Dyslexia: An ounce of prevention is better than a pound of diagnosis and treatment

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Abstract

Dyslexia is a significant developmental disorder that is associated with a host of negative consequences. Most states in the US have recently passed legislation requiring the diagnosis and treatment of dyslexia in school settings. Whereas this legislation brings needed attention to children with dyslexia, diagnosis and treatment are often delayed until several years after school entry. By this time, reading problems and other negative consequences are well underway. In this paper, we argue for an alternative, prevention-based approach that focuses on the early identification of children at risk for dyslexia and the provision of instruction/intervention that is matched to their needs.

Developmental dyslexia is a severe and protracted difficulty learning to read words despite adequate cognitive/perceptual ability and instruction (Lyon et al., 2003). Children with dyslexia face a host of negative consequences because of their reading problems. These often include academic failure and poor overall school performance (Daniel et al., 2006). Children with dyslexia also frequently have secondary psycho-social problems such as low self-esteem, anxiety, and depression, and are at a higher risk for suicide (Arnold et al., 2005; Chapman et al., 2000; McArthur et al., 2020; Morgan et al., 2012). In addition, they may go on to experience behavioral problems, delinquency, and/or incarceration (Baker & Ireland, 2007; Grigorenko, 2006).

Because of the negative consequences associated with dyslexia, advocates have argued for timely and appropriate intervention. In the United States, the Individuals with Disabilities Education Act 2004 (IDEA), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA) mandate that services be provided for individuals with specific learning disabilities including dyslexia. More recently, a grass roots organization of parents and educators have advocated for state legislation to better address dyslexia in public schools (Ward-Lonergan & Duthie, 2018; Youman & Mather, 2018). These efforts have resulted in most states (46 states at the present time) passing laws requiring that specific services be provided to treat children with dyslexia, especially in the early school grades. Many states also have legislation that calls for mandatory screening to identify children with dyslexia.

For the most part, national and state legislation has focused on the diagnosis and treatment of dyslexia as opposed to its prevention. Of course, such a focus does bring much needed help to children with dyslexia and can address some of the problems these children experience. However, waiting to identify and treat children with dyslexia can delay intervention

efforts and allow for the initiation of negative consequences. Alternatively, in this paper, we argue for a prevention-based approach to addressing dyslexia and provide suggestions of what this may entail.

In a recent paper, Ozernov-Palichik and Gaab (2016) also raised concerns about the delay in the identification and treatment of dyslexia. They noted that dyslexia is not generally diagnosed until children are in second grade or later. By this time, the gap between good and poor readers can be well established and unfortunately negative consequences are well underway. In addition, children have reached a point in time at which interventions to address reading difficulties are not as effective as they would have been at an earlier grade. For example, Wanzek and Vaughn (2016), in a meta-analysis, found that word reading interventions were significantly more effective for improving reading outcomes when administered in kindergarten and first grade than they were when administered during later grades. Ozernov-Palichik and Gaab introduced the term “dyslexia paradox” to acknowledge the fact that dyslexia is not typically diagnosed until well past the time that intervention is most effective.

Delays in the diagnosis and treatment of dyslexia occur for a variety of reasons. Some are related to misconceptions about reading problems. For example, some believe that reading problems result from the lack of effort or that these problems typically get better on their own with time. In other cases, delays are due to administrative challenges, for instance, the need for formal referral and full diagnostic examination before any treatment is provided. In response to legislation, schools have begun to address these factors and are working toward earlier diagnosis and treatment. However, the way dyslexia is defined can delay diagnosis and treatment. According to most definitions, the defining characteristic of dyslexia is a severe and unexpected deficit in word reading (e.g., Lyon et al., 2003; Rose, 2009). Because, most children require

explicit instruction to learn to read, accurate identification of a difficulty in word reading is not typically possible until instruction takes place. Even after formal instruction begins, it takes some time for individual differences in word reading ability to clearly emerge.

The slow emergence of individual differences in reading ability is well illustrated in a study by Catts et al. (2009). They examined archival data from DIBELS assessments that were administered 3 times a year in grades K-2nd. Data were available on approximately 18,000 children at each grade. Results demonstrated that DIBELS early literacy (i.e., phonological awareness, letter knowledge) and word reading measures showed that a large proportion of children scored at, or near, the bottom of the distribution when measures were first administered and these “floor effects” gradually lessened over subsequent assessments. For example, strong floor effects were present in DIBELS Oral Reading Fluency (ORF) when it was initially administered in September of 1st grade and remained until December of 2nd grade. As a result, if this measure had been used to screen for difficulties in word reading fluency, the overabundance of children with scores at the low end of the distribution in early administrations would likely have resulted in numerous children being falsely identified as at risk. In other words, not all those who appeared to be a risk because of low initial scores would have ended up with reading problems. Many of these children would have been “false positives,” typically developing children who had not had sufficient instruction for them to show their true abilities. This was confirmed by further classification analyses that found high false positive rates using initial ORF data to predict good and poor reader outcomes at later grades. Similar high false positive rates were observed in classification analyses with the initial assessments of the other DIBELS measures.

Given our results, it would be expected that floor effects and problems in classification accuracy would also be present with most measures of early literacy and word reading. Of course, the specific point in time that floor effects would be observed and classification accuracy compromised would be dependent on the measure used and the instruction that has been provided. Nevertheless, these inherent measurement problems will cause delays in how early dyslexia can be diagnosed and treated because too many children who are typically developing could be identified as having dyslexia, and educators would not be certain who truly has dyslexia.

Prevention

Because of the inherent problems and delays in diagnosing and treating dyslexia, we believe a focus on prevention is a better approach. Such an approach has been used in the healthcare professions for many years. Preventive medicine seeks to prevent the occurrence of a disease by halting the disease (primary prevention) or averting the resulting consequences after its onset (secondary prevention) rather than focusing on treating the disease (Clark, 1974). Well-known examples of preventive medicine include efforts to prevent heart disease, diabetes, and cancer. In the case of heart disease, screening often occurs early in life with assessments of such factors as family history, hypertension, and cholesterol level. When risk factors are present, medical and/or behavioral treatments are prescribed to reduce risk. Not only have these efforts been shown to lead to better health, but they have been more cost effective (Heller et al. 2017; Pharoah & Hollingworth, 1996).

Screening

A similar approach can be used to prevent dyslexia and/or reduce the negative consequences of the condition. Like preventive medicine, the first step in this process is universal screening (i.e.,

screening of all children) to identify children who are at risk for dyslexia. Research on screening for dyslexia has been on-going for nearly 50 years (Jansky & deHirsch, 1972) and has identified multiple factors that are associated with risk for dyslexia (Carroll et al., 2016; Catts et al., 2015; Elbro et al., 1998; Landerl et al., 2013; Lyytinen et al., 2015; Ozernov-Palichik et al., 2017; Thompson et al., 2015). These include, but are not limited to, deficits in phonological awareness, letter knowledge, rapid naming, and oral language. Risk factors also include a family history of dyslexia or language delay. This research further indicates that risk factors do not determine whether or not a child will have dyslexia but rather the probability they will have the condition (Catts & Petscher, 2020). In other words, a screening test (and follow-up assessments) cannot definitively tell that a child will have dyslexia rather they provide the likelihood that they will have dyslexia.

Screening measures for dyslexia are now widely available. Some have been specifically developed to screen for dyslexia (Gaab, 2020; Fletcher et al., 2020; Wood et al., 2005), while many others have been adapted for this purpose. For example, benchmark and/or progress monitor tools such as DIBELS and aimswebPlus are now being used to screen for risk based on deficits in letter knowledge, phonological awareness and/or word reading. The Center for Response to Intervention maintains a screening tool chart that provides information on the nature and quality of screening instruments, including those intended to be used to identify risk for dyslexia. See <https://charts.intensiveintervention.org/ascreening>. Also, the National Center for Improving Literacy has put forth a document concerning policy, emerging research, and best practice in screening for dyslexia (Petscher et al., 2019).

How early can screening take place and how accurate will it be? Most of the screening tools are appropriate for use in kindergarten or first grade, which coincides with when most

states with screening mandates require screening. The Boston Early Literacy Screener (Gaab, 2020), cited above, is designed to be administered as early as preschool. Parent questionnaires that address family history and oral language development can also be used to gauge risk in preschool children (Helland et al., 2005; Lefty & Pennington, 2000; Also see <https://dyslexiaida.org/screening-for-dyslexia/dyslexia-screener-for-preschoolers/>). As for accuracy, high quality screening tools have been shown to accurately identify children who later have significant reading problems, but in doing so they often over identify typically developing children as at risk (i.e., false positives). Classification accuracy is typically quantified in terms of sensitivity and specificity. Sensitivity is an index of the percentage of children who have the condition –dyslexia- and who are identified by the screening tool as high risk based upon their low score. In the case of dyslexia, it is generally recommended that the percentage be as high as 90% (Johnson et al., 2009) so as not to miss many children who will develop dyslexia. However, there is a tradeoff. When sensitivity is high, specificity can be low. Specificity is an index of the percentage of children who do not have dyslexia and who pass the screener. Specificity is also an indicator of the false positive rate since $1 - \text{specificity}$ is the percentage of children who do not have dyslexia but fail the screener, in other words, false positives. A sensitivity closer to 80% may be more manageable in that it will result in better specificity and fewer false positives. A less commonly used, but perhaps a more practical index of accuracy is the positive prediction rate of a screening tool (Petscher et al., 2011). This measure provides an indication of what percentage of children who fail a screener actually have the condition. If this rate is high (i.e., 80%) it means that most children who fail the screener are truly at risk. However if it is low, say 40%, it means that a large proportion of children who fail the screener will be incorrectly identified as at risk and may be provided with costly intervention they did not need.

Response to Instruction

Because of the false positives associated with screening tools, some have suggested that these tools need to be combined with short-term intervention to more accurately gauge risk for dyslexia (Miciak & Fletcher, 2020 JLD). Typically, this would be done within a response to intervention (RTI) or multi-tiered systems of support (MTSS) approach (Gersten et al., 2009; National Center for Response to Intervention, 2020). Such approaches are well situated to assist in the identification of risk for dyslexia. What better way to identify a child who may have difficulties in learning to read than an approach that provides high quality and timely instruction/intervention and monitors which children continue to have problems learning to read? Space prevents a full discussion of how a MTSS approach can be used to assist with identifying and intervening with children at risk for dyslexia. However, there are numerous resources available that provide this information (e.g., Al Otaiba et al., 2009; National Center for Response to Intervention, 2020). Here we briefly draw attention to a number of crucial factors that should be taken into consideration when implementing a MTSS approach for early identification and intervention. First, it is critical that children are provided with high quality Tier 1 instruction (Al Otaiba et al, 2019; Fuchs & Deshler, 2007). Research clearly demonstrates that code-focused instruction involving phonological awareness, phonics, and fluency are essential to all children learning to read words (Petscher et al., 2020; Seidenberg, 2017). Meaning-focused instruction is also essential to build vocabulary and background knowledge to improve comprehension. Not only does such instruction help all children learn to read more effectively, it can also play an important role in early identification. As mentioned above, because reading is a learned skill, inherent individual differences in reading take time to emerge. As high quality instruction is provided, children more quickly differentiate themselves from others in how easy it will be for

them to learn to read. If a school's ELA reading instruction is not high quality and evidence-based, many children may score poorly on early reading assessments even though they do not have dyslexia. These children may appear to have a reading disability but in fact have not received the appropriate reading instruction to learn to read words, even though they have the cognitive/perceptual and language abilities to learn to read. Thus, evidence-based instruction can help gauge the probability children will have severe and protracted word reading problems by ensuring that typically developing children learn to read.

A second important feature for identification and intervention of risk for dyslexia is timely transitions across tiers. Some have suggested that MTSS for dyslexia can function as a “wait to fail” model (Fuch et al., 2012). As noted above it has been common for children at risk for dyslexia to have to experience considerable failure before receiving appropriate intervention (Ozernov-Palichik & Gaab, 2016). This could also be the case in an MTSS approach that is highly regimented and lockstep in its transitions across tiers. For MTSS models to be effective, children need to have instruction matched to their needs as best as possible (Al Otaiba et al., 2009). For some children who fail screening (and follow-up assessments), the most appropriate action is to provide Tier 2 supplemental code-based instruction that involves more explicit instruction, scaffolding, and practice. However, for those at the highest risk, research indicates that a transition from Tier 1 instruction directly to Tier 3 instruction, which is more intensive and carried out by a highly skilled interventionist, will be most effective. For example, Al Otaiba et al. (2014) found that a dynamic MTSS approach that immediately assigned some children to Tier 3 (or Tier 2) based on initial screening resulted in better reading outcomes than those of at-risk children who transitioned across tiers in a more lockstep fashion. Compton et al. (2012) have also shown that careful initial screening can predict who is unlikely to response to Tier 2

instruction and should be immediately assigned to Tier 3 instruction. Also, a dynamic system should allow for children to transition in and out of more intensive tiers based on individual or group data (Coyne et al., 2009; O’Conner et al., 2005).

Another critical feature for MTSS concerns measurement and criteria for decision making. Miciak and Fletcher (2019) note that all thresholds and cut-offs involving continuous, normally distributed scores like those found in literacy assessments are arbitrary and problematic. Two students with similar screening/assessment scores but on either side of a cut-score likely have similar educational needs. Furthermore, measurement error, rather than ability may explain why these students differ in their scores. To address this issue, decisions should not be made on the basis of a single assessment or screening score but should involve multiple measures and data points. Miciak and Fletcher also recommend that assessment teams avoid making decisions using strict interpretation of thresholds and instead, when possible, use confidence intervals and clinical/educational judgement. Confidence intervals address measurement error by providing a range of scores from which a student’s true score lies. Attention to measurement error and decision making should allow educators to better match students with appropriate instruction/intervention and help prevent severe and protracted reading difficulties.

Other Challenges

Some children come to school with more limited language and literacy experience than other children. Children from disadvantaged homes typically have fewer books in their homes, have parents who read less often to them, and who provide less rich language environments than do children from higher SES families (Aikens & Barbarin, 2008; Evans, 2004; Lee & Burkum, 2002; Whitehurst & Lonigan, 1998). These children also may enter schools that have fewer

resources and opportunities, and thus, face a “double dose” of being disadvantaged (Aikens & Barbarin, 2008; Neuman et al., 2018). These more limited experiences and resources can combine with biological differences (e.g., phonological processing difficulties) to lead to the severe and protracted reading problems found in dyslexia (Mascheretti et al., 2013). However, by themselves, these limitations will most likely cause a delay (not a disorder) in word reading development. But, this delay can result in children scoring less well on early literacy screeners and make them appear to be at risk for dyslexia when they are not. Research suggests that high quality literacy instruction can assist us in determining which of these children are truly at risk for dyslexia and which children just need more literacy experience. This work shows that code-focused instruction that emphasizes phonological awareness and decoding skills can considerably reduce the influence of socioeconomic disadvantage if children are provided with instruction early on, before reading problems take hold (Blachman et al., 1999; Hus, 2001; Linan-Thompson & Hickman-Davis, 2002; Lonigan et al., 1999). Many of these children will respond well to this instruction and go on to demonstrate grade appropriate word reading skills. Others will not and they would be candidates for more intensive intervention within an MTSS approach to prevent reading failure.

Another group of children for which good Tier 1 instruction and progress monitoring will be necessary to accurately identify risk are those with a home language other than English (or majority language). Many school districts are now faced with large numbers of English-Language Learners (ELL). Because of their language differences, these children may also score poorly on initial screening tools and appear to be at risk for reading failure. Research has shown that ELL children who have acquired English proficiency by the time they start school will have similar growth in word reading as language-majority children (Kieffer, 2008). However, those

who lack proficiency, will demonstrate a gap in word reading development (Howard et al., 2014; Kieffer, 2008). This may be most prominent for those who are also from economically disadvantage families (D'Angiulla et al., 2004; Howard et al, 2014). However, high quality Tier 1 instruction can attenuate the effects of language differences and should give a clearer indication which of these children are at risk for dyslexia, regardless of their language experiences (D'Angiulla et al., 2004; Hus, 2001; Stuart, 1999).

Summary

Dyslexia is a serious developmental condition that is associated with a host of negative consequences. To address these consequences, educators have increased efforts to diagnose and treat children with dyslexia. We have argued that instead of focusing efforts primarily on the diagnosis and treatment, a prevention approach should be taken. Such an approach does not assume a diagnosis; rather it seeks to prevent such a diagnosis. Evidence-based classroom curriculum, universal screening, and follow-up assessments can be used to identify children at risk for dyslexia prior to, or at the very beginning of, reading instruction. To improve the accuracy of identification, response to intervention within a MTSS approach is also recommended. Not only will such an approach improve the accuracy of identification but it can more quickly provide the type of reading instruction that best matches students' needs. This prevention approach is contrasted with a diagnosis and treatment approach in the infographic in Figure 1.

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Figure 1

Windows of Opportunity