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Maria Cunningham Yale University

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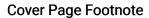
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## Barriers to the Diagnosis of Dyslexia in Children



This paper was originally written as a final paper for Dr. Fred Volkmar's Developmental Psychopathology course.

# Barriers to the Diagnosis of Dyslexia in Children

## By Maria Elena Cunningham<sup>1</sup>

<sup>1</sup>Yale University

### **ABSTRACT**

Dyslexia is a learning disability that impairs reading, writing, and spelling and is estimated to affect 5-20% of people (Shaywitz, 1998; Shaywitz, 2003). Although dyslexia is a life-long disability that has no cure, evidence-based treatments are available for struggling students (Shaywitz, 2003). The earlier these interventions are implemented, the better the student outcomes (Alexander & Slinger-Constant, 2004). However, despite the very high prevalence of dyslexia and time-sensitive need for treatment, many affected individuals slip through the cracks and go undiagnosed until adolescence or adulthood - most never get diagnosed at all (Shaywitz, 2003). This paper addresses potential barriers that contribute to the underdiagnoses of dyslexia in children in the United States.

### **BACKGROUND**

Dyslexia is the most common learning disability, affecting around poor life outcomes. 5-20% of the population (Shaywitz, 1998; Shaywitz, 2003) and accounting for roughly 80% of those with learning disabilities (Lern- Although dyslexia is a lifelong condition that can never be fuler, 1989). Dyslexia impairs reading, writing, and spelling, regard- ly "cured," evidence-based interventions can improve outcomes. less of intelligence (Shaywitz, 1998). Contrary to popular belief, "Structured Literacy" is a term used by the International Dyslexia dyslexia is not a visual disorder; numbers and letters do not appear Association (IDA) to encompass effective approaches to reading backward as if they are visually flipped or moving (Thorwarth, instruction that share similar methods in terms of what is taught 2014). Instead, people have difficulty with phonological processing and how (McLean & Smith, 2017). Common Structured Literacy and decoding, which makes it difficult to break down words into approaches include teaching phonology, sound-symbol association, their components and sounds (Shaywitz, 1998). Although people syllables, morphology, syntax, and semantics, all in a way that does with dyslexia have trouble breaking down words, the deficit does not assume prior knowledge; is flexible to the individual; and alnot impact other higher cognitive processes, like grammar, that are lows concepts to build off of each other logically (Cowen, 2017). involved in comprehension (Shankweiler et al., 1995). Thus, peo- Effective spelling interventions also exist. In a meta-analysis, spellple with dyslexia often read slower, have difficulty with spelling ing interventions that focused on phonics, practicing inflections in and reading out loud, and struggle to read unfamiliar words (Shay- words, and understanding the rules of how specific letters sound witz, 2017). Dyslexia can range from mild to severe (Wadlington together all had a statistically significant positive impact (Ga-& Wadlington, 2005). Finally, it should be noted that dyslexia is luschka et al., 2020). These strategies appear to be logical since also associated with several strengths, such as a heightened ability they target known deficits: phonological processing and decoding/ to think outside of the box, identify the big picture, understand con-building words from broken down sounds. If reading and spellcepts, and think creatively (Shaywitz, 2017).

but it can also have other negative consequences and associations. & Slinger-Constant, 2004). Thus, people with dyslexia can improve Mainly, dyslexia can lead to reduced self-esteem (Eissa, 2010). with treatment, but it is crucial to intervene early to ensure the best When persons with dyslexia cannot read with the same ease of their possible outcomes. peers, they may feel different and inferior. Adolescents with dyslexia have increased rates of anxiety and depression (Eissa, 2010). Children with dyslexia may also benefit from accommodations or Approximately 50% are bullied by peers because of their learning special programming that can help them engage more fully with disability (Humphrey & Mullins, 2002). People with dyslexia have material (McLean & Smith, 2017). Accommodations are granted also been found to have higher rates of aggression and poor behav- under the 504 plan of the United States Department of Education ior (Eissa, 2010). Studies conducted in Texas and Scotland found and can help children receive smaller group instruction, useful that approximately half of prisoners and youth offenders, respect technology (such as text-to-speech software or audiobooks), and tively, had dyslexia, a rate significantly higher than in the general extra time for assignments (McLean & Smith, 2017). For more sepopulation (Moody et al., 2000; Kirk & Reid, 2001). In addition to vere and extreme cases, individualized education programs (IEPs), poor self-esteem and behavioral issues, people with dyslexia have which are granted under the Individuals with Disabilities Education a higher high school dropout rate (Eissa, 2010); estimated rates of Act (IDEA), can also be enacted in public schools; these are free to

not simply stop at basic reading skills, but it can have a lasting emotional toll on persons' lives and place them at a higher risk for

ing interventions are provided at a young age, children can show significant improvement and remediation; for older children and Dyslexia not only causes difficulties in learning to process words, adults, improvement is still possible but harder to attain (Alexander

dropout are as high as 35% (Al-Lamki, 2012). Thus, dyslexia does families and can help students get the help they need beyond what

# "...dyslexia does not simply stop at basic reading skills, but it can have a lasting emotional toll on persons' lives and place them at a higher risk for poor life outcomes."

A diagnosis of dyslexia is essential for access to early reading and spelling interventions and if needed, accommodations and special RTIs to establish the DSM-5 diagnosis of dyslexia may thus miss programming. Receiving the diagnosis may also help children with a significant proportion of children who, despite being dyslexic, the emotional toll of the disorder, since it may help them and their are performing at an average level in school (Colker et al., 2012). family grapple with why they are not performing similarly to their In their criticism, Colker, Shaywitz, Shaywitz, and Simon describe peers (Forrest, 2019). Children may be better able to understand the new DSM-5 diagnosis as more of an achievement disorder than their strengths and weakness, and they may be more likely to find a learning one. role models with dyslexia (Forrest, 2019). Although receiving a diagnosis may also be stigmatizing and cause a child to feel "other," In addition, reliance on RTIs may postpone diagnosis. In essence, it is the crucial first step to recognizing deficits and targeting them one has to wait for a student to fail over a period of time before effectively and efficiently (Forrest, 2019).

effects on our youth, is treatable, and can be best mediated with ear- not be used for older children or adults. Children aging out of when ly intervention. However, although roughly 40 million adult Amer- RTIs are applicable may thus lose the opportunity to be detected icans have dyslexia, only about 5% of them may be aware (Austin and diagnosed (Colker et al., 2012). Some debate whether RTIs are Learning Solutions, 2020). So, how and why do so many people go even a valid tool for diagnostic purposes (Cavendish, 2013). Lastly, undetected? In the next section of this paper, I will detail some of RTIs are not universally implemented across all school districts in the major barriers that children face when it comes to receiving a the United States, and not all teachers and educators are trained in diagnosis of dyslexia.

### BARRIERS TO IDENTIFYING INDIVIDUALS WITH DYSLEXIA

To begin, it is important to understand what a diagnosis of dyslexia entails. Currently, the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) - the handbook used by The second criterion listed, which requires impairment in daily health care professionals to diagnose mental disorders – categoriz- life and study/occupation, also excludes from diagnosis the many es dyslexia as a specific learning disability (SLD) rather than un-individuals with dyslexia who are successful in their occupations der the specific term "dyslexia" (Tannock, 2015). SLDs are broken (Colker et al., 2012). This criterion might exclude those who have down into three subtypes (reading, writing, and math) (Tannock, less severe dyslexia, because again, dyslexia can manifest on a wide 2015). To be diagnosed with an SLD, persons must meet four cri-range, from mild to severe (Wadlington & Wadlington, 2005). Thus, teria: 1) persistence of difficulties for at least 6 months even with at least two of the four DSM-5 criteria for SLD may lead to indispecifically directed help (in at least one of 6 areas, which include viduals with dyslexia not receiving identification and intervention. difficulty reading, difficulty in reading comprehension, difficulty spelling, difficulty writing be it with grammar or organization, Another main criticism of the DSM-5's definition of SLD is that

can be provided by accommodations (McLean & Smith, 2017). In neurological disorders (Deepak, 2018). Thus, in order to meet the many instances of dyslexia, one can qualify for a 504 plan and not first and fourth criteria, there needs to be a well-documented history an IEP (McLean & Smith, 2017). Thus, the United States govern- of a student's performance, strengths, and weaknesses. This often ment has passed measures for schools to help children with dys-comes from school documentation referred to as Response to Intervention (RTI), which tracks how students are performing in the classroom and responding to different kinds of interventions. RTIs help quantify the criteria required for diagnosis (Cavendish, 2013).

> Although RTIs may be useful in establishing a diagnosis of dyslexia, relying on them may be an important barrier. The DSM-5 diagnosis of SLD has sparked criticism from some of the most prominent leaders in dyslexia research, including Yale University's Sally Shaywitz. Among the criticisms is the reliance on RTIs to show lack of response to treatment. While RTIs may help identify children who are performing below average in comparison to their peers, they may fail to identify others who have average reading scores yet exhibit many symptoms, including slow and strained reading (Colker, Shaywitz, Shaywitz, & Simon, 2012). Relying on

being referred for further evaluation (Colker et al., 2012). Allowing a student to fail can be detrimental to self-esteem and may be more In sum, dyslexia is a prevalent issue in our communities, has lasting harmful the longer it is allowed to continue. In addition, RTIs cantheir proper use (Cavendish, 2013). Large numbers of students may thus not receive RTIs, or they may receive ineffective ones. In sum, the DSM-5 inclusion of resistance to treatment, and the common reliance on the not validated and not widely implemented RTI to establish this non-response, may lead to the underdiagnosis of dyslexia and delays in diagnosis.

difficulty with numbers, or difficulty in mathematical reasoning); the diagnosis diverges from the old standard criterion for dyslexia: 2) impairment in academic/professional work or activities and per- an IQ-Achievement discrepancy. The IQ-Achievement discrepanformance that is subpar with what is expected for a particular age cy, which was included in the 4th edition of the DSM, required a group; 3) onset of difficulties at a young age; and 4) ascertainment comparison of an individual's intelligence quotient (IQ) to their that difficulties are not being caused by other disorders or condi-reading ability. This comparison measure, which was used for tions, such as intellectual disability, visual impairment, or other many decades, was able to detect persons who have higher IQs

but only average reading scores. However, some called into ques- mental factors can serve as barriers to diagnosing dyslexia. tion whether or not this comparison method was effective (Tanteria and methods are best, the major shifts in diagnosing dyslexia behaviors, they may be more likely to go undiagnosed. have likely led to confusion and disagreement, leading to potential hesitation in diagnosis.

well informed regarding even the basics of dyslexia, how can they even greater underdiagnosis. be expected to help identify children with the disorder?

tected and be at risk for negative consequences.

the Individuals with Disabilities Education Act (IDEA) (Lee, 2020) likely to advocate for their child to receive a diagnosis. mandates that testing be covered for all children, including those not in public school. However, screenings to determine who should be tested can be expensive as well, and schools may not have the **NEXT STEPS** funds to perform such screenings despite laws that might be in place (Behrens, 2020). The lack of funds and resources may result in I will propose a few potential ideas for how we might be able to school reluctance to identify students as dyslexic (Hanford, 2020).

nock, 2015; Colker et al., 2012). One benefit from eliminating the Another individual predictor of whether or not persons with dys-IQ-Achievement discrepancy criterion is that neuropsychological lexia are detected is sex. Although there is no significant difference testing, which is both expensive and time-consuming, is no longer in the prevalence of dyslexia between males and females (Georgeneeded to arrive at a diagnosis of dyslexia (Tannock, 2015). This town University Medical Center, 2013; Shaywitz et al., 1990), boys theoretically should make diagnosis more accessible, especially for are much more likely to be diagnosed (Arnett et al., 2017) and to those from disadvantaged backgrounds and schools. However, this be referred by schools for testing (Shaywitz et al., 1990). One main benefit comes at the cost of relying more heavily on teachers, par- reason that boys may be more likely to be referred is because of ents, and the previously discussed RTIs to describe the learning accompanying behavioral issues (Arnett et al., 2017; Shaywitz et history of an individual (Tannock, 2015). Regardless of which cri- al., 1990). Because girls may be less likely to display disruptive

People who are learning English are also more likely to experience a delay in the diagnosis of dyslexia or to be missed altogether (Ri-While the current diagnostic criteria for dyslexia in the DSM-5 revera et al., 2009). English learners often account for a large proporquire teacher involvement and assessment, teachers are not nec- tion of children, including almost 10 percent of students in public essarily well equipped to detect children with dyslexia and have schools (Snyder & Dillow, 2015). These children may experience frequently received insufficient instruction regarding the disability. reading difficulties due to dyslexia, or just because they are learning Many educators believe common myths, such as dyslexia consist- a new language; the distinction may be a very difficult one to make ing of letter flipping and movement, or that there is no range in se- (Klingner, Artiles, & Barletta, 2006). It may require significantly verity (Wadlington & Wadlington, 2005). Thus, if educators are not more effort to diagnose dyslexia in English learners, resulting in

Another major barrier alluded to earlier is the stigma of being di-In the United States, laws regarding dyslexia vary across states and agnosed with a learning disability like dyslexia. Students may exterritories. Five states and territories - Idaho, South Dakota, Ha- perience stigma from the process of testing itself, from receiving waii, the District of Columbia, and Puerto Rico - have no legisla- accommodations or different treatment than their peers, or from tion whatsoever regarding dyslexia (National Center on Improving getting tutored (McNulty, 2003). Even in higher education, students Literacy, 2020). Of the remaining states, only 35 require screening, with dyslexia may feel awkward and hesitate to ask for assistance only 25 require teacher training regarding dyslexia, and only 13 from tutors or professors (Mortimore & Crozier, 2006). Students require teacher training on dyslexia prior to certification (Nation- may experience negative emotions or impaired self-esteem from al Center on Improving Literacy, 2020). Since 2013, significant being set apart from their peers (McNulty, 2003). It is possible then, progress has been made, with doubling in the amount of legisla- that parents may want to avoid putting their child through such a tion regarding dyslexia (Youman & Mather, 2013). Although trends process, especially if the child's dyslexia is on the milder side. It is in awareness, guidelines, and laws are improving, many children also possible that parents may themselves not want to experience who would benefit from identification and treatment continue to stigma from having a child with a learning disability. They may fear be missed. Without legally mandated teacher training and required the stigma associated with a disability, or from being labeled by universal screening for dyslexia, children will continue to go unde- others as "bad parents" (Francis, 2012). Parents may not want their child to be considered as having something "wrong with them." If parents fear the stigma that they or their child might incur upon Funding is also a barrier to timely diagnosis. Although expensive, being tested or receiving treatment for dyslexia, they may be less

overcome barriers to detecting dyslexia in the future. First and foremost, future versions of the DSM should reconsider the criteria for Individual differences have also been identified as barriers to di- dyslexia. The diagnosis should include measures that would allow agnosing dyslexia. Individuals who are racial minorities and who for the identification of high functioning individuals with dyslexia. attend schools with higher percentages of racial minorities are more The diagnosis should also reevaluate the standards that are required likely to go undetected, even when universal screenings are in place for diagnosis and should do away with dependence on the unval-(Odegard et al., 2020). This disparity may be at least partially ac- idated RTI method. Perhaps the best way to do this is by creating counted for by lower socioeconomic status (Shifrer, Muller, & Cal- a new, shorter, simpler way of recording the learning history of a lahan, 2011). In addition, individuals who are in a school with a child that is easy to standardize and implement across the country. lower average reading ability are more likely to be missed in uni- All new measures should yield a higher consensus among experts versal screens (Odegard et al., 2020). Thus, personal and environ- in the field than those currently used to establish DSM-5 criteria.

In addition, the future DSM should consider separating dyslexia dividuals with dyslexia not feel alone. In addition, teachers, adminample, people with and without dyslexia have been found to have heightened ability to understand the big picture (Shaywitz, 2017). differences in the left temporo-parietal and the left occipitotemporal regions of the brain (Linkersdörfer et al., 2012). The disability can also be passed down from parent to child; heritability is quite CONCLUSION high, ranging anywhere between 40 to 60% (Raskind et al., 2013). fective treatments.

legislation may be helpful, requiring teachers in training to be ed-barriers that may exist in regard to the provision of evidence-based ucated regarding dyslexia and for current teachers to have regular treatment for the condition. While recent progress has been made in refreshers on the topic. Teachers should receive training not only state legislation, we have a long way to go to make sure that every regarding the main characteristics of dyslexia, but also regarding child can be identified so that they may be more likely to receive how to refer students for evaluation and take subsequent steps. Bet- the help they need in a timely fashion and be best equipped for sucter equipped and empowered teachers will lead to greater detection cess. Most urgently, changes need to happen in diagnostic criteria, of dyslexia.

Schools also need reform. Given the extremely high prevalence of dyslexia of between 5 and 20% of students, universal screening ACKNOWLEDGMENTS should become a nationwide goal and be legislated into practice (Shaywitz, 1998; Shaywitz, 2003). However, in order to establish This paper was originally written as a final paper for Dr. Fred Volkuniversal screening, more funds are needed. School superinten- mar's Developmental Psychopathology course. dents and administrators will also require education and training so as to ensure that they facilitate rather than impede detection and REFERENCES treatment for dyslexia. With proper screening, funds, and education, more students will be identified and diagnosed.

Although specific recommendations are beyond the scope of this paper, awareness of the impact of student race, socioeconomic status, sex, and language capability need to be at the forefront of Al-Lamki, L. (2012). Dyslexia: Its impact on the individual, parents teacher and administrator education efforts. It is crucial that we be and society. Sultan Oaboos University Medical Journal, 12(3), 269. aware regarding the populations of individuals at particular risk for underdiagnosis. There may be a need to offer more intensive and Arnett, A. B., Pennington, B. F., Peterson, R. L., Willcutt, E. G., targeted education in underserved communities and in communities with higher percentages of racial minorities, lower socioeconomic status, and English-learners.

# "Because dyslexia affects just about one out of every five people, we need to normalize the condition and help individuals with dyslexia not feel alone."

cause dyslexia affects just about one out of every five people Journal of learning disabilities, 46(1), 52-57. (Shaywitz, 2003), we need to normalize the condition and help in-

from other SLDs because it has been significantly studied and has istrators, and the general public need to learn about the strengths of distinct neurological underpinnings (Colker et al., 2012). For ex- individuals with dyslexia, which include enhanced creativity and a

Although DSM diagnoses do not currently align with distinct neu-Significant barriers exist to the diagnosis of dyslexia, at both sysrobiological processes, developers of the DSM have expressly tem and individual levels. Many children are not identified or are sought to incorporate advances in neuroscience, genetics, and cog- identified late, which can lead to poorer long-term outcomes. Barnitive science into the construction of more meaningful diagnostic riers include the significant changes in diagnostic criteria between categories (Kupfer & Regier, 2011). More scientifically informed the DSM-4 and DSM-5; constructs included in the DSM-5; overdiagnoses may allow for the development of more targeted and ef- reliance on untrained teachers; inadequate state laws and funding; racial, socioeconomic, and gender inequalities; and stigma. It is important to note that this paper focuses on a handful of the many Teachers need to be better educated regarding dyslexia. Federal barriers to diagnosing dyslexia and does not address the many more law, and teacher education.

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