Extended stereotype threat: Parental concern that a child will confirm a negative stereotype associated with dyslexia

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Extended stereotype threat: Parental concern that a child will confirm a negative stereotype associated with dyslexia

A Senior Thesis submitted in partial fulfillment for the Bachelor’s Degree in Psychology

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Abstract

This study introduces a novel concept, Extended Stereotype Threat (EST). EST is based on stereotype threat, whereby one is concerned that he/she may confirm a negative stereotype associated with being a member of a targeted group. EST extends stereotype threat as someone outside a targeted group (e.g., a parent of a dyslexic child) fears that a member of that group (i.e., his/her child) will confirm a negative stereotype associated with the group. Seventeen parents of dyslexic children between the 3rd and 8th grades were interviewed. Topics included beliefs about dyslexia, interactions with the child’s school, and how parents’ beliefs about dyslexia influenced interactions with their child. While 13 of the 17 parents experienced EST, the ways they interacted with their child and school personnel varied. Once children were determined to be dyslexic, EST parents became more emotionally accommodating, more pragmatic in providing support, or made no changes in their interactions with their child.
Reading is a critical skill for young children to learn. Though many are able to grasp the fundamentals of language and reading at a young age, some are not. Children who have a more difficult time learning how to read and write language are often diagnosed as dyslexic. In the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) the term “developmental dyslexia” was changed to “specific learning disorder” (SLD), though the manifestations remain the same (American Psychiatric Association, 2013). For the purposes of this paper, both developmental dyslexia and specific learning disorder will be referred to as dyslexia.

In the current study, dyslexia will be explored through the parental perspective. In order to do this, I will gain an awareness as to how parents communicate with their child’s school system and classroom teacher. I will also look to understand what, if any, fears develop for parents regarding their child’s dyslexia and the future. Finally, I will evaluate how these aspects may contribute to a parent-child experience with the presence of a dyslexia diagnosis. Through an assessment of these three areas, my goal is to better understand parental feelings and behaviors when dealing with a dyslexia diagnosis. I hope to ultimately raise awareness about ways in which these feelings and actions could affect a child’s educational experience.
What is dyslexia?

Because dyslexia is considered an “invisible disability” (Hettleman, 2003, pg. 3), it can often be more difficult to diagnose than a condition that is more visibly noticeable. As a psychological and neurological disorder, dyslexia has been defined in a variety of ways. Vaughn and Linan-Thompson (2003) discuss the idea of intraindividuality, first suggested by Samuel Kirk in 1971. Kirk believed that learning disabilities were “differences of ability within a single child” (Kirk, 1971; as cited by Vaughn & Linan-Thompson, 2003, pg. 141) and that educational tests could be used in order to determine what specifically a given child struggled with academically. In order to best help each child succeed, it has been suggested that remediation programs are both individualized and validated. In order to implement an individualized plan whereby a student is given the supports they need in order to best succeed, the method of intervention must have previously been tested and validated through previous research or successful implementations (Vaughn & Linan-Thompson, 2003).

Though dyslexia is often measured by unexpected differences in ability, there is substantial research supporting the neurological abnormalities that exist for students with dyslexia. The International Dyslexia Association (IDA) debates the cognitive and biological reasons that dyslexic students are inefficient in completing reading-related tasks, as compared to their expected success (IDA, 2013). Elise Temple (2002) discovered some ideas behind dyslexia
as a neurobiological diagnosis. In doing this, Temple used diffusion tensor imaging (DTI).

Temple refers to dyslexia as a “disconnection syndrome” (Temple, 2002, pg. 181) where it was found that although white brain matter was functioning during specific language assessments for dyslexic participants, this matter was disorganized, and thereby it took longer for them to complete reading-based tasks (Temple, 2002).

Tunmer and Greaney (2010) refer to previous work conducted where there is a focus on cues that are helpful for children when learning to read. The authors discuss visual, structural, and meaning cues that are important as children begin to understand language. Some believe that dyslexia may become prominent if there is too strong of a focus on letters within words rather than the greater meaning of those words, when children are learning to read (Smith & Elly, 1994; Clay, 2005; as cited by Tunmer & Greaney, 2010). Chapman, Tunmer and Prochnow (2004) agree that the lack of attention to the ‘big picture’ when learning to read likely contributes to the difficulties that these students face in regard to understanding language, phonetics and decoding, over time.

**How is dyslexia diagnosed?**

Similar to many diagnoses, dyslexia is infrequently diagnosed based on only one measure. Sally Shaywitz, a well-known researcher in the field, uses the Comprehensive Test of Phonological Processing (CTOPP) (Shaywitz & Shaywitz, 2003) in assessing children for
dyslexia. This test includes multiple areas of evaluation including phonological understanding, working memory, and decoding ability. Shaywitz and Shaywitz (2003) also use the Woodcock Reading Mastery Test to assess reading ability, fluency, and understanding of language. Finally, Shaywitz and Shaywitz (2003) have children obtain a basic neurological exam in order to ensure that there are not genetic disorders such as Klinefelter’s syndrome (Shaywitz & Shaywitz, 2003). By having multiple ways of assessing children for dyslexia, there is confidence and reliability in the results, as multiple possibilities have been considered, though all but one have been ruled out. Thereby, a diagnosis of dyslexia is determined “by the unique circumscribed nature of the phonological deficit, which does not intrude into other linguistic or cognitive domains” (Shaywitz & Shaywitz, 2003, pg. 149). Dyslexic children often struggle with reading, understanding rhymes, and difficulty in learning the alphabet while they appear to excel in other areas of schooling (Shaywitz & Shaywitz, 2003).

Vaughn and Linan-Thompson (2003) suggested the three-tier model that is still used today. It has been suggested that this model is helpful in determining the level of difficulty a child faces in the classroom and whether or not s/he has a learning disability, such as dyslexia. Additionally, this method is proactive in that if a child is struggling in the classroom due to a specific learning disability or dyslexia, s/he can begin receiving help early in order to cope with his/her reading difficulties. It is believed that this model allows for some children to improve
their reading skills with minor additional help while others who may need more lengthy assistance are able to receive it through these services along with the increasing levels of intensity with each tier of the model. If children reach the third tier of intervention, they often qualify for special education services as the primary and secondary interventions were not enough to help a child succeed in the classroom (Fuchs & Fuchs, 2006; Vaughn & Linan-Thompson, 2003).

Elena Boder approached testing children for dyslexia from multiple perspectives, though her method was more traditional. Boder used a “Diagnostic Screening Procedure for Developmental Dyslexia” (Boder, 1973). In this, she observed not only whether or not a child was capable of reading or spelling, but more so, how they approached tasks that require reading and spelling. Boder observed whether the ways in which a child’s capabilities in reading and spelling made sense in relation to a child’s approach to reading and spelling; ultimately Boder assessed whether or not these factors were age-appropriate (Boder, 1973). Boder’s method also identified whether or not a child could repeat a list of words or numbers that they were told (Boder, 1973).

**Treatment for dyslexia**

The Orton-Gillingham (O-G) method is one way in which dyslexic students are often taught the fundamentals of reading and language (Ritchey & Goeke, 2006). The O-G method is
an interactive way of learning, where children are taught both how to articulate words and sounds through auditory means (i.e., hearing their teacher sound out words) and how to explore phonetics in their own ways that make sense to them. In teaching dyslexic students letter sounds and combinations of sounds, a deck of cards is often utilized (Sheffield, 1991). An example of this would be having the letter “a” on the front of the card and having the child learn the two different ways in which “a” can be pronounced. Then, on the back of the card there would be two words that display these uses, for example, “apple” and “ate.”

One of the main ways in which the O-G method is approached is through multi-sensory means. Through this, students are able to learn visually, aurally, and kinesthetically (Ritchey & Goeke, 2006). This method allows children to think in more of a internal way about the words and sounds they are learning so that they are able to have a better understanding of language. This method encourages children to think in a more “out-of-the-box” way in opposition to the traditional methods they learn in the general education classroom. The hope with the O-G method is that children will conceptualize language in whatever way is most accessible to them which will, in turn, lead to their success in reading-based tasks and school.

Another way in which management of dyslexia has been approached is through reading intervention programs. Shaywitz and Shaywitz (2003) discuss the importance of children improving their phonetic skills and awareness of word sounds and meanings. Shaywitz and
Shaywitz (2003) believe that the most helpful way for dyslexic students to grasp language is through oral reading with the guidance of a teacher (Shaywitz & Shaywitz, 2003). Through reading aloud, students will better be able to understand their mistakes, recognize words, and comprehend what they are reading.

**Negative stigmatizations and learning disabilities**

It is natural for individuals to think of others in accordance with certain characteristics that may be associated with another person’s race, socio-economic status, or culture. When these views and perceptions lead individuals of a targeted group to feel negatively about themselves and their group, Claude Steele and Joshua Aronson (1995) determine ‘stereotype threat’ to be present:

Their prevalence in society raises the possibility for potential targets that the stereotype is true of them and, also, that other people will see them that way. When the allegations of the stereotype are importantly negative, this predicament may be self-threatening enough to have disruptive effects of its own (Steele & Aronson, 1995, pg. 797).

When negative views of non-targeted individuals lead targeted individuals to develop negative beliefs and expectations of themselves and their group there can be harmful outcomes to these targeted individuals’ self-esteem and performance on tasks that they are given to complete. A seminal example of this was studied by Steele and Aronson (1995) with an African-American population in testing situations. When the test-takers were told that they would be judged based
on individual attributes in regard to reading and verbal abilities, performance on tests were worse than when participants were not primed to think about their verbal skills (Steele & Aronson, 1995). Similarly, Edward Jones (1989) touches on the idea of individual competence and that perceived ability can affect the ways in which people view themselves. He continues with a brief discussion as to how one’s perceived competence can influence self-esteem, social status, personal well-being, and mental health (Jones, 1989).

To continue this idea of self-confidence and competence, Steele, Spencer, and Aronson (2002) continued their research from 1995 with a focus on self-image in a different population: women. Steele et al. (2002) assessed areas where women may feel threatened. Women were then assessed about the extent to which they felt a sense of a “situation-specific form of stigma” (Steele et al., 2002, pg. 380) when presented with a difficult math problem. Steele et al. (2002) did not believe that women were considered a stigmatized group, though it was believed that the stress of the math-problem situation led women in this study to under-perform in this area in comparison to other types of problems (i.e., passage comprehension).

Aronson and McGlone (2009) also conducted a study regarding the idea of social identity threat. Social identity threat explores “abilities of certain groups…thus stereotyped tend to be as aware of their groups’ reputation as anyone in the culture—whether they personally agree with the reputation [or not]” (Aronson & McGlone, 2009, pg. 154). The idea of being aware of a
negative stereotype associated with oneself though doing all possible to not believe the stereotype, is a difficult balance to maintain in our society today. Understanding the ideas of stereotype threat and the influence they can have on the ways in which one views their own attributes and abilities in life will be critical for the purposes of this study.

Stereotype threat has come into play in regard to learning disabilities through a number of studies and works. Lisle (2011) discussed stigmatization in relation to learning disabilities, stating: “a negative attitude is adopted with regard to a group in general as opposed to basing one’s judgements on the specific characteristics of individuals” (Lisle, 2011, pg. 3). Throughout her work Lisle (2011) discovered numerous examples that she referenced which exhibited the discomfort and uncertainty that students with dyslexia felt both within and outside of the classroom setting. Lisle (2011) describes students’ fear of being labeled as ‘dumb’ or being thought of as incapable of succeeding. These have both been common stereotypes that people have had about dyslexia whereby negative beliefs and associations have been projected onto an individual with a learning disability without taking the time to get to know and assess them for their unique abilities. The belief that because someone has a learning disability means they are ‘dumb’ or unable to succeed shows the ways in which stereotypes are created; societal stereotypes likely lead to the development of stereotype threat.
Shifer (2013) conducted a study where the beliefs of and about high school students with learning disabilities were compared to those of students without learning disabilities who had similar potential for academic success. In this study it was found that both teachers and parents held negative views and low expectations for students with learning disabilities, thereby fueling these students to have negative views of their own educational abilities (Shifer, 2013). It was found that of the teachers surveyed, most believed that students without learning disabilities were 82 percent more likely to go to college or get an advanced degree in relation to their learning disabled peers (Shifer, 2013). This fact alone greatly influenced how these teachers interacted with their students, and thereby how their students viewed themselves. This negative series of perceptions led students in this study to believe that they were in fact incapable of future success, confirming the ideas behind stereotype threat (Shifer, 2013).

A final study that will be referenced here was conducted by Riddick, Sterling, Farmer, and Morgan (1999). In their study, self-esteem and anxiety were assessed in university-aged dyslexic students in comparison to a non-dyslexic control group:

…[for] school-aged children the strongest relationship is between poor reading performance and low self-concept or self-esteem; this has been found to be independent of general ability and therefore indicates the powerful mediating effects of literacy performance on how individuals perceive themselves and are perceived by others (Riddick et al., 1999, pg. 241).
The relationship between reading ability and social standing is critical for students of all ages. If a student feels and is treated differently than the majority of their peers, while they simultaneously become the target of misinformation, there can be extreme, long-lasting effects. Though the above examples are only the surface of the issues that surround stereotypes around learning disabilities, it is my hope that these studies give a framework for the current study.

**Other ‘invisible disabilities’**

Similar to dyslexic individuals, children who have severe epilepsy struggle on a regular basis to fit in with their peers and society. In a study conducted by Elliott, Lach, and Smith (2005) it was found that not only do children who struggle with severe seizures have physical handicaps that are not always seen, but there are other invisible struggles that are experienced on a daily basis. One participant reported how frustrated he was being a teenager and not being able to take a shower alone, go to the movies with friends, or go to school on a regular basis, as there were concerns for his safety (Elliot et al., 2005).

Epilepsy, in this case, relates to dyslexia in that in both cases it was reported that feelings of depression and isolation were experienced as a result of the condition (Elliott et al, 2005; Raviv & Stone, 1991). Though epilepsy may be considered a more serious condition, in some ways, the two relate in that they isolate the affected individual from “normal” social interactions and daily experiences. In the same way that Raviv and Stone (1991) found dyslexic students to
have negative feelings of self-worth, Elliott et al. (2005) found children who struggled with epilepsy to view themselves more negatively as they felt bullied by their peers due to their condition.

**Applied stigmatization and positive labels**

Though labels are more often than not viewed as negative, this is not always the case. Having the label of being dyslexic can help a student explain his/her situation to another individual without coming off as ‘stupid’ or ‘lazy,’ as dyslexics are often perceived (Riddick, 2000). It has been found that when seen in a positive light, labels can help individuals understand their struggles and learn how to best cope with their differences while viewing themselves and their situations from a more positive and realistic perspective (Barga, 1996).

To further this point, Andy Clark explores the importance of understanding language as he states:

> …linguistic structures contribute to some of the most important yet conceptually complex of all human capacities: our ability to reflect on our own thoughts and characters and our limited but genuine capacity to control and guide the shape and contents of our own thinking (Clark, 2011, pg. 44).

Through understanding language and how we individually conceptualize it, Clark argues that we become better able to understand ourselves and make the best decisions for our future. Our society is competitive enough as it is. Adding the stress of having a disability makes social survival that much more difficult. The way in which Clark (2011) expresses the idea of having
control over our thought processes has potential to make an extreme difference in the lives of dyslexic individuals, helping them view their label of being dyslexic more positively. Even if their teachers and peers have negative views of their diagnosis, if dyslexic students are able to positively shape their own thinking, their academic experience will likely be more enjoyable.

*Stereotype threat compared to extended stereotype threat*

The current study is investigating the novel idea of extended stereotype threat (EST).

Extended stereotype threat, defined by the researcher, is when an outside but associated individual fears that someone within a stigmatized group will confirm a negative stereotype associated with being in that targeted group. For the purposes of this study, the researcher will be observing to what extent parents of children with dyslexia fear that their children will confirm a negative stereotype associated with being dyslexic. EST is different from stereotype threat in that in the latter, a person within the group fears that they will confirm a negative stereotype of their own group, whereas with EST, it is someone from outside the group (in this case, the parent) that fears someone within the group with whom they associate (in this case, the child), will confirm a negative stereotype associated with his/her being in that targeted population (in this case, dyslexic individuals).
Child self-concept due to dyslexia diagnosis

Children spend a large part of their day at school and in academic settings. It has been previously suggested that children with dyslexia struggle socially more than their non-dyslexic peers within the school environment (Chapman & Tunmer, 1997). Terras, Thompson and Minnis (2009) investigated this concept through a study on self-esteem of seventy-five dyslexic students, averaging 11.2 years old. The researchers used three scales, including self-esteem, emotional and behavioral problems, and the “Understanding and Perceived Impact of Dyslexia Scale” (UPIDS), in order to further understand how children view themselves, in being dyslexic (Terras et al., 2009).

Self-esteem can have a significant effect on and negatively initiate social, emotional, and behavioral issues. It has been found that when a child is diagnosed with dyslexia, it becomes more common for these issues to develop (Terras et al., 2009). This was further investigated through a follow-up study, conducted by Snowling, Muter, and Carroll (2007) where both controls and ‘at-risk non-impaired’ students were evaluated for self-esteem and psycho-social adjustment. The ‘at-risk non-impaired’ group includes students that have behavioral issues that show in reading difficulties, although they have been found to be due to genetic or environmental factors, rather than learning difficulties (Snowling et al., 2007). It was found that at-risk impaired children, in comparison to at-risk non-impaired and control children, showed lower levels of
confidence in their academic abilities which led to emotional struggles and insecurities (Snowling et al., 2007). Raviv and Stone (1991) also compared dyslexic and non-dyslexic readers and found that dyslexics reported increased difficulty with behavioral and emotional adjustment and additionally expressed struggling with ideas of self-concept in comparison to their non-dyslexic counterparts.

The previous study suggests that the increasing importance of academic success in our society puts additional pressures on dyslexic children, causing them to experience newfound struggles both emotionally and behaviorally within the school setting (Snowling et al., 2007). It has been found that students who struggle in the academic setting, because of their dyslexia, feel as if they are a minority within the classroom environment. Therefore these students experience higher levels of stress and poorer views of themselves in comparison to their peers who do not struggle in this way (Terras et al., 2009). Additionally, it was found that dyslexic children, who have more positive views about their reading abilities and are more optimistic, show higher levels of self-esteem than their less optimistic dyslexic peers (Terras et al., 2009).

A different way to approach the issues of self-esteem and improved academic ability was highlighted by Zeinab, Elias, Nor, and Mahmud (2010) in assessing the Barton Intervention Program (BIP). The BIP teaches and then assesses dyslexic students in order to help them improve their attitudes toward and ideas of self-concept in regard to reading. Zeinab et al. (2010)
studied whether or not students who went through the BIP showed improved feelings toward themselves in relation to their peers, who did not go through the BIP. It was found that students who did receive this intervention improved their self-perception, and thereby their ability to complete language based tasks, increased (Zeinab et al., 2010). When students have a more positive view of themselves, they are often more confident and successful in their academic endeavors. Therefore, the BIP is a good way to help dyslexic students improve both academically and individually.

Raviv and Stone (1991) conducted a similar study with an older age group where negative feelings of self-worth remained to be an issue for students in academic and social settings. In their study, students were more likely to confirm feelings of helplessness, low self-confidence, and inferiority in comparison to their non-dyslexic peers; these students also found themselves to be sad, depressed, and overwhelmed (Raviv & Stone, 1991). Because this study was conducted with students who were in integrative classrooms, they were constantly comparing themselves to their non-dyslexic peers, which likely contributed to their negative feelings of self-worth (Raviv & Stone, 1991). Had these students been in an exclusively special education classroom, they likely would not have had the same feelings, as there would be no point of comparison for them to reference on a regular basis (Raviv & Stone, 1991). It was also discovered in this study that the timing of a diagnosis of dyslexia greatly contributes to the way
in which a child views themselves. Raviv and Stone (1991) believe that children who are diagnosed before second grade tend to have more negative views of themselves and their academic abilities, because they had a negative label of “differentness” from such a young age (Raviv & Stone, 1991, pg. 607).

Those who are able to understand their diagnosis of dyslexia have shown increased feelings of self-worth. Gibson and Kendall (2010) conducted a study with college-age dyslexic students who were first given a diagnosis upon entering higher education. In general, these students were relieved to finally have an explanation as to why they struggled academically for so long. These students felt as if they were academic failures and were unable to figure out the educational system, when really they had a learning disability that was never addressed. Knowing their educational status allowed these students to embrace and further understand their condition rather than being confused and upset about their academic trajectory (Gibson & Kendall, 2010).

Through the findings of Raviv and Stone (1991) and Gibson and Kendall (2010), it is clear that the timing of a diagnosis plays a major role in how a student views themselves. Diagnoses that are made before second grade often leave children feeling as if they are a minority in the classroom at the start of their academic experience, while students who are not diagnosed until college feel lost and confused throughout their academic years. It is apparent that
dyslexia plays a large role in regard to self-concept for dyslexic students both academically and socially (Raviv & Stone, 1991; Snowling et al., 2007). These issues begin with children diagnosed in the second grade and continue all the way through those identified in college, as both academics and social interactions are constant in our lives.

Teacher attitudes toward dyslexia, its affect on students and parents

Individuals with dyslexia may face more difficulties than their atypical reading. It is these ‘invisible disabilit[ies]’ that lead to the stigma that many dyslexic individuals endure. It has been suggested that the combination of accommodations that are needed for a dyslexic child to succeed and the misconceptions that teachers have about a dyslexic child’s motivation in the classroom results in their unfair punishment on language-focused assignments (Lisle & Wade, 2014).

Considering that teachers spend a large portion of the day with their students, their perceptions of dyslexia could potentially have an enormous impact on a child’s experience with his/her diagnosis. In a study conducted by Gwernan•Jones and Burden (2010), the Theory of Planned Behavior was investigated among teachers who were entering the field of education with a focus in special education. This model suggests that teachers will approach a given situation based on their preconceived notions of a specific diagnosis, such as dyslexia. It is suggested that if a teacher’s perception is negative, they could severely harm their students’
views of themselves (Gwernan•Jones & Burden, 2010). Though the majority of teachers who completed this Theory of Planned Behavior training had positive views of dyslexia, it was suggested that if they had negative attitudes and beliefs about dyslexia, it would make a significant negative difference in the classroom for their dyslexic students. Gwernan•Jones and Burden (2010) found this to be true through their research with teachers who did have negative views about dyslexia as they were found to teach their dyslexic students differently than their non-dyslexic students, due to their preconceived notions about the diagnosis (Gwernan•Jones & Burden, 2010).

The way in which teachers and students interact within the classroom setting will likely influence how students perceive their own education and therefore how parents feel about their child’s academic experience. If this is a negative series of relationships, it is more likely that parents will develop negative feelings toward their child’s education. In order for teachers to positively influence their students, it is necessary for them to believe in their own capabilities in helping a child with dyslexia, succeed. Though teachers may sometimes grade students harshly without fully considering their academic compensations, it is often unintentional and rather a result of the teacher’s lack of knowledge and confidence within the field of dyslexia.

Tschannen-Moran and Hoy (2001) explored different ways that teacher efficacy can be measured in order to best understand teacher needs in helping their dyslexic students. The
researchers examined a variety of measures, including the Rand measure. The Rand measure investigates the extent to which teachers take responsibility for their students’ ability to succeed in comparison to teachers who believe that they cannot compete with the external environment of a given student (Tschannen-Moran & Hoy, 2001). Teachers who believe that a child’s condition is due to the environment and that they, as teachers, cannot contribute to their students’ outcomes, are seen as external thinkers and may be less motivated to help their struggling students succeed. On the other hand, teachers who believe in their ability to help these children thrive, are thought to be internal thinkers and will likely go out of their way to help these students make academic progress (Tschannen-Moran & Hoy, 2001). This is an important distinction to make; the way in which teachers perceive their students may affect how their students view themselves. If children feel negatively about their situation due to teacher attitudes, parents will likely feel more discouraged about their child’s academic experience as well.

In order to study teacher perceptions and attitudes toward dyslexia, Hornstra, Denessen, Bakker, van den Bergh, and Voeten (2010) either presented participants with a “dyslexia prime” or a “neutral prime” and either a negative or positive word. This procedure was considered a measure of implicit teacher attitudes. For each trial, an attitude score was determined by collecting the reaction time of participants for negative target words following both dyslexic and neutral
primes. A high score indicated a more negative view of dyslexia among participants (Hornstra et al., 2010). Participants who had positive implicit beliefs about dyslexia were able to help their dyslexic students succeed more so than their those who had negative explicit beliefs about dyslexia (Hornstra et al., 2010). This finding parallels the ideas Tschannen-Moran and Hoy reported through analysis of the Rand measure, as those who have more positive internal feelings toward dyslexia are best able to help their students succeed while those who believe dyslexia is out of their control put less effort toward helping these students (Tschannen-Moran & Hoy, 2001; Hornstra et al., 2010).

**Parental understandings of and reactions to a child’s dyslexia**

Considering the variety of parental reactions that exist when learning of a child’s dyslexia, along with the level of school support that is available, (Earey, 2013; Griffiths, Norwich, & Burden, 2007) the ways that parents understand their child to be experiencing both school and social interactions likely plays a large role in how a parent best helps their child succeed.

Terras, Thompson, and Minnis (2009) investigated how parents view their child’s psycho-social adjustment. Though parents were acutely aware of their child’s overt social behaviors, they were not as perceptive about internal feelings regarding his/her diagnosis and situation. This study found that students reported high levels of anxiety and depression due to
their dyslexia, while parents were less in-tune to these introverted feelings the children experienced. It seems as if parents of children who have dyslexia become so engrained in helping their child learn to read and become successful academically, that they sometimes became unable to recognize their child’s need for help emotionally (Raviv & Stone, 1991). This is not to say that parents are insensitive to their child’s feelings, but rather that they become most concerned with helping their child minimize what they see as his/her largest struggle, maybe even so that they feel better about the situation themselves, instead of recognizing the emotional support their child feels he/she needs.

Prior to their child being diagnosed with dyslexia, many parents do not know the extent to which their child’s diagnosis is integrated in other aspects of everyday life. Terras et al. (2009) emphasized the importance of peer relationships in influencing ideas of self-worth. For students who struggle with dyslexia, it is apparent not only to them, but also to their peers who are doing well in school. Due to this, dyslexic students struggle more socially, as they do not feel as if they are on the same playing field as their non-dyslexic peers. This causes them to fall into a cycle of academic and social isolation. This interaction between social and academic experiences is something that parents are often less aware of as they often do not see how a child’s dyslexia in the classroom influences their relationship with peers outside of the classroom (Terras et al., 2009).
As mentioned above, when parents find out about their child’s diagnosis of dyslexia, a variety of emotional reactions are reported. Earey (2013) found parents to have feelings of guilt, for example. She found guilt, in this circumstance, to manifest in one of two ways. Parents either felt guilty for having genetically given their child dyslexia or for having assumed that their child was not trying in school and therefore not sympathizing with them. Though these were both difficult realizations for parents to come to, some parents also felt relieved to finally understand why their child was struggling, or not doing well in school. Other parents were found to have different emotional reactions, e.g., cry, feel disheartened and/or helpless (Earey, 2013). Though many of these responses differ, the origins of the feelings mostly come out of fear and trepidation as to what the future may hold for their child (Riddick, 2010). This idea will be further explored through the hypothesis of the current study regarding EST.

Through investigating how parents perceived dyslexia, I predicted that parental experiences would influence their interactions with their child’s school and teacher. I hypothesized that depending on the ways in which parents experienced their child’s dyslexia, they would have a more or less positive outlook on the diagnosis, and for their child in the future. Finally, I believed that parental experiences with their child’s dyslexia would influence the ways in which they helped and explained dyslexia to their children.
Methods

This qualitative study aimed to investigate the relationships between parents and children in the context of a dyslexia diagnosis. In speaking with parents of children with dyslexia, I aimed to assess whether or not parents experience EST, as defined above. Additionally, I investigated reasons as to why parents develop their views of dyslexia and whether or not the ways in which the schools handled the diagnosis played a role in their perspective on it. Further, I wanted to better understand how parents’ experiences with dyslexia influence the ways in which they interact with their children after a diagnosis.

Participants

The sample for this study consisted of seventeen parents of children with dyslexia. These children ranged in age from nine to thirteen years-old and were between the 4th and 8th grades in school. Parents of these children ranged in age from thirty-seven to fifty-two years old. There were no socio-economic or educational requirements for participants, though all of the parents who were interviewed had either a bachelors or masters degree. All parents who were interviewed had children who had a dyslexia or specific learning disability (SLD) diagnosis. Participants were recruited through both personal connections and advertising on social media through Connecticut Parent Advocacy Center (CPAC) and Decoding Dyslexia-CT. Decoding Dyslexia-CT is a grassroots movement led by parents, educators and supporters concerned with
the limited identification and interventions for students with dyslexia in Connecticut Public Schools. The information gathered for this study was not through DDCT but was represented by individual parents who chose to talk to me (A. Quirion, personal communication, March 17, 2015). Thanks to the support of the above organizations, I reached eight participants from Massachusetts, five participants from Connecticut, and four participants from Virginia.

Participants were made up of sixteen mothers and one father.

Six parents took their children out of public school and put them into a school that specialized in dyslexia, referred to as School X, School Y or School Z, below in Results. Other parents had considered this option but did not have the financial means to do so.

Materials

An interview schedule was created with questions that pertained to my primary research questions. Questions were spilt up into sections such as: Family history and demographics, reasons for getting child assessed, conceptions of dyslexia and its impact, and who the parent reached out to for help (see full interview schedule in Appendix A).

Procedure

Participants were either interviewed in person, over Skype, or over the phone. Due to physical distance from participants in Connecticut, Massachusetts, and Virginia it was not possible to do all interviews in person.
All participants were given a consent form to read and sign. If I was not able to meet with a participant in person, they were sent this form via email and asked to sign and send it back prior to the interview. Before beginning the interview process, I asked participants if they had any questions and I then proceeded to ask parents the interview questions I had prepared, with occasional additional or clarifying questions asked. Interviews lasted for between 20 and 75 minutes with most being about 30 minutes long. At the close of each interview participants were given a debriefing form that outlined the reasons they were asked the kinds of questions that they were. All participants were informed about a short write-up that would be provided for them of results that were found at the conclusion of the study.

Data Analysis

Information gathered through speaking with parents of children with dyslexia were analyzed through quotes compiled from these interviews along with a qualitative analysis of the major themes found across respondents. All interviews were transcribed and de-identified to maintain confidentiality for participants.

Results

Parents interviewed discussed a variety of important issues that they encountered through their experience with their child’s dyslexia. A variety of quotes have been compiled that best represent the issues that are being studied. The first issue that will be discussed is that of parent-
school interactions concerning children’s dyslexia. Next, advocacy and the difference it has
made in both parents’ and their children’s experience will be explored. This will be followed by
an analysis of academic decisions that were made due to the interactions that parents had with
their child’s school. Following, stereotypes that parents expressed will be highlighted with an
emphasis on whether or not parents are concerned that their children will confirm such
stereotypes about dyslexia (EST). Finally, the impact that dyslexia has had on children’s self-
esteem, according to their parents, will be evaluated. Connections across all of the previously
mentioned areas will be identified.

Parent-School Interactions

Similar experiences between parents were found when reporting on their experience in
discussing their child’s dyslexia with their child’s school. All parents expressed at one point or
another their dissatisfaction with their experience in their respective school systems, though the
ways in which participants approached conversations with their children’s schools differed.

Parent EM1 communicated that one of the reasons she was able to be pragmatic about her
interactions with the school system was because she knew she would be taking her son out of
public school the following year and would be putting him in School X, a school that specializes
in dyslexia and learning disabilities. Parent EM1 spoke about her interactions with the public
school system in a very matter-of-fact way. For example, she told the researcher: “I kept my
conversations with his public school teachers very much about data…I was never going to join their side and they were never going to come over and see my side.” Another parent spoke positively about her interactions with the school systems, despite knowing that the school could not provide their children with enough services. In talking about accommodations during the school day, parent KG6 stated: “They have been willing to do it [provide services for her child], they have been more than willing to do it, but I definitely feel like I drive the bus in terms of these conversations.” This feeling of having to initiate conversation and change was common across all participants. A number of parents reported that they and their children were the ones who would write their Individualized Education Plans (IEPs) or the 504 plans. Parents and children were the ones making the suggestions regarding different accommodations in order to make the school day easier, while teachers, special education teachers, and school administrators did less of this planning, according to parents. In many cases, similarly to what parent KG6 expressed above, the schools were willing to make the accommodations once they were told what should be done.

Though schools may want to make accommodations for dyslexic children, these services were not always possible. Parents discussed the lack of resources both financially and in regard to personnel both in the classroom and in the school at large. Two parents expressed this issue. Parent EN17 stated: “The special education teacher is fairly knowledgeable on dyslexia….the
problem is that she is completely overloaded, her workload is too much.” While parent FT7 expressed the same concern in a slightly different way: “I feel like I have a pretty good relationship with the school. I mean, I like the people but I just feel like they just can’t do what she needs done.” Though the previous two quotes were stated in relatively positive ways, they were expressed with a great deal of concern for their children and for the school systems.

Alternatively, some parents expressed their dissatisfaction with the school’s approach to their child’s needs in a more negative light. As mentioned above, schools say that they can and will make accommodations once parents let them know what is needed, though the resources are not always available. This idea was discussed by parent MU13 as she stated: “They say the right things. They talk the talk but they don’t always walk the walk.” In her experience, the school recognized what she had requested, though her daughter was not receiving the in-school services to the extent that they had discussed. Due to this, parent MU13 felt the need to pay for additional out-of-school remediation so that her daughter could succeed in the classroom. Similarly, parent OL9 expressed frustration with the philosophy behind receiving additional services: “…public schools don’t understand dyslexia. They don’t know what to do. They don’t know how to help them. They don’t know what to do. As long as a kid scores 25% on the state mandated test, they’re all set. So they don’t care.” In this case, the school was pretty clear as to their expectations being those of the state rather than those of the students’ potential. Similarly to
parent MU13, this parent opted for out-of-school tutoring along with a summer intensive program at School Y (similar to School X referred to above).

As teachers see students in academic settings more-so than parents, there was a consistent expression of frustration in regard to the lack of engagement on the school’s part. Two parents expressed this feeling well in saying: “…my frustration is with their lack of knowledge….if I did nothing my child would walk out of that school with the inability to read at grade level, no question in my mind” (Parent EN17) and “I am frustrated, because I don't think he's understood academically. Even though he's doing well, he could be doing better if properly intervened” (Parent BN10).

Other parents expressed their difficult interactions with the school systems in more confrontational ways. In speaking with parent TC8 she said that upon informing her son’s teacher about his dyslexia she was told: “Oh my God, that’s so 90s!” When I asked this mother what she thought this meant, she said that she believed that as ADHD is thought to be over-diagnosed currently, dyslexia was diagnosed in the 1990’s and this was the teacher’s way of discounting her son’s diagnosis. Parent TC8 saw this as “incredibly insensitive and very ignorant” and felt that from that point on, she “…was sort of teaching the educators how to educate him.” This is certainly a hard position for any parent to be in. Parents send their children to school in order to be educated, though as some parents expressed, they did not expect to have
to play such a large role in order for their children to get a free and fair education. A similar idea was expressed by another parent, parent KQ15, whereby she discussed her experience in talking to her daughter’s teachers about her dyslexia: “They see it more as a disability and less as a learning difference.” Parent KQ15 had strong feelings toward her daughter’s school district as she declared: “It’s like they’ve slowly been trying to me give things to shut me up for a while. But at the beginning I didn’t know better, I thought that was how it worked…. I think the school has turned me into a fighter, I have to fight for what I believe she deserves.”

The previous experiences as illustrated above should provide a framework for the information that follows, as much of the issues that will be discussed stem from the parental experience with their given school system and child’s teachers.

Advocacy

Considering the struggles that parents of children with dyslexia face within the school environment, it was found that many parents have become advocates, for both their own child and dyslexic students at-large. Though a number of participants for this study were recruited through advocacy agencies, issues that were discussed regarding dyslexia in public schools are likely not unique to these parents. Regardless, it is important to consider the underlying issues that exist and revolve around a diagnosis such as dyslexia, so much so that such agencies exist and are seemingly quite active.
Many parents expressed their feeling and need to fight for what they believed their child deserved. This idea was expressed in numerous ways across interviews. Parent KG6 expressed:

“You have to take a deep breath and fight for *everything* that you get from schools. And it’s a lot of really educating yourself and being strong about it…you really have to fight to get what you need.” Parent TC8 ended up taking her child out of public school and enrolling the child in School X; she recalled:

I think that you have to be a fighter, that’s the biggest thing. And you know, I feel, I always feel bad for kids that don’t have parents that fight for them, cause not everyone has the means to do that or hire and advocate or do a lawyer through the school. The things that are going to get you somewhere else and the help you need, I think that you have to fight for your kid whatever it is and I think that’s the biggest thing that I learned.

Both of the previously cited parents viewed their role as a parent of a child with dyslexia as encompassing advocacy. Though, as parent TC8 expressed later on: “I never anticipated being in a role like I am now when my kids were born.” This feeling of being lost was something that came up in many interviews throughout this study. Parents were all able to recognize their child’s needs and fight for what they felt he/she deserved. At the same time, for those who have not found the proper avenues to help their children, these parents are working extremely hard to help fill that role, as parent LKO5 stated: “We have become advocates for all dyslexics. It is not to say that all kids have her [daughter’s] potential, but they may and they need to be advocated for. *She isn’t the exception even though she is exceptional.*”
As previously mentioned, parents send their children to school with the expectation that they would not have to guide the school as to how to best educate their children. Despite these parents playing a large role for their children throughout their education and helping create and enforce their educational plans, parents recognize they cannot play such a large role for their child forever. Many parents touched on this idea, though parent TE11 expressed the premise well, in saying: “Everything in our house is positive about dyslexia and we, you know, we work through the issues that we come across and she kind of has to advocate at school and in life.”

This parent, like many in this study, emphasized the need for her child to learn to be an advocate for herself both in the classroom (to get the services that she is entitled to) and in the real world. Parents recognize that this will be something their children struggle with for the rest of their lives, and therefore are trying to give them the tools to succeed both in regard to reading and advocating. A number of parents reported that they had included their children in the IEP construction and even in some team meetings, so that they learn how to best stand up for what they need and believe.

The feeling of “extra credit work” as parent MU13 put it, added a clear strain and stress on these parents. As expressed above, the children of parents interviewed for the purposes of this study were lucky in that their parents became passionate, caring advocates and did not become removed and discouraged caretakers. In summary, it is important to recall (as both parent TC8
and parent LKO5 stated above): not all children are lucky enough to have people fighting for their education. To a large extent, due to their experiences, these parents took it upon themselves to raise awareness and increase services for all children who struggle with dyslexia.

**School decisions**

As previously mentioned, all parents who participated in the current study sought outside services for their children in order to provide them with an education they believed they were not receiving from their public school education alone. Parents consistently took one of two paths in doing this. Of the seventeen parents interviewed, six decided to take their children out of the public school system. The remaining eleven parents provided their children with afterschool tutoring in order to learn decoding strategies, usually through the Wilson Program (an O-G based program), and to learn additional skills that would help them be most successful in school and in the long-run (i.e. organizational and note taking skills).

**School change**

Accounts from parents who took their children out of the public school system were continually positive, encouraging, and transformational. After having been in a school system where parents felt they were discouraged from discussing their child’s academic needs and their personal concerns, these parents felt increasingly at ease once being removed from these environments. Parent OK4 chose to enroll her daughter at School X; she remarked:
It’s just such a different experience to go in and they praise your child and point out all their strengths and talk about how much they enjoy her in class. You know versus feeling like you’re really just fighting with the public school system, it’s just such a different experience.

Parent OQ16, whose son was enrolled in School Y, expressed a parallel idea:

> Oh my heavens, at public school in 2\textsuperscript{nd} and 3\textsuperscript{rd} grade they just nodded their heads and they said things like “oh” and then they would never use the word [dyslexia]… they just they would say nothing and they kinda pretended…it was so bizarre. At the private school they are like “oh yeah that’s dyslexia for you, we are gonna work on this for him, we will use the Wilson and work on writing.

These institutional changes of attitude about dyslexia encouraged both parents and children to believe that there was hope for a successful education and future. No parent in this study expressed concerns for their child in the long run (this will be further explored below), though the confirmation that a school experience can be positive, lightened the load that many of these parents felt they were carrying. At School X, for example, parents are not expected to help children with their homework. If they struggle and cannot figure it out, they are not penalized but rather the teacher will address it and help the child through it the following day. Every parent from School X the researcher spoke with mentioned this as a relief and one less stress for them to be concerned with.

Another School X parent, parent LD2, expressed the positive ways in which the school discussed dyslexia, that she believed would encourage her son’s growth both academically and
individually, in the present and future. This parent stated: “School X has just framed it, that they are different. But the kids are more creative and they have different… its just different. So it’s a good thing. You know that’s just the way they put it… If he can continue to learn he’ll do fine.”

Conversely, as discussed above, parent TC8 did not feel as if her child’s teacher would be supportive of him, as his teacher viewed dyslexia as a diagnosis from the 1990s; therefore parent TC8 ended up taking her son out of his public school and enrolling him in School X where she felt she had a great deal of support.

**Out-of-school tutoring**

The majority of parents interviewed in the current study used tutoring services that employed the O-G method through the Wilson program. Some parents expressed the desire to take their children out of their public school systems, but did not have the means to do so, while others believed this to be the best accommodation for their child’s needs.

All of the parents who used outside tutoring services felt as if their child had progressed since they began their tutoring instructions. Parent OL9 spoke of the outside resources he had used and the ways in which he believed they had made a difference:

She started to really take off because of the tutoring, the O-G tutoring. Without the tutoring, oh my god…public school will probably be fine, the progress that she’s been making in the last year with both the O-G tutoring and the summer at School Z, she is making progress.
Parent MQ14 expressed this same idea in talking about the positive relationship that her daughter had fostered with her tutor and how it really helped her both in remediation and self-esteem; she notes: “Her tutor is one of the few adults she really looks up to more than anyone. It has been an amazing bonding experience for her… I don’t know where she would be without that. It was necessary.”

Two parents interviewed expressed the issue of expenses, as mentioned briefly above. Parent BN10 presented the concern:

I can’t get them [remediation services] through the school right now so I have to pay [for] private tutoring or do it myself at home which he doesn’t like…nobody really knows how or is able to provide yet, good intensive intervention to help these kids really get the skills they need unless parents are willing to pay for it.

Parent EN17 discussed the same issue in saying: “Parents that can’t afford private school in the long-run do the best they can but with a child with moderate to severe dyslexia…He has tutoring 3 days week for an hour each day. So we are doing a better intervention program then the school is using.” The financial barrier that these parents spoke of was cited as a common struggle across parents in this study, as they tried to provide their children with appropriate services. All parents were are able to provide their children with out-of-school tutoring to account for the lack of remediation in school; unfortunately, there remain to be additional
services only private institutions are able to provide, while other forms of support, such as tutoring, cannot.

**Stereotypes and dyslexia**

Though all parents expressed frustrations or difficulties they experienced with their public school systems, not all parents believed there were stereotypes associated with dyslexia. Parent LD2, who had taken her child out of the public school system, recalled: “I think before kids get diagnosed they’re looked at as “lazy” and “stupid”. But once they have the diagnosis I don’t think people associate it negatively. I really just think they don’t understand it.” Though she recognized that people tend to make assumptions before they understand the situation, she seemed to believe that once there is a known reason for a dyslexic child’s difficulties, they are no longer seen in a negative light. Similarly, parent MU13 expressed the ways in which she believed we, as a society, have progressed so that dyslexia is no longer seen as a negative:

> I think society has gotten to a point where we all seem to have labels, and so it’s not questioned as much, or not stigmatized as much, as when for example, when I was in school…now, students get pulled from class for whatever reason and so there’s just not an association with that being negative.

These two parents express what many other parents were hoping to feel one day, though others did not necessarily share the same views currently.
That is, this study found that many parents do believe that negative stereotypes existed about dyslexia. Though no parent believed the stereotype to be true, there was recognition that such stereotypes may be believed by others. In agreement with what parent MU13 stated above, parent BN10 discussed the idea of progression from a different lens:

My biggest fear is that people would expect less instead of just expecting it in different ways…scares me the most is the idea that it’s just people flipping letters around, cause I think a lot of teachers out there still have that kind of old school perception of it, and are missing a lot of the things that need help because they don’t classically present the way they think dyslexia is…even in the education circles and that makes it harder for children and parents who have concerns to get them addressed.

Parent BN10 expressed the concerns of many participants interviewed as part of this study. The idea that the stigma around dyslexia has decreased, is generally recognized, though the misconceptions that the general population continues to believe, are concerning for those who are affected by dyslexia. Parent OQ16 also expressed her concerns around the general perception on dyslexia:

Here’s an extreme example, but a long time ago, in the 80s let’s say, when I was in college and people had HIV/AIDS, people thought that being in a same room as them, talking to them, or having any contact would give them the disease. There were so many stereotypes but then people learned more and now know that you can’t catch it from just being in the same room. It’s a similar idea with dyslexia right now I feel like—like interactions with dyslexics, people think if they can’t give them accommodations therefore they can’t work hard, but it really all comes back to a lack of education.
In a more global context, Parent OK4 expressed the idea of dyslexia being seen as a negative label in our society, as well:

I think people perceive them [dyslexic students] to be unintelligent or lazy and I think that’s still, even as education is becoming more knowledgeable about the ways to teach kids who are dyslexic how to read, I still think there’s a stereotype, you know, that the kids are lazy and that they don’t try.

Parents’ confirmation of EST

One of the main areas of investigation in the current study regards stereotypes about dyslexia—if they exist, and to what extent they may exist. Of the 17 parents that the researcher interviewed, 12 expressed that they believed there were stereotypes associated with dyslexia. Additionally, I looked for whether or not parents worried that their child may confirm a negative stereotype associated with dyslexia, (Extended Stereotype Threat, or EST); 13 did.

In order to assess whether or not parents experienced EST, I looked for common words and phrases among these 13 interviews. One main question was examined in making this analysis: “Do you fear that your child may confirm a negative stereotype associated with dyslexia?” where I encountered words and phrases such as “worry” “anxiety” “teased” “worried that they may do or say something to hurt her feelings” and “alienated.” Though not every parent with EST used these exact words to express their experience, a form of these words were expressed by all 13 parents with EST. Through this assessment, five parents were found to clearly express current EST whereby they answered “yes” to the above question and then went
on to explain their experience and fears. Three parents were categorized with “slight” EST whereby parents said “no” to the above question though went on to explain that they did in fact feel EST. Finally, five parents seemed to have experienced EST in the past. Parents who experienced past EST reported having once felt that their child would confirm a negative stereotype associated with dyslexia though they no longer did, due to their increased involvement in advocacy or their child’s academic improvement due to tutoring services they received.

Parent TK12 expressed her concerns in regard to the future as she mentioned: “I do, I worry more in high school when the class choices are a little more ranked” into ability levels, that her child could experience stigmas due to her needs. Two parents expressed similar concerns about the ways in which their children would be viewed and treated due to their dyslexia. Parent EN17 accounted: “I do think people will judge him and I don’t want them treating him differently or saying he’s slow or tell their kids to treat him differently.” Parent EN17 had previously discussed her frustration with a neighbor and mother of her son’s friend about her resistance to listen and learn about dyslexia. She felt as if her neighbor was ill-informed about dyslexia and there may be a negative impact on their children’s relationship as a result. Parent MQ14 expressed a similar concern, saying: “I don’t want people to look at her and see her that way…I do worry about what people might think if they knew, I make assumptions that people are ignorant about it, so sometimes I go a long time without bringing it up.” These quotes
highlight the fear that parents have that their children will be treated differently and judged due to their diagnosis of dyslexia.

**The impact of dyslexia on parent-child relationships**

In order to best understand the impact of EST, I looked at ways in which EST has or has not changed parent-child relationships since a diagnosis of dyslexia. To understand the correlation between the diagnosis and ways in which parents and children interact, two questions were analyzed. The first question that was evaluated was “How do you feel about your child having dyslexia?” and the second question was “Have your interactions with your child changed since his/her diagnosis of dyslexia?”

In assessing the first question, parents were categorized either as feeling positively, concerned, or mixed, whereas for the second question parents either generally increased their emotional accommodation, increased their pragmatic support, or made no changes. A parent who felt positively stated: “I view dyslexia as just a fabulous way to look at the world and that it is a much more interesting perspective than most people have” (Parent EM1), a parent who was concerned said: “…it’s a real struggle. Before he got diagnosed and before he went School X he had major depressive disorder. He talked about killing himself it was a nightmare…” (Parent LD2) and a parent who felt mixed said: “I don’t know whether I feel any which way about it” (KG6). In the case of a parent who increased their emotional accommodation, it was reported:
“we do a lot more celebrating of the little stuff” (Parent EM1) or “I’m much more patient I think, much more understanding, less frustrated and you know I try to help him understand what’s going on now” (Parent LD2). Parents who became more pragmatically supportive made statements such as: “… it all comes down to trying to get her to read…” (Parent OL9) or “I make accommodations at home as I expect them to at school. I reinforce organizational skills and tools….it is not how we feel about it but how we respond” (Parent LKO5).

It was found that 3 EST parents felt positively while 2 non-EST parents felt this way; 8 EST parents were concerned and only 2 non-EST parents were concerned; 2 EST parents felt mixed while no non-EST parents felt mixed (see Chart 1). In terms of ways in which parents changed their interactions with their children: 5 EST parents increased their emotional support, while 2 non-EST parents did this. It was also found that 5 EST parents increased their pragmatic support while no non-EST parents did this. Finally, it was found that 3 EST parents reported having made no changes while 2 non-EST parents made no changes. The abundance of EST parents who are concerned and increase either pragmatic or emotional support should be noted.
Chart 1. EST and parent-child interactions

Positive spin on dyslexia

Though parents recognized struggles that their children face in having dyslexia, some parents in this study saw hopeful aspects of the diagnosis as well. Parent BN10 had her son screened for dyslexia prior to getting full testing, by which the screener framed the diagnosis for her and her son in saying: “All it meant was that his brain was wired a little bit different, and his brain tried to trick him when he was reading and he had to learn ways to trick it back.” This is now how parent BN10 talks about dyslexia with her son, and how he is growing to understand the ways in which his brain works. Other parents expressed similar ideas as they often reminded their children that it was not their fault, as they believed it was the inability of their children’s teachers to teach them in the way in which their brain works that was the issue. Parents who take
on dyslexia in this fashion may be aiming to decrease their own worry and anxiety about ways in which other people may see their children. Through looking at dyslexia this way, parents may no longer fear that others will view their child negatively as they become more comfortable with the diagnosis themselves.

Not all parents did experience EST. Parent EM1 was one of the four parents who did not have this fear. Parent EM1 talked about dyslexia as if it was the best news she could have gotten. Though she was not dyslexic herself, her husband was. I did not speak with her husband, but parent EM1 expressed her husband’s disagreement with her own view of dyslexia due to his childhood experience with it. Parent EM1 said: “I view dyslexia as just a fabulous way to look at the world and that it is a much more interesting perspective than most people have and so I viewed it as a tremendous gift to be able to picture things the way a dyslexic would.”

Parent TE11 expressed this idea in saying: “She’s gonna find a wonderful career, she’s gonna add value to society.” No parent in this study believed that their child’s dyslexia would inhibit them from being successful and doing what they enjoy in the future; many saw it as a more short-term issue to be dealt with and that once getting through the educational system, they would excel. Though she did not see her child’s future as inhibited, parent TC8 believed that her daughter’s dyslexia may influence her as it would limit jobs she could do (e.g., law, as there is a great deal of reading). All other participants framed the same issue positively in saying that they
believed their child would do things that were creative or that highlighted his/hers strengths, rather than avoided his/her weaknesses. It is important to note that despite the EST that many parents did experience, there was also uniform belief in children’s abilities and futures.

**Self-esteem**

Interestingly enough, parent TC8, who expressed the last quote from above: “She’s gonna find a wonderful career, she’s gonna add value to society” also described another issue that many dyslexic families reported to face—self-esteem. She stated: “How many times should she have to take, you know, take a hit? I have no control over that, I can only build her up so that she is more prepared for what the world has to offer her.” Though she believes that her daughter will be able to be extremely successful, parent TC8 also recognized the struggles that she will face.

In many interviews it was noted that children struggle with self-esteem and self-confidence once diagnosed with dyslexia. This section will discuss the extent to which self-confidence becomes an issue for children who stayed in public school in comparison to children who were taken out of the public school environment.

The children who really suffered in regard to their feelings of self-worth while in public schools, when taken out of this environment, were able to begin a recovery process. In talking about her son’s transition to School X, parent TC8 said: “Now that he’s at School X, he’s not ashamed to be dyslexic anymore, and when he was in public school he… it really impacted him
socially. Like he didn’t want people to know that he was in therapy and didn’t have any
confidence and all that has kind of started to return.” A similar remark was made from another
School X parent, parent OK4, in saying: “Her third grade year, her self-esteem just plummeted
you know over the course of that year. And over the last 2 years its slowly been building back
up.” These parents believed that the public school environment was negatively impacting their
children and they thereby decided to remove them from those environments. Parent LD2
expressed a much more extreme case of her son’s dyslexia effecting his day-to-day functioning:

Before he got diagnosed and before he went to School X he had major depressive
disorder. He talked about killing himself…it was a nightmare. And it all stemmed
from school… School X has just framed it that they are different but the kids are
more creative and they have different… its just different. So it’s a good thing. You
know that’s just the way they put it.

Parent OQ16 did not send her child to School X but had a similar story, by which her son could
no longer remain in the public school system and function on a daily basis. Parent OQ16
accounted:

I think he has low self-esteem around his school work because writing is hard. Spelling
is abysmal…So like last summer he was with a youth group and they did an ice breaker
activity and…he misspelled whatever he wrote and kid laughed who pulled it out of a
hat and said something about spelling. When it happens over and over its like ‘oh gosh
here we go again’… So, we had to take him out of public school for 3 years and put
him in private school because he hated school and had so much school anxiety. Like he
was a generally happy person but was completely falling apart because of the school
situation. Teachers wanted him to work harder but that kind of thing stays with you for
long time.
Though some parents were unable to provide their child with full-time intensive remediation, they were able to help their children through alternative summer programs and out-of-school tutoring to support them academically, socially, and emotionally. Parent MU13 spoke about the ways in which she felt her son had progressed after attending a summer camp in North Carolina (the family is from the New England area) he had attended for the past three summers. Parent MU13 remarked: “I think he was a little sensitive to feeling different, but once we got to the camp and he came back out, he was ok with it. He no longer felt intimidated by it, so it had a real effect on him and how we perceived it.” Though this camp seemed to have helped her son’s emotional well-being on his dyslexia, parent MU13 went on to later mention: “I think, it effects his overall ability to feel successful…it causes frustration, which causes conflict. He’s a model student at school. He totally keeps it together, but a lot of the times he lets that frustration out on us at home.”

Parent OL9 discussed School Z and how his daughters’ attending of their summer program made a remarkable difference in their experience with her dyslexia. This child’s father recalled:

She’s had a tutor on and off since 3rd grade [now in 7th grade]…She’s gone to do some O-G outside of school, she went to the School Z for 5 weeks…I hear from a lot of families that have their kids going to the summer school—she sees the benefit of being with her peers, and then they buy into it. And they get taught the way that is gonna help them.
Similarly to parent MU13’s child above, this student was able to conceptualize her dyslexia in a different way, after attending the School Z summer program. Though this also seems like great progress, as the North Carolina camp did, parent OL9 went on to discuss the ways in which her dyslexia continues to impact her, despite the great camp experience she was able to have: “It affects how that poor kid must have been for so long. It was such a struggle for her, now she won’t even allow us to read to her at night. We haven’t gotten over that yet, haven’t fully bought into it yet.”

In comparing the previous quotes from parents of children who were able to leave their public school districts to those who were not able to have the same opportunities, there are clear differences in regard to psychological impacts. Though parents used camps and tutors as ways to remediate the coding skills and the social and emotional issues, these did not seem to be enough. Being in a private school and having the everyday confirmation and reminder that these children are not alone and that they are capable of success seems to have had an extreme positive impact on a child’s sense of self, even for a child who had mentioned suicide. Unfortunately, even for families that are able to provide their children with summer programs similar to School Z, going back to their public school districts seems to discount what they had learned and felt over the summer months. The previous accounts highlight the under-recognized struggle that parents and
children face—without everyday intensive remediation and emotional support for dyslexics who are affected emotionally and/or socially due to their diagnosis, there can be long-lasting impacts.

It is important to keep in mind that the population that was reached through this study was self-selected, and many were advocates themselves. The added fact that these parents were outspoken about their views on dyslexia and their experiences emphasizes the levels of difficulty that parents of dyslexic children likely face on a daily basis. Parents who are less-involved and less-outspoken about their child’s dyslexia were not included in this study, due to lack of volunteers. This is not surprising as parents who are very out-spoken and involved, struggle with these issues to a great extent.

**Discussion**

I will next discuss the issues that parents raised regarding their experience with their child’s school and classroom teacher and ways that these issues could be lessened. I will then indicate how recognizing one’s own EST can be helpful to a dyslexic child’s experience. Finally, I will explore options that parents have for helping their child through their dyslexia, considering the choices that parents in this study made.

As reported in the Results, parents in this study tended to have either positively or negatively charged experiences with their child’s school and classroom teacher. Though some parents, like parent EN17, did recognize the lack of resources and personnel that the school was
allocated, others, like parent BN10, did not feel as if her child’s school was doing everything to help her son best thrive. The issue presented here is a hard balance to find, as schools are only given so much funding and personnel.

In order to help teachers best support their students and make parents feel comfortable with their child’s public education, I suggest the need of a parent-teacher training program. This program would begin in kindergarten, or if possible, before kindergarten, and would help raise awareness about learning disabilities, such as dyslexia and specific learning disabilities (SLDs) for both parents and teachers. This program would focus on “red flags” for dyslexia that do not include seeing letters backwards or numbers upside down, but deeper issues that parents in this study discussed. Issues that should be covered in this program include: being aware of a child’s intelligence and whether or not it aligns with their language-based abilities, assessing a child’s creativity, and looking at a child’s overall sense of self. The suggested program could both help parents and teachers identify and diagnose dyslexia early while using minimal additional funds and resources. This program would also help parents and teachers feel as if they were able to work on a team, if a child did present dyslexic symptoms, in order to best help the child succeed. Finally, this program would hopefully give teachers more ideas as to best help their dyslexic children thrive in the classroom and would encourage both parents and teachers to explore out-
of-school services and supports for dyslexic children and families, if the school was unable to fully remediate for them.

All participants in the current study became greater advocates for their children and dyslexia, at large. Becoming an advocate, for many parents in this study, was liberating. Many parents expressed having felt alone and unsure as to what to do until they reached out to advocacy agencies, such as Decoding Dyslexia. It was often reported that involvement with advocacy work and knowledge that advocacy agencies exist, alone, made parents feel better about their child’s dyslexia. In order for parents to be aware that such agencies exist, they first have to know that their child has dyslexia, what it is, and that it can be treated. Parents who do not feel as if they are supported by their child’s school and cannot identify their child’s academic struggles on their own, presumably finding such support and help is difficult.

Considering parental reports about their experiences with their respective school systems, and schools’ general lack of willingness to identify and diagnose dyslexia, parent advocacy agencies will be critical for parents of dyslexic children in the future. Given this important controversy I would suggest that organizations such as Decoding Dyslexia implement the program suggested above. This would improve parent and teacher knowledge and comfort with the term and diagnosis of dyslexia. It would also inform parents who did not feel fully supported by their child’s school of that fact and that there are alternative options where parents can find
support. Though advocacy agencies generally provide more emotional support than academic, it is possible that through these agencies, parents would learn of alternative educational options for their children. Having the emotional support of other parents of children with dyslexia, parents may feel more confident in making educational changes and decisions for their children.

Thirteen of 17 parents in this study did experience feelings of EST. It is important for parents to recognize their EST in making educational and social decisions for their children. This is not to say that EST is bad, but rather that parents need to be aware as to their feelings on their child’s dyslexia when helping them through their diagnosis. It is hard for parents to not be affected by their own perceptions when doing what they feel is best for their children. In this case, parents equally increased their emotional or pragmatic support for their children; parental feelings were not found to influence educational decisions. It remains important for parents to be aware that their feelings could influence their actions taking away from their child’s independence.

Parent EN17 discussed a neighbor and her unwillingness to listen and learn about the truths regarding dyslexia. Parent EN17 expressed that she did not want her son treated differently or as less-than because of how her neighbor may present his diagnosis to her own children. Though parental instinct is to help one’s children make their difficulties easier, it is just as important for parents to let their children develop their own sense of self and character. If parents
decide who children will and will not associate with, due to the perceptions that other people
may have, parents may be sheltering their children more than they intend to. In this case, parent
EN17 did fear that other people would (or did) view her child differently due to his dyslexia.
Acknowledging her own fears would allow parent EN17, and other parents with EST, to be more
aware of their own feelings and whether or not they influence opportunities they provide for their
children. Though this aspect was not further explored through the current research, it is
suggested that a further analysis of this secondary influence of lack of opportunities provided be
investigated in the future.

It is important for parents to recognize that they do possess such beliefs and fears when
helping their children on a day-to-day basis, as sometimes these fears and perceptions are helpful
to children while other times they may inhibit children from developing on their own. It is my
hope that through expanding parental understanding of EST, there will be an increased
awareness for parents regarding their own beliefs about dyslexia and how those beliefs affect
their actions in regard to their child’s dyslexia. As parents’ understanding of their own EST
develops, it is important for them to become aware of advocacy agencies that exist, as discussed
above. Based on interviews for this study, organizations such as Decoding Dyslexia have helped
parents feel more comfortable helping their children through their dyslexia, feel less alone, and
feel as if they no longer have to fear for their children. Such organizations are important for
parents with EST to get involved with in order to help them recognize and decrease their fears about their children’s dyslexia. As parents begin to realize they are not alone and that they can make a difference through advocacy and work on state policies, their levels of EST have decreased.

Though EST can drive parents to unintentionally inhibit their children’s opportunities, EST can also be helpful as parents support their children through their diagnosis of dyslexia. As discussed in Results, five parents who experienced EST became more emotionally accommodating. Though one may see increased emotional accommodation as adhering to one’s EST, I do not argue this to be the case. For parents who increase their emotional accommodations, they have become more perceptive and aware of their child’s needs. Parents in this category often reported having noticed the anxiety and distress their children suffer from in certain social and academic situations, due to their dyslexia. By being able to recognize and address this, parents are helping their children best deal with their dyslexia rather than helping themselves deal with their own feelings. Despite many parents being concerned about their child’s dyslexia, the accommodations that were made, according to participants in this study, were in line with what they felt their child needed. By improving children’s self-esteem and decreasing their anxiety, parents aimed to allow their children to thrive more both academically
and individually, and no longer be held back by their fractured perceptions of dyslexia and themselves.

Though many parents increased their emotional accommodations and became more sensitive, an equal number of parents interviewed (n=5) increased their pragmatic support for their children. Among parents who increased pragmatic support, tutoring services, reading tools, and reading-based summer camps were common. In adding these supports for their children, parents hoped that their children would become better and more confident readers, and in turn, would be more comfortable with their own dyslexia. These parents found that once their children improved their reading, through their tutoring help, they seemed as if they were the happy kids they once were. As school is such a large part of a young child’s life, the ability to feel successful is invigorating. Dyslexic students struggle in many ways outside of academics including self-esteem. Once having the confidence in one’s reading ability and academic success, the possibilities are endless.

Though EST parents generally took the route of increasing emotional accommodations or increasing pragmatic support, as briefly discussed above, these two approaches were not mutually exclusive. All of the parents who participated in my study recognized the importance of both academic and emotional success, though parents did not always approach these goals in the same way (i.e., some more emotionally based, some more pragmatically based). Again, though
the majority of parents in my study (76 percent) did experience EST, I do not argue that they let
their EST harm the decisions they made for their child, either academically or otherwise. I rather
argue that it is important for parents to recognize their own perceptions about dyslexia and use
these feelings to help them best help their children and not hinder their child’s potential for the
future. It is important for parents to understand where their own beliefs lie in order to ensure that
decisions they make for their children are truly for their children and not to make themselves feel
more at ease with their child’s diagnosis and situation. Though this was not an issue that
participants for this study seemed to encounter, the population reached for this study was quite
educated and advocate-oriented, so this is not surprising.

Future Research

There are two major suggestions that I would like to give to someone doing further
research on EST. The first suggestion that I would make pertains to the last point above, about
the demographic of parents interviewed for this study. It was great that I was able to obtain
participants from different areas of the East Coast; the downside to having used advocacy
agencies in finding participants is that parents had to seek out these agencies and presumably
have a relatively high level of education. This was found to be true as all of my participants had a
bachelors degree, or higher. A comparison between this group of individuals and a group that is
less educated, potentially less informed about dyslexia, and less readily able to pay for out-of-school services, would be valuable to this area of research.

Another future addition that could be made to this study would be to add the children’s perspectives. Initially, this was intended to be part of this study, though due to difficulties with recruitment, this did not seem feasible. This would likely be most successful if the researcher had previously established a relationship with parents and children who would qualify for the study, within a willing school system.

In doing future research on the topic of EST, it would also beneficial to increase the number of participants and add a quantitative aspect to the study. Though 17 participants is not small for qualitative research, by adding some more parents, the study may have been enhanced. Additionally, by either coding qualitative responses numerically or by adding a quantitative aspect to the study, more empirical evidence may be found regarding reliability and validity along with themes and trends that exist for families who experience a dyslexia diagnosis.

**Conclusion**

Overall, the current study found that parents do experience EST. Parental experience with their child’s school did not influence their feelings about dyslexia, as predicted, but that these interactions did influence educational decisions that parents made for their child (i.e., school change or out-of-school tutoring). Finally, I concluded that parent’s experience with their child’s
dyslexia does influence the changes they make as some parents became more emotionally accommodating while others became more pragmatically supportive, though I cannot conclude that these changes were due to EST but rather what parents felt was best for their child.

It is important for parents to be able to recognize their own EST in order to ensure that they make decisions for their child rather than out of their own fears and apprehensions. Though parents did not do this in the current study, the sample size was relatively small; it is possible that some parents do act out of their own fears for their child. Once parents are able to recognize their own EST, they become more able to help their child through their dyslexia. This study is important as it raises awareness about EST for parents and teachers. Overall, it was found that parents do what they feel is best for their children whether that be stay in public school or transition to private school, and increase emotional accommodation or pragmatic support.
Appendices

Appendix A

Part I: Family history/demographics

1. What is your relation to (child’s name)?
2. How old are you? How old is your child? What grade is your child in currently?
3. Were you ever diagnosed with dyslexia? If so, do you remember when you were diagnosed?
4. Are there other members of your family who have been diagnosed with dyslexia? If yes, who?
5. What is your highest level of educational attainment: high school diploma, 2 year associates degree, 4 year bachelors degree, or advanced degree?

Part II: Reasons you got your child tested

1. When did your child initially get tested for dyslexia?
2. What prompted you to seek assessment for your child? (potential probe: Did your child mention s/he was struggling? Did his/her teacher suggest it?)
3. Has your child been diagnosed with any other special needs that may be related to education?

Part III: Conceptions of Dyslexia and its impact

1. Did you know anything about dyslexia before (child’s name) was diagnosed?
2. What do you currently understand dyslexia to be?
3. Have you wanted to learn more about it since? Have you actively looked for more information on it?
4. How do you feel about your child having dyslexia, now?
5. Is that different from how you felt when you first learned of his/her diagnosis?
6. How do you think (child’s name)’s dyslexia will impact him/her in the long run?
7. In what ways do you notice (child’s name)’s dyslexia affecting him/her currently outside of academics?
8. Were you able to provide (child’s name) with any extracurricular activities to complement their academic experiences?
9. Do you think accommodations can be made so that your child’s dyslexia will be fully and successfully manageable?
10. Do you think there are negative stereotypes associated with dyslexia?
    a. If no, could the diagnosis affect your child now or in the future?
    b. Yes, what are they?
11. Are you worried that (child’s name) might confirm a negative stereotype associated with being dyslexic? If yes, how?

12. One of the myths of dyslexia is that intelligence and ability to read are linked and thereby if someone cannot read, they are less intelligent… do you believe this to be true? Why or why not?

13. Is your child aware of having a diagnosis of dyslexia?
   a. If yes, who first told your child about his/her diagnosis? Has having the label of dyslexia affected your child in any noticeable ways?

14. Has your child’s relationships with their family or friends changed because of the diagnosis? How so?

15. Has your child’s diagnosis of dyslexia affected how you interact with him/her? Has it affected how you interact with your other children?
   a. Has your child’s diagnosis affected their relationship with their siblings?

16. Was your child at the same school from K-5? If not, how often did they change schools?

Part IV: Who did you talk to?

1. What have you talked to the child’s teachers about in regard to (child’s name)’s dyslexia?
   a. What have they said to you? Have they been helpful? What was that conversation like?
   b. How often do you touch base about your child’s academic progress?

2. How did/do you talk to your child about their dyslexia?
   a. Do you and your child agree as to what should be done about it or is it a source of disagreement?

3. You mentioned that you feel “X” about the diagnosis. Do these feelings influence how you talk to the child’s teacher about their dyslexia? What about the child?

4. On a scale of 1-10 (1 being “we don’t talk about it” and 10 being “very comfortable talking about it in any situation”) how open would you say you are about talking about your (child’s name)’s dyslexia with the following people: him/her, your child’s teacher, your spouse (if applicable), the child’s siblings, other family members, or your own friends?

5. Do you encourage your child to talk to family members (siblings, cousins) about their dyslexia and experience with it?

Final Question:
Is there anything I haven’t asked you in regard to your child’s dyslexia and/or your experience with it, that you think might help me further understand these issues?
Appendix B

CONSENT FORM
Parent-Child Relationships among Children with Dyslexia
Researcher: Berkley Singer

Purpose:
The purpose of this study is to further understand the parent-child relationship when a child is diagnosed with dyslexia. In this study, parents will be interviewed in order to further understand their experiences with their child’s diagnosis of dyslexia.

Commitment:
Interviews will take approximately 20-30 minutes. All information disclosed in this time will remain confidential. All parents who agree to participate in this study are doing so by choice and therefore are allowed to either skip questions or stop the interview process at any time, if they choose to do so.

Risk and Benefits:
There is minimal risk in this study. This means that the risks involved in participating are no different from what participants may experience in everyday life. Though there is no direct compensation, the researcher hopes that this process will help parents understand their situation and open up a comfortable dialogue for talking about dyslexia with their child. Parents understand that they will not receive any further expert consultation or services as a benefit of participating; however, upon request a referral for more information about services may be made. Interviews will be audio-recorded at parent’s consent; transcripts will be edited so that no individually-identifying information remains and the original audio-recording file will be deleted.

Questions?
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Elizabeth Casserly (Research Advisor)- Elizabeth.casserly@trincoll.edu, (860) 297-2356
David Reuman (Research Advisor)- David.reuman@trincoll.edu, (860) 297-2341

If you agree to the above terms, please sign below confirming that you will participate in this study with the understanding that all disclosure of information is voluntary and confidential.

______________________________________________ Printed Name

______________________________________________ Signature

______________________________________________ Date

Parent Contact Information:
______________________________________________ E-mail
______________________________________________ Phone
Appendix C

Core Research Questions:

1. How does dyslexia play a role in parent-child relationships?
2. How do parents’ relationships with the school system influence how parents approach their child’s dyslexia?
3. How do parents feel their child’s dyslexia will affect their child in the long-run?

Kinds of Questions Asked:
Throughout the interview I asked you questions in order to better understand how your child’s dyslexia influenced different aspects of his/her daily life. I also looked to see how you believe their diagnosis will influence them later in life. Finally, I asked questions to better understand how your child’s dyslexia may or may not influence different kinds of relationships in his/her life and how those relationships have developed.

How is this information useful and important?
Dyslexia has become increasingly common in our youth today, although the awareness about the diagnosis and what other factors accompany it, are under-researched. For this reason, I believe this is important to study in order for parents to best understand their own and their child’s situation, along with the diagnosis in general. I hope that this study will encourage more research in this field, as it is a widespread diagnosis.

Questions?
If you have any further questions, feel free to contact me at Berkley.singer@trincoll.edu or 781-439-4879.

Thank you again for your participation,

Berkley Singer
References


