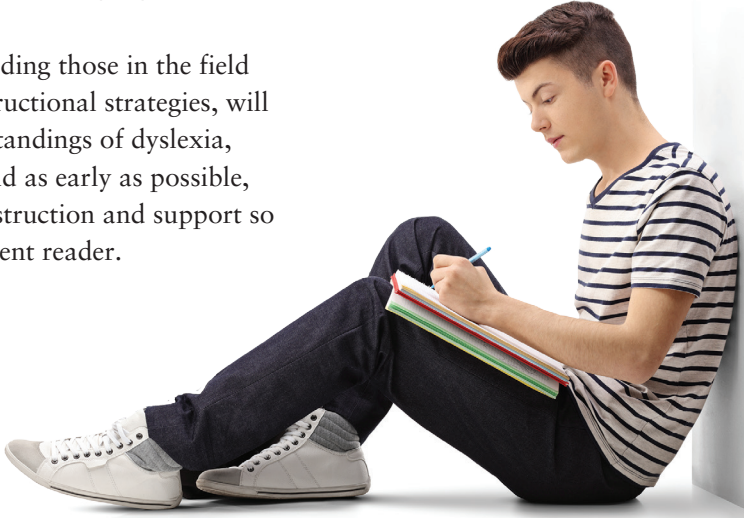
— Steve Dykstra, Ph.D.



The Future of Dyslexia Research

While we have already learned an amazing amount about dyslexia, there is definitely more to discover. Cutting-edge research is continuing today in several different areas. Dr. Nadine Gaab and her team at Boston Children’s Hospital are currently conducting research to track the development of the neural structures involved in the reading network in the brains of children from infancy through PreK. Dr. Stanislas Dehaene, a French psychologist and cognitive neuroscientist, heads the Cognitive Neuro-Imaging Unit at the Commissariat à l’énergie atomique. His team is studying how learning to read appears to depend on a process of “**neuronal recycling**” that causes brain circuits, originally evolved for object recognition, to recognize letters and words. Dr. Guinevere Eden at the Center for the Study of Learning at Georgetown University in Washington, D.C. was the first to apply **functional magnetic resonance imaging (fMRI)** to the study of dyslexia. Her current research continues to use brain-imaging techniques to understand the neural basis of dyslexia. Dr. Fumiko Hoeft, a psychiatrist and cognitive neuroscientist, is a professor of psychological sciences, director of the Brain Imaging Research Center at the University of Connecticut, and director of the Laboratory for Learning Engineering and Neural Systems (brainLENS) at UConn/UCSF. She is currently studying dyslexia in children who are learning English as a second language.

These researchers and many others, including those in the field of education who study high-impact instructional strategies, will likely provide us with even better understandings of dyslexia, including how to identify it accurately and as early as possible, and how to provide the most effective instruction and support so every student can be a skillful and confident reader.



Reading is Recent

"We were never born to read. Human beings invented reading only a few thousand years ago. And with this invention, we rearranged the very organization of our brain, which in turn expanded the ways we were able to think, which altered the intellectual evolution of our species."

—Maryann Wolf,
*Proust and the Squid: The Story
and Science of the Reading Brain*
(2007).

The Dyslexia Debate

Although as we have seen there has been a significant amount of research conducted on dyslexia, and it is accepted today as an official category of specific learning difficulty, a debate continues among some educators and cognitive researchers over whether any kind of label is necessary to describe this category of children with learning difficulties (Lawrence, 2009). In “The Dyslexia Debate”, Elliott and Grigorenko (2014) state: “...the primary issue is not whether biologically based reading difficulties exist (the answer is an unequivocal ‘yes’)” p. 4, but rather “Is dyslexia a scientifically rigorous construct that has meaningful value for research and educational/clinical practice?” (p. x)

This debate about using the term “dyslexia” to describe problems with accurately and fluently reading words and text continues in part because some students may have significant reading difficulties for reasons other than dyslexia. Poor quality, low-skilled reading can be caused by brain injuries, low levels of language proficiency or language disorders, a hearing or visual impairment (i.e., blindness or deafness), a severe intellectual disability, or simply as the result of a lack of adequate or appropriate instruction.



Dyslexia occurs around the world, in every language.

Prevalence of Dyslexia

Estimates of the prevalence of dyslexia in the general population range widely, from 3% to 20% (Elliott & Grigorenko, 2014), or from 1% to 15% (Fletcher et al., 2019). This discrepancy may be due at least in part to differences in the samples used in various studies of dyslexia and how the disorder is defined (Berninger & Wolf, 2009).

The question is, How can we help anyone who struggles with reading, writing, and spelling regardless of the presumed cause?

The International Dyslexia Association (IDA) concedes that the exact number will not be accurately identified until there is universal agreement on the definition of dyslexia and more precise ways to differentiate the symptoms of dyslexia from other reading problems. However, as many researchers and dyslexia specialists argue, the question is not how many people actually have dyslexia, but rather, How can we help anyone who struggles with reading, writing, and spelling regardless of the presumed cause? Elliott and Grigorenko (2014, p. 40) suggest: “Identify individuals with reading-related problems as early as possible, and then monitor their response to high-quality, evidence-based intervention.” Then, a diagnostic label is unnecessary and a “wait-to-fail” scenario is avoided.

10 Common Myths About Dyslexia —10 Facts to Debunk Them

Now, let’s look at misconceptions that continue to surround dyslexia. Technologies such as positron emission tomography (PET), functional magnetic resonance imaging (fMRI), magnetic source imaging (MSI), and magnetic resonance spectroscopy (MRS) have been our best myth busters concerning dyslexia, by providing concrete evidence that disproves many prevailing theories and unfounded beliefs. But because these tools are relatively new, myths persist. Here are 10 common misconceptions about dyslexia and the research findings that debunk them.



10 Myths and Facts About Dyslexia	
MYTH 1: A sign of dyslexia is writing letters backwards or upside down (b for d; p for q, etc.).	FACT: It is actually quite common for beginning readers to confuse letters that have a similar shape such as b/d; p/q; f/r; m/w; or n/u and to confuse words with similar letter patterns (was/saw; mad/dam, etc.). These confusions are not symptoms of dyslexia in young, beginning readers.
MYTH 2: Students with dyslexia read words or text backwards (“was” for “saw”; “mad” for “dam”, etc.).	FACT: Some students with dyslexia do not reverse or transpose their letters, which may result in having their dyslexia being overlooked. If by third grade students continue to have problems correctly identifying or writing letters, these difficulties could be a result of unidentified and unaddressed dyslexia. Additional assessments would have to be conducted. That process will be discussed in Chapter 3: How is Dyslexia Diagnosed?
MYTH 3: Dyslexia is caused by problems with vision (the eyes don’t track correctly, or other vision problems).	FACT: While vision problems can certainly create challenges for learning to read print, dyslexia is not caused by problems with eyesight or vision (American Academy of Pediatrics, 2009).
MYTH 4: Intelligence (or IQ) is related to dyslexia (the belief that students with dyslexia have low IQs or that students with a high IQ cannot have dyslexia).	FACT: We now understand that “dyslexia is a specific learning disability that is neurobiological in origin” (IDA, 2002). It has no correlation with intelligence, either high or low (Elliott & Grigorenko, 2014; Shaywitz, 2003).
MYTH 5: Far more boys have dyslexia than girls.	FACT: In general, more boys than girls are referred for both academic and behavioral concerns in school, but research has verified that only slightly more boys than girls have the neurological markers of dyslexia (Fletcher et al., 2019).

10 Myths and Facts About Dyslexia (Cont'd)	
MYTH 6: Dyslexia cannot be identified before third grade.	FACT: Students who are at-risk of reading difficulties due to dyslexia can be accurately identified as early as 4 years old, and research is continuing that may move that age significantly earlier (Gaab, 2019).
MYTH 7: Students with dyslexia are lazy; they just need to focus and try harder.	FACT: Students with dyslexia do not need to be encouraged to “just work harder.” Children with dyslexia use nearly five times the brain area as their neurotypical peers while performing a simple language task (University of Washington, 1999). Readers with dyslexia are already working very hard!
MYTH 8: ADHD is a part of dyslexia.	FACT: Attention deficit/hyperactivity disorder (ADHD) often occurs in students identified as having specific learning disabilities, including dyslexia, but they are separate disorders and do not always co-occur with academic problems (Brown, 2013).
MYTH 9: All children with dyslexia have trouble with spelling and handwriting.	FACT: Many students with dyslexia also have dysgraphia , described by Berninger and Wolf (2009) as a “transcription disorder”. Students with dysgraphia have mild-to-severe problems with handwriting and/or spelling. Like ADHD, dysgraphia and dyslexia are separate but closely related disorders.
MYTH 10: Children will outgrow dyslexia.	FACT: No one ever “outgrows” dyslexia. However, one of the most exciting outcomes of dyslexia research is the firm conclusion that with early identification and appropriate instruction, it is possible to “overcome” dyslexia (Shaywitz, 2003), or even “prevent” it (Fletcher et al., 2019; Gaab, 2019). Or, as indicated in the title of this book, we can conquer dyslexia!

Looking Ahead

I encourage you to share the list of myths and facts with the entire school staff and parent community. One of the most powerful things we can do to support students with dyslexia is to educate the learning community of which they are a part. Please feel free to share the firsthand account that follows, and all the personal perspectives at the end of each chapter. The more we hear from experts, as well as the personal experiences of those who have dyslexia or who support students with this disorder, the better prepared we are to develop and support instructional environments that address both the learning needs and the social-emotional needs of every reader who faces the challenge of dyslexia. When we know better, we do better! In the next chapter, we will take a closer look at the signs and symptoms to look for.

Questions to Consider

- What role do you play in the Support Success Circle?
- What new understandings do you have after reading this chapter?
- Does the perspective of an adult with dyslexia (see next page) make you think any differently about your experience as a caregiver or educator?



An Adult’s PERSPECTIVE



by Nikki Schneiderman

I was lucky enough to be in first grade and have a teacher who noticed that there was something up. I remember a lot of parent-teacher whispering, a lot of being pulled out of the classroom, and being the only one who had a tutor in the summer. My mother took on the job of being my advocate and fought for my public school to pay for testing needed to figure out exactly what the issue was, and what could be done about it. There were many little tips she collected from other moms, and she would take what they regretted not doing and do that first.

From elementary school to high school, like many others with dyslexia, I hated school. I would wake up “sick” all the time and would convince the nurse at school I was ill so she’d call my parents and send me home. I lived in constant fear of reading out loud to my class, participating in “fun” classroom spelling games, or having someone look over at my paper and realizing every word was spelled wrong. I remember during reading time staring at the pages and having to reread the same page over and over to catch at least one sentence while everyone around me was flying through their chapters and loving them. I would come home, no matter what my age was, and have a meltdown about how stupid I was.

“Fake it ’til you make it” is something I have always done.

There was hope though. Since this all started in the first grade, it meant that I now had all these years of school ahead of me for what my school administration referred to as the “learning center”. This is where all the kids with learning disabilities were taken during the day to work on reading, math, and writing. We bonded and I felt brilliant there. By the end of elementary school, I was on a fifth-grade level, catching up with the rest of my class.

Learning algebra in middle school brought a whole new struggle, because of the cruelty of mixing numbers and letters! But with a lot of extra help and eating lunch with the math teacher every other day, eventually I was

able to memorize and solve problems. “Fake it ’til you make it” is something I have always done; I feel like a lot of people who have dyslexia can relate.

The way school is taught isn’t for people who learn like I do. When I got to college, I was able to learn the way I wanted to, and I loved every second of it! I got to bring my laptop to class, so there were no more pointless notes that I couldn’t understand later because of the misspelled words. I was able to record my professors and listen back; all my textbooks could be bought online (which meant now I could actually find audio versions or the PDFs online) and again, I could have my laptop read it to me. With the amazing improvements in technology, I could speak to my phone and have it write the words I was getting frustrated with. I did way better in college than I ever dreamed of in high school.

I’ve learned that in the moment, when you’re mad at everything because your teacher randomly calls you up to read to the class, that it’s important to remember school doesn’t last forever. So what if I had problems reading! I was always the best dancer in my class, a competitive soccer player, captain of cheer squad, and in college I was in charge of Greek life. When there isn’t a book in front of me, I thrive better than anyone around me! Being a people person and working the crowd is a valuable skill that the learning center experience and my parents indirectly taught me. When being observed in the class, my humor and wit would charm teachers into passing me on whatever they were testing me on. I was lucky enough to study abroad and I had several wonderful internship experiences throughout college. I am now out of college and because of my “fake it ’till you make it” attitude, I am now a successful project manager for one of the largest research companies in the world.

If I could tell my younger self what I know now, or tell a young child who has dyslexia anything, it would be this: my struggle drove me to develop my strengths and other talents. And let’s be real—everyone is secretly, or not so secretly, conquering something.



Nikki and her mother, Laurie Berger.