2021

Barriers to the Diagnosis of Dyslexia in Children

Maria Cunningham
Yale University

Follow this and additional works at: https://elischolar.library.yale.edu/yurj

Part of the Psychiatry and Psychology Commons

Recommended Citation
Cunningham, Maria (2021) "Barriers to the Diagnosis of Dyslexia in Children," The Yale Undergraduate Research Journal: Vol. 2 : Iss. 1 , Article 15.
Available at: https://elischolar.library.yale.edu/yurj/vol2/iss1/15

This Article is brought to you for free and open access by EliScholar – A Digital Platform for Scholarly Publishing at Yale. It has been accepted for inclusion in The Yale Undergraduate Research Journal by an authorized editor of EliScholar – A Digital Platform for Scholarly Publishing at Yale. For more information, please contact elischolar@yale.edu.
Barriers to the Diagnosis of Dyslexia in Children

Cover Page Footnote
This paper was originally written as a final paper for Dr. Fred Volkmar’s Developmental Psychopathology course.
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 5-20% of the population (Shaywitz, 1998; Shaywitz, 2003) and accounting for roughly 80% of those with learning disabilities (Lerner, 1989). Dyslexia impairs reading, writing, and spelling, regardless of intelligence (Shaywitz, 1998). Contrary to popular belief, dyslexia is not a visual disorder; numbers and letters do not appear backward as if they are visually flipped or moving (Thorwarth, 2014). Instead, people have difficulty with phonological processing and decoding, which makes it difficult to break down words into their components and sounds (Shaywitz, 1998). Although people with dyslexia have trouble breaking down words, the deficit does not impact other higher cognitive processes, like grammar, that are involved in comprehension (Shankweiler et al., 1995). Thus, people with dyslexia often read slower, have difficulty with spelling and reading out loud, and struggle to read unfamiliar words (Shaywitz, 2017). Dyslexia can range from mild to severe (Wadlington & Wadlington, 2005). Finally, it should be noted that dyslexia is also associated with several strengths, such as a heightened ability to think outside of the box, identify the big picture, understand concepts, and think creatively (Shaywitz, 2017).

Dyslexia not only causes difficulties in learning to process words, but it can also have other negative consequences and associations. Mainly, dyslexia can lead to reduced self-esteem (Eissa, 2010). When persons with dyslexia cannot read with the same ease of their peers, they may feel different and inferior. Adolescents with dyslexia have increased rates of anxiety and depression (Eissa, 2010). Approximately 50% are bullied by peers because of their learning disability (Humphrey & Mullins, 2002). People with dyslexia have also been found to have higher rates of aggression and poor behavior (Eissa, 2010). Studies conducted in Texas and Scotland found that approximately half of prisoners and youth offenders, respectively, had dyslexia, a rate significantly higher than in the general population (Moody et al., 2000; Kirk & Reid, 2001). In addition to poor self-esteem and behavioral issues, people with dyslexia have a higher school dropout rate (Eissa, 2010); estimated rates of dropout are as high as 35% (Al-Lamki, 2012). Thus, 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.

Although dyslexia is a lifelong condition that can never be fully “cured,” evidence-based interventions can improve outcomes. “Structured Literacy” is a term used by the International Dyslexia Association (IDA) to encompass effective approaches to reading instruction that share similar methods in terms of what is taught and how (McLean & Smith, 2017). Common Structured Literacy approaches include teaching phonology, sound-symbol association, syllables, morphology, syntax, and semantics, all in a way that does not assume prior knowledge; is flexible to the individual; and allows concepts to build off of each other logically (Cowen, 2017). Effective spelling interventions also exist. In a meta-analysis, spelling interventions that focused on phonics, practicing inflections in words, and understanding the rules of specific letters sound together all had a statistically significant positive impact (Galuschka et al., 2020). These strategies appear to be logical since they target known deficits: phonological processing and decoding/building words from broken down sounds. If reading and spelling interventions are provided at a young age, children can show significant improvement and remediation; for older children and adults, improvement is still possible but harder to attain (Alexander & Slinger-Constant, 2004). Thus, people with dyslexia can improve with treatment, but it is crucial to intervene early to ensure the best possible outcomes.

Children with dyslexia may also benefit from accommodations or special programming that can help them engage more fully with material (McLean & Smith, 2017). Accommodations are granted under the 504 plan of the United States Department of Education and can help children receive smaller group instruction, useful technology (such as text-to-speech software or audiobooks), and extra time for assignments (McLean & Smith, 2017). For more severe and extreme cases, individualized education programs (IEPs), which are granted under the Individuals with Disabilities Education Act (IDEA), can also be enacted in public schools; these are free to families and can help students get the help they need beyond what
can be provided by accommodations (McLean & Smith, 2017). In many instances of dyslexia, one can qualify for a 504 plan and not an IEP (McLean & Smith, 2017). Thus, the United States government has passed measures for schools to help children with dyslexia.

"...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 programming. Receiving the diagnosis may also help children with the emotional toll of the disorder, since it may help them and their family grapple with why they are not performing similarly to their peers (Forrest, 2019). Children may be better able to understand their strengths and weakness, and they may be more likely to find role models with dyslexia (Forrest, 2019). Although receiving a diagnosis may also be stigmatizing and cause a child to feel “other,” it is the crucial first step to recognizing deficits and targeting them effectively and efficiently (Forrest, 2019).

In sum, dyslexia is a prevalent issue in our communities, has lasting effects on our youth, is treatable, and can be best mediated with early intervention. However, although roughly 40 million adult Americans have dyslexia, only about 5% of them may be aware (Austin Learning Solutions, 2020). So, how and why do so many people go undetected? In the next section of this paper, I will detail some of the major barriers that children face when it comes to receiving a 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 health care professionals to diagnose mental disorders – categorizes dyslexia as a specific learning disability (SLD) rather than under the specific term “dyslexia” (Tannock, 2015). SLDs are broken down into three subtypes (reading, writing, and math) (Tannock, 2015). To be diagnosed with an SLD, persons must meet four criteria: 1) persistence of difficulties for at least 6 months even with specifically directed help (in at least one of 6 areas, which include difficulty reading, difficulty in reading comprehension, difficulty spelling, difficulty writing be it with grammar or organization, difficulty with numbers, or difficulty in mathematical reasoning); 2) impairment in academic/professional work or activities and performance that is subpar with what is expected for a particular age group; 3) onset of difficulties at a young age; and 4) ascertainment that difficulties are not being caused by other disorders or conditions, such as intellectual disability, visual impairment, or other neurological disorders (Deepak, 2018). Thus, in order to meet the first and fourth criteria, there needs to be a well-documented history of a student’s performance, strengths, and weaknesses. This often 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 RTIs to establish the DSM-5 diagnosis of dyslexia may thus miss a significant proportion of children who, despite being dyslexic, are performing at an average level in school (Colker et al., 2012). In their criticism, Colker, Shaywitz, Shaywitz, and Simon describe the new DSM-5 diagnosis as more of an achievement disorder than a learning one.

In addition, reliance on RTIs may postpone diagnosis. In essence, one has to wait for a student to fail over a period of time before being referred for further evaluation (Colker et al., 2012). Allowing a student to fail can be detrimental to self-esteem and may be more harmful the longer it is allowed to continue. In addition, RTIs cannot be used for older children or adults. Children aging out of when RTIs are applicable may thus lose the opportunity to be detected and diagnosed (Colker et al., 2012). Some debate whether RTIs are even a valid tool for diagnostic purposes (Cavendish, 2013). Lastly, RTIs are not universally implemented across all school districts in the United States, and not all teachers and educators are trained in their 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.

The second criterion listed, which requires impairment in daily life and study/occupation, also excludes from diagnosis the many individuals with dyslexia who are successful in their occupations (Colker et al., 2012). This criterion might exclude those who have less severe dyslexia, because again, dyslexia can manifest on a wide range, from mild to severe (Wadlington & Wadlington, 2005). Thus, at least two of the four DSM-5 criteria for SLD may lead to individuals with dyslexia not receiving identification and intervention.

Another main criticism of the DSM-5’s definition of SLD is that the diagnosis diverges from the old standard criterion for dyslexia: an IQ-Achievement discrepancy. The IQ-Achievement discrepancy, which was included in the 4th edition of the DSM, required a comparison of an individual’s intelligence quotient (IQ) to their reading ability. This comparison measure, which was used for many decades, was able to detect persons who have higher IQs...
but only average reading scores. However, some called into question whether or not this comparison method was effective (Tannock, 2015; Colker et al., 2012). One benefit from eliminating the IQ-Achievement discrepancy criterion is that neuropsychological testing, which is both expensive and time-consuming, is no longer needed to arrive at a diagnosis of dyslexia (Tannock, 2015). This theoretically should make diagnosis more accessible, especially for those from disadvantaged backgrounds and schools. However, this benefit comes at the cost of relying more heavily on teachers, parents, and the previously discussed RTIs to describe the learning history of an individual (Tannock, 2015). Regardless of which criteria and methods are best, the major shifts in diagnosing dyslexia have likely led to confusion and disagreement, leading to potential hesitation in diagnosis.

While the current diagnostic criteria for dyslexia in the DSM-5 require teacher involvement and assessment, teachers are not necessarily well equipped to detect children with dyslexia and have frequently received insufficient instruction regarding the disability. Many educators believe common myths, such as dyslexia consisting of letter flipping and movement, or that there is no range in severity (Wadlington & Wadlington, 2005). Thus, if educators are not well informed regarding even the basics of dyslexia, how can they be expected to help identify children with the disorder?

In the United States, laws regarding dyslexia vary across states and territories. Five states and territories – Idaho, South Dakota, Hawaii, the District of Columbia, and Puerto Rico – have no legislation whatsoever regarding dyslexia (National Center on Improving Literacy, 2020). Of the remaining states, only 35 require screening, only 25 require teacher training regarding dyslexia, and only 13 require teacher training on dyslexia prior to certification (National Center on Improving Literacy, 2020). Since 2013, significant progress has been made, with doubling in the amount of legislation regarding dyslexia (Youman & Mather, 2013). Although trends in awareness, guidelines, and laws are improving, many children who would benefit from identification and treatment continue to be missed. Without legally mandated teacher training and required universal screening for dyslexia, children will continue to go undetected and be at risk for negative consequences.

Funding is also a barrier to timely diagnosis. Although expensive, the Individuals with Disabilities Education Act (IDEA) (Lee, 2020) 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 funds to perform such screenings despite laws that might be in place (Behrens, 2020). The lack of funds and resources may result in school reluctance to identify students as dyslexic (Hanford, 2020).

Individual differences have also been identified as barriers to diagnosing dyslexia. Individuals who are racial minorities and who attend schools with higher percentages of racial minorities are more likely to go undetected, even when universal screenings are in place (Odegaard et al., 2020). This disparity may be at least partially accounted for by lower socioeconomic status (Shifrer, Muller, & Callahan, 2011). In addition, individuals who are in a school with a lower average reading ability are more likely to be missed in universal screens (Odegaard et al., 2020). Thus, personal and environmental factors can serve as barriers to diagnosing dyslexia.

Another individual predictor of whether or not persons with dyslexia are detected is sex. Although there is no significant difference in the prevalence of dyslexia between males and females (Georgetown University Medical Center, 2013; Shaywitz et al., 1990), boys are more likely to be diagnosed (Arnett et al., 2017) and to be referred for schools testing (Shaywitz et al., 1990). One main reason that boys may be more likely to be referred is because of accompanying behavioral issues (Arnett et al., 2017; Shaywitz et al., 1990). Because girls may be less likely to display disruptive behaviors, they may be more likely to go undiagnosed.

People who are learning English are also more likely to experience a delay in the diagnosis of dyslexia or to be missed altogether (Rivera et al., 2009). English learners often account for a large proportion of children, including almost 10 percent of students in public schools (Snyder & Dillow, 2015). These children may experience reading difficulties due to dyslexia, or just because they are learning a new language; the distinction may be a very difficult one to make (Klingner, Artiles, & Barletta, 2006). It may require significantly more effort to diagnose dyslexia in English learners, resulting in even greater underdiagnosis.

Another major barrier alluded to earlier is the stigma of being diagnosed with a learning disability like dyslexia. Students may experience stigma from the process of testing itself, from receiving accommodations or different treatment than their peers, or from getting tutored (McNulty, 2003). Even in higher education, students with dyslexia may feel awkward and hesitate to ask for assistance from tutors or professors (Mortimore & Crozier, 2006). Students may experience negative emotions or impaired self-esteem from being set apart from their peers (McNulty, 2003). It is possible then, that parents may want to avoid putting their child through such a process, especially if the child’s dyslexia is on the milder side. It is also possible that parents may themselves not want to experience stigma from having a child with a learning disability. They may fear the stigma associated with a disability, or from being labeled by 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 being tested or receiving treatment for dyslexia, they may be less likely to advocate for their child to receive a diagnosis.

**NEXT STEPS**

I will propose a few potential ideas for how we might be able to overcome barriers to detecting dyslexia in the future. First and foremost, future versions of the DSM should reconsider the criteria for dyslexia. The diagnosis should include measures that would allow for the identification of high functioning individuals with dyslexia. The diagnosis should also reevaluate the standards that are required for diagnosis and should do away with dependence on the unvalidated RTI method. Perhaps the best way to do this is by creating a new, shorter, simpler way of recording the learning history of a child that is easy to standardize and implement across the country. All new measures should yield a higher consensus among experts in the field than those currently used to establish DSM-5 criteria.
In addition, the future DSM should consider separating dyslexia from other SLDs because it has been significantly studied and has distinct neurological underpinnings (Colker et al., 2012). For example, people with and without dyslexia have been found to have 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 high, ranging anywhere between 40 to 60% (Raskind et al., 2013). Although DSM diagnoses do not currently align with distinct neurobiological processes, developers of the DSM have expressly sought to incorporate advances in neuroscience, genetics, and cognitive science into the construction of more meaningful diagnostic categories (Kupfer & Regier, 2011). More scientifically informed diagnoses may allow for the development of more targeted and effective treatments.

Teachers need to be better educated regarding dyslexia. Federal legislation may be helpful, requiring teachers in training to be educated regarding dyslexia and for current teachers to have regular refreshers on the topic. Teachers should receive training not only regarding the main characteristics of dyslexia, but also regarding how to refer students for evaluation and take subsequent steps. Better equipped and empowered teachers will lead to greater detection of dyslexia.

Schools also need reform. Given the extremely high prevalence of dyslexia of between 5 and 20% of students, universal screening should become a nationwide goal and be legislated into practice (Shaywitz, 1998; Shaywitz, 2003). However, in order to establish universal screening, more funds are needed. School superintendents and administrators will also require education and training so as to ensure that they facilitate rather than impede detection and 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 teacher and administrator education efforts. It is crucial that we be aware regarding the populations of individuals at particular risk for underdiagnosis. There may be a need to offer more intensive and 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."

Lastly, to address stigma, we need greater public education. Because dyslexia affects just about one out of every five people (Shaywitz, 2003), we need to normalize the condition and help individuals with dyslexia not feel alone. In addition, teachers, administrators, and the general public need to learn about the strengths of individuals with dyslexia, which include enhanced creativity and a heightened ability to understand the big picture (Shaywitz, 2017).

**CONCLUSION**

Significant barriers exist to the diagnosis of dyslexia, at both system and individual levels. Many children are not identified or are identified late, which can lead to poorer long-term outcomes. Barriers include the significant changes in diagnostic criteria between the DSM-4 and DSM-5; constructs included in the DSM-5; over-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 barriers to diagnosing dyslexia and does not address the many more barriers that may exist in regard to the provision of evidence-based treatment for the condition. While recent progress has been made in state legislation, we have a long way to go to make sure that every child can be identified so that they may be more likely to receive the help they need in a timely fashion and be best equipped for success. Most urgently, changes need to happen in diagnostic criteria, law, and teacher education.

**ACKNOWLEDGMENTS**

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

**REFERENCES**


Rivera, M. O., Moughamian, A. C., Lesaux, N. K., & Francis, D. J. (2009). Language and Reading Interventions for English Language Learners and English Language Learners with Disabilities. Center on Instruction.


science-based program for reading problems at any level: Knopf.


