

Dyslexia—Part 1 of 2: Defining Dyslexia

This white paper and its companion piece, *Addressing Dyslexia*, are based on the book *Conquering Dyslexia: A Guide to Early Detection and Intervention for Teachers and Parents* by Jan Hasbrouck, PhD. (Benchmark Education; PD Essentials).

In this piece, we will explore:

- What is dyslexia?
- A brief history of dyslexia and our current understandings.
- The future of dyslexia research.
- Common myths about dyslexia.
- Parent activism and advocacy.

Introduction

Reading is the most fundamental of all academic skills. Being able to read well is necessary for success in every area—in school and life. Unfortunately, for a significant number of our children, learning to read, write, and spell are daunting challenges. While the process of learning to read seems so effortless and joyful for many children, for students with dyslexia, it can be complicated, mysterious, and even frightening. Dyslexia can make children feel deeply discouraged and even believe that something must be seriously wrong with them. Parents become frustrated and confused: “Why is my bright and eager child suddenly struggling and hating school?” Teachers wonder what dyslexia really is, which of their students have it, and how it should be addressed in their classrooms. This white paper will attempt to address these concerns for parents and teachers by defining dyslexia, explaining how research has changed our understanding of this once mysterious learning disorder, and dispelling common misconceptions.

Defining Dyslexia

There are many different descriptions and definitions of dyslexia. Dr. David Kilpatrick, in an online posting to the SPELLTalk listserv (1/22/18), wrote that “Dyslexia refers to poor word-level reading despite adequate effort and opportunity. That’s it. Pretty simple.”

The following definition, adopted by the Board of Directors of the International Dyslexia Association (IDA) in 2002 and recently validated by over 30 international researchers on dyslexia (Dickman, 2017) goes into a bit more detail:

“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.” (From <https://dyslexiaida.org/definition-of-dyslexia/>)

A Brief History of Dyslexia

For more than 100 years, professionals have taken note that while some students seem to learn to read quite easily, others, rather mysteriously, have great difficulty despite adequate intelligence, an absence of brain injury, and significant, demonstrated strengths in other domains. By the early 20th century, there had been substantial progress in understanding this concern. Samuel Orton, an American psychiatrist and neuropathologist, helped confirm that the basis of dyslexia was indeed neurological but that its treatment must be instructional. In the late 1920s, Orton partnered with Anna Gillingham, a psychologist, educator, and language scholar, to develop guidelines for an instructional program to be used with students with dyslexia. In the late 1930s, Romalda Spalding learned the Orton-Gillingham method and adapted it to successfully tutor students and train teachers in effective teaching methods for students with dyslexia. The work of Orton, Gillingham, and Spalding, along with that of many, many others, has contributed immensely to the development of a more accurate conceptualization of dyslexia (Berninger & Wolf, 2009; Shaywitz, 2003).

Our Current Understanding of Dyslexia

Since the end of the 19th century, researchers from around the world working in the medical fields of neuroanatomy, pediatrics, ophthalmology, and optometry; cognitive and educational psychology; developmental cognitive neuroscience; and audiology and speech pathology, have attempted to describe and define dyslexia which occurs to varying degrees in readers who speak many, different languages.

Today, as a result of this systematic, scientific research—especially the most recent studies conducted over the past 30 years 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 (Dehaene, 2009; Wolf, 2007). Reading is not learned in the same way we learn to talk (Seidenberg, 2017).

These findings have allowed us to draw several firm conclusions about dyslexia and have transformed our understanding of how it should be addressed in the classroom. We now know where and how dyslexia manifests itself in the brain and understand that dyslexia involves unexpected struggles with reading and spelling accurately and automatically despite adequate effort and instruction. Although there is some disagreement among dyslexia researchers about the prevalence of dyslexia because of varying ways dyslexia is defined, the most common estimate is that dyslexia

affects about ten to fifteen percent of the general population. Readers with dyslexia 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. When a student's difficulties reading words accurately and automatically are not adequately addressed with effective instruction and intensive intervention, many students with dyslexia go on to have difficulties reading and understanding text.

We know that, like all learning disabilities, dyslexia is a spectrum disorder that varies in the level of impact, from mild to severe. Through research conducted with children learning to read across many different languages, we have discovered the 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 print (or orthography) that represents the speech sounds of the language are more regular or "transparent" (e.g., Spanish, Turkish, Serbo-Croatian, Finnish, and Korean), so more students learn to read words without extra intervention. In those languages, students with dyslexia may initially learn to read words accurately but have difficulties later with reading text fluently. When students are learning to read in languages such as English where many of the sounds in words (phonemes) are often represented with several different spellings and result in many "irregular words" (such as "one," "eight," "have," and "enough"), dyslexia is more commonly manifested as word-level reading challenges (Brady, 2019).

Perhaps the most important finding from this emerging scientific research is that we 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; Dehaene, 2009; Fletcher et al., 2019; Kilpatrick, 2015; Seidenberg, 2009; Shaywitz, 2003), including those who have dyslexia, no matter where they fall on the spectrum.

Research Recap

1. Dyslexia is a spectrum disorder, ranging from mild to severe, which varies its level of impact on students as they learn to read and write.
2. Word-reading difficulties are more common in some languages than others.
3. We know what to do to help students at all levels and at any age become skillful and confident readers and writers.

The Future of Dyslexia Research

While we have already learned an amazing amount about dyslexia, there is definitely more to discover! Research is continuing today in several different areas. Here is a look at some of the promising research being performed by leading cognitive neuroscientists from around the world:

- 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 Pre-K.
- Dr. Stanislas Dehaene, a French psychologist and cognitive neuroscientist, heads the Cognitive Neuro-Imaging Unit at the Commissariat A l'Energie Atomique. His team is studying how learning to read may depend on a process of "neuronal recycling" that causes brain circuits, originally evolved for object recognition, to recognize letters and words.

- Dr. Guinevere Eden, from 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 and 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.

Other researchers study what kinds of instruction and intervention have the most positive impact on students with dyslexia. These include Dr. Joe Torgesen, Dr. Sharon Vaughn, Dr. Jack Fletcher, Dr. Sally Shaywitz, Dr. Doug Carnine, Dr. Patricia Mathes, Dr. Carolyn Denton, and many others. Findings from all of this research are providing us with an improved understanding of dyslexia, including how to accurately identify it as early as possible and how to provide the most effective instruction so every student can be a skillful and confident reader.

Common Myths About Dyslexia

The growing convergence of findings from this large body of scientific research has helped to disprove several prevalent myths that developed around our understanding of dyslexia. Unfortunately, despite research proving otherwise, many of these myths still persist today, especially within popular culture.

Until a few decades ago, researchers did not have tools like positron emission tomography (PET), functional magnetic resonance imaging (fMRI), magnetic source imaging (MSI), and magnetic resonance spectroscopy (MRS) available to them. These technological innovations have empowered researchers to find concrete evidence that has transformed our understanding of dyslexia from theories and beliefs (often mistaken) to factual knowledge.

Many of us were told myths about dyslexia, some of which are listed below:

- The most important early warning sign of dyslexia is writing letters backwards or upside down (b for d; p for q, etc.).
- Students with dyslexia read words or text backwards (“was” for “saw”; “mad” for “dam”, etc.)
- Dyslexia is caused by problems with vision (the eyes don’t track correctly or other vision problems).
- People with dyslexia have lower intelligence or a low IQ score.
- Children who are gifted or have high IQ scores cannot have dyslexia.
- Children who have low IQ scores cannot have dyslexia.
- Far more boys have dyslexia than girls.
- Dyslexia cannot be identified before third grade.
- Students with dyslexia are lazy; they just need to focus and try harder.
- Children will outgrow dyslexia.

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Every one of these beliefs about dyslexia has been disproven by research. 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). While vision problems can undoubtedly create challenges for learning to read print, dyslexia is not caused by problems with eyesight or vision (American Academy of Pediatrics, 2009).

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. And some students with dyslexia do not reverse or transpose their letters, which may result in 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 the second white paper: Addressing Dyslexia.)

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In general, more boys than girls are referred for both academic and behavioral concerns in school. Still, research has verified that only slightly more boys than girls have the neurological markers of dyslexia (Fletcher et al., 2019). Students who are at-risk of reading difficulties due to dyslexia can be accurately identified as early as four years old, and continuing research may eventually allow us to detect dyslexia at a significantly earlier age (Gaab, 2019).

Attention-deficit/hyperactivity disorder (ADHD) often occurs in students identified as having specific learning disabilities, including dyslexia. Still, they are separate disorders and do not always co-occur with academic problems (Brown, 2013). And, 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.

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! And 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).

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Parent Activism and Advocacy

In the past decade, across the United States, Canada, the United Kingdom, and Australia, a growing number of parents of children with dyslexia have formed awareness and/or advocacy groups. Some of these parents may feel that their children and others with dyslexia are being ignored in schools or are being provided with outmoded, unscientific, and ineffective instruction or delayed intervention, while others are looking to inform policymakers and form better partnerships with educators to improve outcomes.

Lichtenstein (2019) found that every parent advocate shared similar experiences that included:

- Recognizing that their young child had unexpected difficulties with reading.
- Being met with an unsatisfactory response from school or district personnel and/or policymakers.
- Exchanging information with other parents.
- Tapping into the power and support of an advocacy group.

These activist parents formed networks of local, grass-roots organizations, including Decoding Dyslexia (<http://www.decodingdyslexia.net/home.html>) and #saydyslexia (<https://www.saydyslexia.org/>) with the goal of raising dyslexia awareness, empowering families to support their children, and informing policymakers on best practices to identify, teach, and support students with dyslexia. These parent groups have also advocated for new state laws that require:

- A universal definition and understanding of dyslexia in the state education code.
- Mandatory teacher training on dyslexia, its warning signs, and appropriate intervention strategies.
- Mandatory early screening tests for dyslexia.
- Necessary dyslexia intervention programs, which can be accessed by both general and special education populations.
- Access to appropriate assistive technologies in public schools for students with dyslexia.

As of this writing, more than 40 states have laws, pilot programs, or bills ready to be signed to address dyslexia and the implementation of the science of reading in their schools. Legislation in the United States related to dyslexia can be tracked on Dyslexia.com.

Conclusion

Over a century of research has proven that dyslexia is neurobiological in origin and is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. This learning disability typically results from a deficit in the phonological component of language. In recent years, increased advocacy from parents has raised awareness for dyslexia as scientists have disproved common myths about the learning disability that has no correlation to intelligence. We know that dyslexia cannot be “cured.” However, with early intensive, explicit intervention combined with the proper social and emotional supports, students can overcome dyslexia, and with early detection, we can prevent students from ever struggling with it in the first place.

In part two of this white paper—*Addressing Dyslexia*—we will explore how we can implement effective interventions that are proven to meet the needs of students struggling with dyslexia and how it impacts them both in and out of the class.

See Part 2: *Addressing Dyslexia* to learn more and review additional Dyslexia resources.