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The Demanding Nature of Advocating for Dyslexia Services: A Survey Study

by
Catherine Day

A thesis to be
submitted in partial fulfillment
of the requirements for the degree of
Master of Science in the Department of Communication Sciences and Disorders
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Committee Approval

To the Graduate Faculty:

The members of the committee appointed to examine the thesis of CATHERINE DAY find it satisfactory and recommend that it be accepted.

Heather L. Ramsdell, PhD CCC-SLP, ALT in Training
Major Advisor

Kristina Blaiser, PhD CCC-SLP
Committee Member

Robert Rieske, PhD
Graduate Faculty Representative

Human Subjects Committee Approval

November 9, 2022

Heather Ramsdell
School of Rehabilitation Comm Sciences
MS 8116

RE: Study Number IRB-FY2023-71: Advocacy and Efficacy Parent Survey

Dear Dr. Ramsdell:

Thank you for your responses to a previous review of the study listed above. I agree that this study qualifies as exempt from review under the following guideline: Category 2.(i). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording).

The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects.

This letter is your approval, please, keep this document in a safe place.

Notify the HSC of any adverse events. Serious, unexpected adverse events must be reported in writing within 10 business days.

You are granted permission to conduct your study effective immediately. The study is not subject to renewal.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Tom Bailey (208-282-2179; fax 208-282-4723; email: humsubj@isu.edu) if you have any questions or require further information.

Sincerely,

Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair

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Abstract

Thesis Abstract--Idaho State University (2023)

Dyslexia is a diagnosis that professionals often avoid, yet one in five individuals qualify. Due to negative or ill-informed attitudes towards dyslexia, many students find themselves under-diagnosed and without accommodations. Therefore, parents commonly play a key role in helping their children receive a diagnosis of dyslexia and subsequent school services. This study explored, via survey methodology, the knowledge and confidence of parents to advocate for appropriate dyslexia related services, as well as the impact advocacy has on parent well-being. A Qualtrics survey targeted parents of children with dyslexia and gathered feedback on demographics, knowledge about dyslexia, confidence to advocate, and the impact of advocacy. Most parents surveyed felt confident enough in their understanding of dyslexia to advocate for their child and reported advocacy to be demanding (either regarding mental health, family relationships, friendships, job security/ability to work, and/or finances). Implications, limitations, and future directions are discussed.

Key Words: dyslexia, advocacy, parent advocates, knowledge, confidence, impact

The Demanding Nature of Advocating for Dyslexia Services: A Survey Study

Parents play an essential role in the special education process for their children, as evident in the *Individuals with Disabilities Education Act* (IDEA; 2004), which mentions “parent” over 120 times throughout Chapter 33- Education of Individuals with Disabilities. Children with disabilities are vulnerable in society and often are not able to communicate their struggles and needs to others around them. It is therefore the expectation that parents will advocate and speak on behalf of their children, provide information and details to help intervention specialist diagnosis and support children with disabilities.

Parents are defined as “a natural, adoptive, or foster parent, a guardian, an individual acting in the place of a natural or adoptive parent with whom the child lives (e.g., grandparent, stepparent, other relatives), an individual who is legally responsible for the child’s welfare” (United States, 2004, 12). Because of their assumed commitment to the well-being of their children, Smith-Young et al. (2022) describe parents as natural advocates. Good advocates are informed and educated on the related environments and issues, actively involved, and dedicated self-learners on topics for which they are advocating (Smith-Young et al., 2022). Parents take on a new role when their children struggle, with persistent undertakings when necessary to support their new title of parent advocate.

A parent is often the only one aware of signs that their child is struggling. Often parents begin looking for answers when they recognize low self-esteem, lack of confidence, and a pattern of failure in their children. The few signs listed above are some of the hallmarks of undiagnosed dyslexia in school-aged children. Dyslexia is not simply defined as difficulties with reading and spelling. Dyslexia is a specific learning disability that effects most aspects of reading, including persistent difficulties with fluent and accurate word recognition and reading

comprehension, despite normal intelligence and learning opportunities (Leitão et al., 2017).

Frustration develops in children with dyslexia because of their atypical need to work substantially harder to reach an achievement level equal to their peers. These frustrations have led to parents reporting their children having a lack of confidence and low self-esteem and seeking a diagnosis of dyslexia to dispute their child's self-view of being "dumb" (Leitão et al., 2017).

Identifying a child who is struggling with skills such as phonemic awareness or symbol recognition or who has low self-esteem due to his/her frustration with school assignments is often the first step toward identifying a child with dyslexia. Ultimately, a professional (psychological) evaluation and label identifying the child's needs to be successful in the classroom is necessary for services to be implemented. Unfortunately, it is often left to the parents to find a resource outside of the school system to confirm a diagnosis of dyslexia and perform the evaluation needed to identify what services a child with dyslexia needs in the classroom. In a survey from *Decoding Dyslexia Florida*, out of 264 responses, 80% of parent responders reported the need to obtain a diagnosis outside of the school to advocate for school-based services, and only 4% obtained the evaluation at public expense (Lichtenstein, 2019). This survey depicts very clearly the importance of the parent's role as an advocate for their child; parents often cannot rely on the public educational system to identify and diagnose a child struggling with dyslexia.

Being a parent advocate can be a full-time job, yet research has not looked at how this role affects the parent of a child with dyslexia. A limited number of studies have been done related to parents and advocacy with other disabilities, each reporting that little is known on how taking on the role of advocate affects parents (Rios et al., 2021). Out of all the different forms of

reading disabilities, dyslexia has been reported to be the most common form and most vastly studied reading disability. Advocacy for dyslexia has been led and dominated by parents throughout the United States. As of January of 2022, parent advocates have made their voices heard by U.S. politicians, leading to dyslexia-specific legislation in all but 3 states; Idaho, Hawaii, and Vermont (Odegard et al., 2021). In April 2022, Idaho parent advocates had their voices heard as the legislature signed into law Senate Bill 1280 providing for dyslexia legislation for early identification and intervention (2022). The purpose of this study is to gain a better understanding of what it takes for parents to successfully advocate, and what sacrifices they make in putting their personal and other family needs aside to fight for their struggling student's needs.

A Note on Terminology

For the purposes of this paper, we use the term dyslexia exclusively, but recognize inconsistencies and confusion in terminology across professions. While reading and reading difficulties are perhaps the most studied aspect of human psychology, lack of student learning in reading nationally could be considered a public health crisis. At least part of the crisis stems from inconsistent use of terminology across professions. The term *dyslexia* is, most simply, a descriptive label for a word reading and spelling problem that originates with specific language processes, most often those involving the brain's system for identifying, remembering, thinking about, and manipulating elements of speech (phonemes). These terms are used in the formal definition of dyslexia adopted by the International Dyslexia Association (IDA). However, there are professions who do not formally recognize the term dyslexia, given disorder definitions put forth by other governing bodies such as that printed in the Diagnostic and Statistical Methods Manual of Mental Health, 5th Edition (DSM-5; American Psychiatric Association - APA, 2013),

that instead uses the term *specific learning disability* (SLD) “with impairment in reading.” It defines SLD as “a pattern of learning difficulties characterized by problems with accurate or fluent word recognition, poor decoding, and poor spelling abilities” (p.67). Specific learning disabilities are the most common disability that plague school children. It is estimated that 5-15% of school-age children struggle with a learning disability (APA, 2013), with as many as 80% of those children having an impairment in reading (dyslexia; Shaywitz et al., 2021).

To further complicate the issue, there is the debate/misuse of the related and relevant terms *developmental language disorder* (DLD) and *specific language impairment* (SLI). A DLD is a lifelong neurodevelopmental condition affecting understanding and use of language, with the absence of brain damage, hearing impairment, or intellectual disability (McGregor et al., 2020). As with most disorders, DLD presents variably across individuals and can be identified by difficulties in word learning, morphosyntactic skills, vocabulary, and discourse-level language (Lancaster & Camarata, 2019). Similar to SLD, DLD is one of the most common developmental disorders, occurring in around 7.5% of the population (e.g., Norbury et al., 2016). And relevant to the topic of dyslexia, children with DLD are at greater risk for having reading difficulties (Catts et al., 2002). Conversely to DLD, SLI is a more widely used, more narrowly defined term that generally refers to an impairment specific to language that cannot be attributed to hearing loss, neurological damage, or intellectual disability (Leonard, 2014, 2020).

Adding to the confusion, although dyslexia, SLD, DLD, and SLI, among other terms, are used, sometimes interchangeably throughout the literature, these research-oriented terms, are not always the terms used by clinicians, insurance providers, educational policymakers, and stakeholders at large, all of whom operate under different labeling systems (Georgan et al., 2023). In the United States, while clinicians across settings may refer to the DSM-5 (*language*

disorder and *specific learning disorder*), insurance providers more often use codes outlined in the World Health Organization's International Classification of Diseases (F80.1 Expressive language disorder and F80.2 Expressive and receptive language disorder). Still alternate, educational policymakers and speech-language pathologists working in school settings are likely to use broader disorder categories defined in the Individuals with Disabilities Education Act (IDEA). These inconsistencies add to the confusion and make it difficult for researchers across professions to work together. Further, it quickly becomes clear that such terminological barriers are going to prevent people in different sectors from efficiently/effectively communicating with one another, from generating awareness, and from making unified progress toward reading success in school children (Georgan & Hogan, 2019; Leonard, 2020; Schuele & Hadley, 1999).

Dyslexia

Reading is an ability that is unique to humans. Learning to read, however, is not an innate process. Learning to read involves the coordination of multiple cognitive processes (phonological processing, syntactic awareness, working memory, morphological awareness, and semantic processing), and if any one of those processes are impaired, the ability to develop reading skills will be impacted (Rupley et al., 2009). Given the multifaceted nature of reading, defining the breakdown in this ability is ambiguous. The inability to read falls under the category of a *Specific Learning Disability* (SLD) which affects the ability to perform in reading, writing, and math. One specific type of SLD is dyslexia.

Although it is controversial, the label of dyslexia assists in distinguishing and defining reading difficulties, aligns these difficulties with effective intervention approaches, and brings out motivation in parents to get their child the help they need. Without the label of “dyslexia”, often children with dyslexia are perceived as being lazy or not intelligent. The misperception that

students with dyslexia are lazy can occur for several reasons. One reason is that the deficit in fundamental processing skills can make a student feel overwhelmed by the task at hand, often not knowing where to start to complete the task. Another reason is that some students with dyslexia lose motivation because they feel that even though they put forth the expected effort they will still not be successful at the task. The misperception that the struggle with dyslexia is related to a lack of intelligence stems from the fact that many students with dyslexia struggle with early reading skills, specifically those related to phonemes. Phonemes are the units of sound in the English language that make up words and are taught in early childhood education. When children, with dyslexia struggle with phonemes, they often appear to be slower learners than the rest of their peers. Past and current literature display great variety in the definition of dyslexia, but the literature supports that dyslexia is not an indicator of a lack of intelligence. It has also been observed that individuals with dyslexia have average to above, or high intelligence.

Dyslexia is not only a label surrounding the substantial difficulties experienced when reading compared to one's chronological age, but also impacts spelling and writing skills (Snow 2021). Some distinguishing characteristics of dyslexia include **short-term memory problems**, word recognition difficulties, and **impaired reading fluency** (accurate decoding, appropriate expression, and rate; Svidnicki et al., 2013). These components are included in **phonological processing**. **Phonological processing** is defined as the ability to hear a speech sound, store it, retrieve it, and manipulate the sound to use it in different contexts. **Short-term memory** is required for the temporary storage, processing, and organization of letters as sounds, known as phonological representations. The manipulation of letters into the sounds they represent to recognize a word is performed within the short-term memory. Essentially, all of this combines into the understanding that "t" is a letter/grapheme, that represents the sound/phoneme /t/, and is

produced with the tip of the tongue tapping the roof of the mouth behind the top/front teeth.

Word recognition is the ability to identify groups of graphemes as written words (morphemes) paired with their sound/phoneme/pronunciation and meaning. When an individual's word recognition is impaired, it will lead to a break down in the ability to read fluently. To increase academic success in students with dyslexia, accommodations must be implemented through the school system to assist with the learning process. To get accommodations, a diagnosis of dyslexia is required. And while dyslexia is increasingly being defined, assessed, diagnosed, and treated in educational systems, there has been varied and inequitable implementation of services.

Advocacy

Advocacy is a term that is a common topic of conversation when someone is wanting equal opportunity for a group of people. Advocacy occurs when someone is defending what they believe in. *Alliance for Justice* (2019, n.p.) defines advocacy as “any action that speaks in favor of, recommends, argues for a cause, supports, or defends, or pleads on behalf of others”. For parent advocates, the “behalf of others” refers to their child. A parent becomes a parent advocate as soon as the child is born. Doctors will make recommendations from hour 1, and parents will make choices on behalf of their child.

As the ones who know their child best, observing their strengths and weaknesses, and getting to know them by spending the most time with them, parents are needed to take on the role of advocate when the opportunity arises. Parents are needed as parent advocates because if they are not standing up for their child, there is no guarantee that someone else will. When defining a parent advocate for a child with a disability, East & Nicholson define the parents as one “who argues in favor of technology, intervention services, and educational accommodations that they believe best meet the unique needs of their individual child” (2008, p. 63). When

advocating, parents can take on responsibility in two different ways, through individual or systemic endeavors (Trainor, 2010). Individual advocacy is when a parent advocates for their own child. Here, the focus is on acquiring new knowledge, understanding procedures, and building relationships with school personnel. This includes the intuitive advocate, the disability expert and strategist. Intuitive advocates incorporate their knowledge of their child to access services, while disability experts depend on the information related directly to the disability to access services, and strategist use IDEA and their knowledge of the individual with disability's rights to access services. Systemic advocacy is a less frequent type of advocacy, but is important to use in advocacy training programs. Systemic advocacy focuses on informing the larger population to better serve these children with disabilities. This includes advocating for teacher trainings, educating a local school board, educating legislators, and educating the public via radio, television, and social media. Systemic advocates are also called change agents (Rossetti et al., 2021b). Combined advocacy across all of these realms is needed, which can be a full-time and demanding job for parents, who often already have a full-time job that requires appropriate attention.

Purpose

Accordingly, the **long-term goal** of this research is to acquire an understanding of parents' capacity to help their children with dyslexia. We want to receive information to be able to inform parents on how to facilitate success for these children and the important role they, as parents, play as advocates. The **objective** of this study is to explore what is required of parent advocates regarding dyslexia in terms of knowledge obtained, confidence in advocating, and the sacrifices made by these parents, via survey methodology. The **central hypothesis** is that parents will report they have acquired knowledge to help their child, which led to increased confidence

to advocate through major life changes. The **rationale** for the research is that parents have an important role in the success of their children, which includes the need to assist with and encourage services for their children. Parents have been the leading force in legislature for dyslexia services, so understanding the correlation between parent knowledge and confidence related to this reading disability will better outline the advocacy process and how taxing it is on the parent to help their child succeed.

Through three aims, we tested the central hypothesis. To determine parent capacity to help their children be successful, we looked at parent responses regarding:

- **Aim #1-** Parent knowledge of dyslexia
- **Aim #2-** Parent confidence in advocating for their child with dyslexia
- **Aim #3-** The personal, socioemotional, financial (etc.) impact afforded by parents who advocate for their children who are struggling to read.

For the **working hypothesis for aim #1**: We expected the parents who are advocating for children with dyslexia have obtained a large amount of knowledge related to the disorder. For the **working hypothesis for aim #2**: We expected that parent confidence to advocate for their child increases as their understanding of the disability increases. For the **working hypothesis for aim #3**: We expected that advocating for children who struggle with a reading disability adversely impacts parent well-being.

Methods

Survey Development

As a test of our hypotheses, we created a Qualtrics survey after review of the literature, existing surveys, expert input, and caregiver feedback. Based on a Likert scale, participants were asked to rate the extent to which they agreed or disagreed with the statements in the survey (see

Appendix A for a complete copy of the survey). The survey contained 90 items, exploring respondent's demographics, knowledge, confidence to advocate, and the demanding job advocacy is. The survey also included questions pertaining to self-efficacy that are addressed in another study.

Participants

Approval was obtained from the Human Subjects Committee at Idaho State University prior to collection of data. Each participant provided voluntary informed consent prior to participation in the study. All participants were parents of children with dyslexia. Participant responses were gathered via an online survey link that was distributed via social media networking (e.g., through posts on Facebook, Instagram, Twitter, etc.) and email. Emails containing the survey link, were sent to the Decoding Dyslexia groups from the 50 states where they were asked to share with members of their groups. Participants were recruited using convenience sampling, which is not random and is used to target members of a group of interest who are readily available. The recruitment methods detailed are considered convenience sampling because all parents with children who have a diagnosis of dyslexia, or who struggle to read, will be asked to complete the survey, but we will only receive responses from those who choose to fill out the survey, incorporating an element of volunteerism.

Materials and Procedure

The survey was expected to take roughly 10 minutes to complete. The survey contained 92 items which fell within the broad categories of demographics, parent knowledge, parent confidence to advocate, the impact advocating has on the parent advocates, and self-efficacy. The survey followed two forms of the Likert scale, which allowed participants to rate the extent

to which they agree or disagree with the statements presented or to rate the extent of occurrence with the statement presented.

Research Design and Data Analysis

Descriptive statistics (frequencies, percentages, mean, and range) were calculated to describe demographics and response rates. Survey response comparisons between parents who felt informed enough to advocate for their children with dyslexia, or those who struggle to read (sorted by a response of agree, disagree, I don't know, and neither) are represented in tables for the following categories: parent advocacy, demographics, knowledge, confidence, and impact.

Chi-square tests of independence were completed using Jamovi, an open statistical software, to explore the relationship between parent advocacy and knowledge, confidence, and impact. A standard alpha of .05 was used to determine statistical significance between the criterion and predictor variables. In addition to exploring the significance of the relationships between variables, effect size was calculated using Cramer's V. Cramer's V is an effect size measurement for the chi-square test of independence, and it measures how strongly categorical fields are associated. In interpreting effect sizes, those lower than or equal to 0.2 are considered only weakly associated, those between 0.2 and 0.6 are considered moderate results, and those greater than 0.6 are considered to be strongly associated.

Some of the response categories were collapsed to decrease the number of response options explored. Data were collapsed as follows. When "level of agreement" was questioned, responses were collapsed from 6 categories to four categories such that somewhat agree and strongly agree became agree; strongly disagree and somewhat disagree became disagree; I don't know remained; and neither disagree nor agree became neither (nothing was collapsed here, the agreement label was simply shortened for presentation purposes). State of residence was

collapsed from 50 response options to 5, per census geographic classification. Accordingly, Connecticut, Maine, Massachusetts, New Jersey, New Hampshire, New York, Pennsylvania, Rhode Island, and Vermont were collapsed into the Northeast; Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin were collapsed into the Midwest; Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia were collapsed into the South; Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming were collapsed into the West; and Other remained the same. Finally, one question's response options were collapsed such that most of the time and always became greater than half, about half the time remained approximately half, never and sometimes became less than half, and I don't know remained.

Results

Of the 112 surveys obtained, 73 were complete and useable (65.18% of the total response rate). Surveys were excluded if participants only responded to informed consent, but no other survey questions, or if they completed less than half of the survey questions. Also, for each specific variable of interest detailed below, you will see the number of respondents (n) varies slightly. We only included respondents who answered all questions for each statistical analysis, resulting in slightly different numbers of respondents across comparisons (e.g., 55 parent advocates under the category of “a family history with a reading disability” versus 50 parent advocates under the category of “income” in Table 1). We queried parent knowledge of dyslexia, confidence in advocating, and social/emotional impact of advocating. Combined with demographic data, this allowed for comparisons between the following four groups of parent

respondents: those who felt 1) they had enough understanding of dyslexia to advocate for their child, 2) they did not have enough understanding of dyslexia to advocate for their child, 3) they did not know whether or not they had enough understanding of dyslexia to advocate for their child, and 4) those who did not fit into any of the above categories.

Variables of Interest

Parent Advocacy and Demographics

For information related to demographics and parent advocacy, see Table 1. The majority of parent respondents indicated that they agreed with the statement “I have enough understanding of dyslexia to advocate for my child” (76.39%). With respect to family history of reading disabilities, parent responses varied such that the majority of those who understood enough or did not know whether or not they understood enough to advocate had a family history of reading disabilities (72.7% and 100% respectively), while the majority of those who did not understand enough to advocate did not have a family history of reading disabilities (54.5%), and the majority of those who felt neutral with respect to whether or not they understood enough to advocate did not know if they had a family history of reading disabilities (60%). With respect to income status, parent responses varied such that the majority of those who understood enough to advocate made more than \$150,000 a year (46.00%), while the majority of those who did not understand enough to advocate made \$100,000 to \$149,999 a year (45.5%), the majority of those who did not know whether or not they understood enough to advocate made \$60,000 to \$69,999 a year (100%), and there was no majority income for those who felt neutral with respect to whether or not they understood enough to advocate (25% made \$20,000 to \$29,999, 25% made \$30,000 to \$39,999, 25% made \$60,000 to \$69,999, and 25% made \$100,000 to \$149,999). Regardless of advocacy status, the majority of respondents had either a professional or 4-year

(N=71)	(n = 54)		(n = 11)		(n = 1)		(n = 5)	
Never married	1	1.9	0	0.0	0	0.0	0	0.0
Married	49	90.7	11	100.0	1	100.0	5	100.0
Divorced	4	7.4	0	0.0	0	0.0	0	0.0
In what geographical region do you live?								
N=72	(n = 55)		(n = 11)		(n = 1)		(n = 5)	
Northeast	13	23.6	3	27.3	1	100.0	1	20.0
South	21	38.2	1	9.1	0	0.0	0	0.0
Midwest	2	3.6	1	9.1	0	0.0	2	40.0
West	18	32.7	6	54.5	0	0.0	2	40.0
Other	1	1.8	0	0.0	0	0.0	0	0.0
Does your child have a formal diagnosis of dyslexia (or a reading disability)?								
N=72	(n = 55)		(n = 11)		(n = 1)		(n = 5)	
Yes	51	92.7	8	72.7	1	100.0	4	80.0
No	4	7.3	3	27.3	0	0.0	1	20.0
Does your child have any other formal diagnoses? - Yes (please list)								
(N=63)	(n = 50)		(n = 8)		(n = 1)		(n = 4)	
Yes	40	80.0	7	87.5	1	100.0	1	25.0
No	10	20.0	1	12.5	0	0.0	3	75.0
How long ago was your child's reading disability diagnosed?								
(N=64)	(n = 54)		(n = 11)		(n = 1)		(n = 5)	
They do not have a diagnosis	1	2.0	0	0.0	0	0.0	0	0.0
Within the last 6 months	2	3.9	5	62.5	0	0.0	0	0.0
1-3 years ago	15	29.4	1	12.5	0	0.0	2	50.0
3-6 years ago	15	29.4	0	0.0	1	100.0	1	25.0
6+ years ago	18	35.3	2	25.0	0	0.0	1	25.0
Where was the assessment conducted when your child was diagnosed with dyslexia (or reading disability)?								
(N=64)	(n = 54)		(n = 11)		(n = 1)		(n = 5)	
School	11	21.6	0	0.0	0	0.0	0	0.0
Private Practice	28	54.9	6	75.0	1	100.0	3	75.0
Both	11	21.6	2	25.0	0	0.0	1	25.0
Does not apply	1	2.0	0	0.0	0	0.0	0	0.0

The statistical relationships between demographics and level of agreement with statements related understanding of dyslexia to advocate listed in Table 2. As can be seen, the comparisons of family history of reading disorders and employment status were statistically significant at the $p < 0.05$ level or smaller, all other comparisons were not statistically significant. Effect sizes ranged from weak to moderate.

The majority of respondents answered yes to their child having an additional diagnosis along with the diagnosis of dyslexia or a reading disability. The subsequent question allowed the respondent to write in the additional diagnosis, some of the additional diagnoses included ADD, ADHD, anxiety, Auditory processing disorder, autism spectrum disorder (ASD), disruptive mood dysregulation disorder (DMDD), dysgraphia, dyscalculia, intellectually gifted, OCD, sensory processing, social communication disorder, and visual communicative disability.

Table 2

Parent Advocacy and Demographics: Chi Square (χ^2) and Cramer's V (ϕ_c)

Variables of Interest	χ^2	df	p	ϕ_c	Effect size
Do you have a family history of reading disabilities?	20.2	6	0.003	0.374	Moderate
What is your highest level of education?	5.41	12	0.943	0.158	Weak
What is your current employment status?	28.7	12	0.004	0.365	Moderate
Income	33.1	24	0.102	0.409	Moderate
Marital status	1.69	6	0.946	0.109	Weak
In what geographical region do you reside?	17.7	12	0.126	0.286	Moderate
Does your child have a formal diagnosis of dyslexia (or a reading disability)?	4.25	3	0.235	0.243	Moderate
Does your child have any other formal diagnoses? - Selected Choice	7.31	3	0.063	0.341	Moderate
How long ago was your child's reading disability diagnosed?	4.25	3	0.235	0.243	Moderate
Where was the assessment conducted when your child was diagnosed with dyslexia (or reading disability)?	4.28	9	0.892	0.149	Weak

Aim #1. Parent Advocacy and Knowledge

In Aim # 1, we sought to explore parent knowledge of dyslexia. As shown in Table 3, for parents who both agreed and disagreed with their adequate understanding of dyslexia for advocacy purposes, the majority knew about dyslexia before it was a concern for them or their child (58.2% and 78.7% respectively). Conversely, the majority of parents who did not know with respect to advocacy, also did not know about dyslexia before it was a concern (100%), and parents who were neutral with respect to advocacy either did or did not know about dyslexia before it was a concern (40% each). For parents who either agreed, did not know, or were neutral with respect to their adequate understanding of dyslexia for advocacy purposes, the majority

stated that people with dyslexia often excel in science, music, art, and/or technical fields (74.5%, 100%, and 100% respectively). The majority of parents who disagreed with respect to advocacy, on the other hand, did not know if people with dyslexia excel in these fields (54.5%). Regardless of advocacy status, the majority of respondents reported doing research on their own to understand dyslexia (84.7%), that an individual can be dyslexic and gifted (95.8%), that it is possible to diagnose a child with dyslexia before the third grade (80.6%), that dyslexia often causes social/emotional/family problems (84.7%), that dyslexia does not only affects a student's performance in reading (not in math, social studies, etc.; 95.8%), that individuals with dyslexia have trouble understanding the structure of language (83.3%), that some indirect impacts of dyslexia include reduced reading comprehension and reduced reading experience (97.2%), that individuals with dyslexia are usually extremely poor spellers (87.5%), that spelling practice is important for reading improvement (58.3%), that readers with dyslexia experience deficits in their ability to break words down (resulting in difficulty identifying printed words; 90.3%), that multisensory instruction is absolutely necessary for students with dyslexia to learn (76.4%), that difficulty with phonological processing is a major contributing factor to dyslexia (83.3%), that phonics is how letters correspond to speech sounds (93.1%), that phonemic awareness is the ability to recognize and manipulate speech sounds in words (88.7%), and that reading instruction should include lessons in all essential components (phonemic awareness, phonics, reading fluency, vocabulary, and reading comprehension; 90.3%). Further, regardless of advocacy status, the majority of respondents reported that dyslexia cannot be cured with intervention (81.9%), that dyslexia is not usually outgrown (94.4%), that pediatricians do not perform diagnostic evaluations to determine if a child has dyslexia (91.7%), reading to children does not impact a dyslexia diagnosis (98.6%), that most students with dyslexia do not have difficulties with

Yes	50	90.9	9	81.8	1	100.0	5	100.0
No	1	1.8	0	0.0	0	0.0	0	0.0
I don't know	4	7.3	2	18.2	0	0.0	0	0.0
Phonics is how letters correspond to speech sounds.								
Yes	52	94.5	10	90.9	1	100.0	4	80.0
I don't know	3	5.5	1	9.1	0	0.0	1	20.0
Spelling practice is important for reading improvement.								
Yes	32	58.2	5	45.5	1	100.0	4	80.0
No	13	23.6	0	0.0	0	0.0	0	0.0
I don't know	10	18.2	6	54.5	0	0.0	1	20.0
Phonemic awareness is the ability to recognize and manipulate speech sounds in words.								
(N=71)	(n = 54)		(n = 11)		(n = 1)		(n= 5)	
Yes	47	87.0	10	90.9	1	100.0	5	100.0
No	0	0.0	0	0.0	0	0.0	0	0.0
I don't know	7	13.0	1	9.1	0	0.0	0	0.0

The statistical relationships between respondent level of agreement with understanding of dyslexia for advocating and knowledge of dyslexia are listed in Table 4. Statistically significant differences in levels of agreements for advocacy between groups were present for the statements, “I knew about dyslexia before it was a concern for me or my child” (moderate effect size) and “People with dyslexia often excel in science, music, art, and/or technical fields” (moderate effect size). All other comparisons generated statistically nonsignificant findings at a probability level of $p < 0.5$ and weak to moderate effect sizes.

Table 4
Parent Advocacy and Knowledge: Chi Square (χ^2) and Cramer's V (ϕ_c)

Variables of Interest	χ^2	df	p	ϕ_c	Effect size
I knew about dyslexia before it was a concern for me or my child.	16.0	6	0.014	0.334	Moderate
I have been doing research on my own to understand dyslexia.	3.50	6	0.745	0.156	Weak
In school, dyslexia only affects a student's performance in reading (not in math, social studies, etc.).	1.94	3	0.585	0.165	Weak
People with dyslexia often excel in science, music, art, and/or technical fields.	13.8	6	0.032	0.310	Moderate
Individuals with dyslexia have trouble understanding the structure of language.	6.46	6	0.374	0.212	Moderate
Individuals with dyslexia are usually extremely poor spellers.	3.18	6	0.786	0.149	Weak

Readers with dyslexia experience deficits in their ability to break words down, resulting in difficulty identifying printed words.	6.24	6	0.396	0.208	Moderate
Some indirect impacts of dyslexia include reduced reading comprehension and reduced reading experience.	11.4	6	0.077	0.281	Moderate
Dyslexia can be cured with intervention.	1.60	6	0.953	0.105	Weak
Most students with dyslexia have difficulties with listening comprehension.	1.83	6	0.935	0.113	Weak
Dyslexia is usually outgrown.	2.70	3	0.441	0.193	Weak
Dyslexia can contribute to low self-esteem.					
If parents read to their children, then their children will likely not develop dyslexia.	0.313	3	0.957	0.066	Weak
Most pediatricians perform diagnostic evaluations to determine if a child has dyslexia.	6.31	3	0.098	0.296	Moderate
In most cases it is not possible to diagnose a child with dyslexia until the third grade.	6.62	6	0.358	0.214	Moderate
An individual can be dyslexic and gifted.	6.20	6	0.401	0.208	Moderate
Multisensory instruction is absolutely necessary for students with dyslexia to learn.	8.26	6	0.220	0.239	Moderate
Dyslexia often causes social, emotional, and/or family problems.	2.97	6	0.813	0.144	Weak
Difficulty with phonological processing is a major contributing factor to dyslexia.	11.0	6	0.088	0.277	Moderate
Phonological awareness is another term for phonics.	4.55	6	0.603	0.178	Weak
Reading instruction should include lessons in all of the following: phonemic awareness, phonics, reading fluency, vocabulary, and reading comprehension.	2.32	6	0.888	0.127	Weak
Phonics is how letters correspond to speech sounds.	1.66	3	0.646	0.152	Weak
Spelling practice is important for reading improvement.	10.4	6	0.107	0.269	Moderate
Phonemic awareness is the ability to recognize and manipulate speech sounds in words.	0.969	3	0.809	0.117	Weak

Aim #2. Parent Advocacy and Confidence

In Aim # 2, we sought to explore parent confidence in advocating for their child with dyslexia. As shown in Table 5, for parents who agreed, neither agreed/disagreed, and did not know whether they understood dyslexia enough for advocacy purposes, the majority reported they could help other parents (85.7%, 40.0%, and 100% respectively). Conversely, the majority of those who did not understand enough to advocate was split between agreeing and disagreeing with having adequate knowledge to help others (36.4% in each instance). With respect to having an adequate amount of knowledge of dyslexia to actively participate in Individualized Education Program (IEP) meetings, parent responses varied such that the majority of those who understood

enough to advocate reported they could actively participate in IEP meetings (87.5%), while the majority of those who did not understand enough to advocate reported they could not actively participate in IEP meetings (54.5%). Further, the majority of those who felt neutral with respect to whether or not they understood enough to advocate, equally agreed and disagreed that they could participate in IEP meetings (40.0% in each instance), and those did not know whether or not they understood enough to advocate reported that they neither agreed or disagreed with being able to actively participate in IEP meetings (100%). The majority of parents reported having an adequate amount of knowledge of dyslexia to encourage their child (87.7%). The majority of parents who agreed and did not know with respect to advocacy responded they could advocate at the state level (60.7% and 100% respectively). On the other hand, parents who both disagreed and neither agreed/disagreed with their adequate understanding of dyslexia for advocacy purposes, reported they could not advocate at the state level (72.7% and 80.0% respectively). The majority of parents who agreed, disagreed, and did not know with respect understanding for advocacy purposes, responded that they could get their child needed services (80.4%, 54.5%, and 100% respectively), while the majority of those who neither agreed/disagreed with respect to understanding for advocacy purposes reported they could not get their child needed services (40.0%). Regardless of advocacy status, the majority of respondents did not use an advocate/attorney to attend an IEP meeting (67.6%), did not have someone else (not an advocate) attend an IEP meeting (73.2%), and disagreed to having advocated at the District or State level for dyslexia services (42.2%). Also, regardless of advocacy status, the majority of respondents did attend a workshop about special education rights (50.7%), had searched the internet for special education rights (81.7%), had read a copy of special education rights or procedural safeguards (76.1%), and had talked with another parent or professional about special education

(N=71)	(n = 55)		(n = 11)		(n = 1)		(n= 4)	
Yes	14	25.5	2	18.2	1	100.0	1	25.0
No	40	72.7	9	81.8	0	0.0	3	75.0
I don't know	1	1.8	0	0.0	0	0.0	0	0.0
I attended a workshop about special education rights.								
(N=71)	(n = 55)		(n = 11)		(n = 1)		(n= 4)	
Yes	27	49.1	4	36.4	1	100.0	4	100.0
No	28	50.9	7	63.6	0	0.0	0	0.0
I have called an agency to ask about special education rights.								
(N=71)	(n = 55)		(n = 11)		(n = 1)		(n= 4)	
Yes	25	45.5	5	45.5	1	100.0	4	100.0
No	29	52.7	6	54.5	0	0.0	0	0.0
I don't know	1	1.8	0	0.0	0	0.0	0	0.0
I have searched the internet for special education rights.								
(N=71)	(n = 55)		(n = 11)		(n = 1)		(n= 4)	
Yes	44	80.0	9	81.8	1	100.0	4	100.0
No	11	20.0	2	18.2	0	0.0	0	0.0
I read a copy of special education rights or procedural safeguards.								
(N=71)	(n = 55)		(n = 11)		(n = 1)		(n= 4)	
Yes	43	78.2	6	54.5	1	100.0	4	100.0
No	11	20.0	5	45.5	0	0.0	0	0.0
I don't know	1	1.8	0	0.0	0	0.0	0	0.0
I have talked with another parent or professional about special education rights.								
(N=71)	(n = 55)		(n = 11)		(n = 1)		(n= 4)	
Yes	47	85.5	11	100.0	1	100.0	4	100.0
No	7	12.7	0	0.0	0	0.0	0	0.0
I don't know	1	1.8	0	0.0	0	0.0	0	0.0
I have advocated at the District or State level for dyslexia services.								
(N=71)	(n = 55)		(n = 11)		(n = 1)		(n= 4)	
Agree	22	40.0	3	27.3	1	100.0	2	50.0
Disagree	24	43.6	4	36.4	0	0.0	2	50.0
I don't know	2	3.6	1	9.1	0	0.0	0	0.0
Neither	7	12.7	3	27.3	0	0.0	0	0.0

The statistical relationships between parent advocacy and confidence are listed in Table 6. Statistically significant differences in levels of agreement between groups were present for the statements, “I have an adequate amount of knowledge about dyslexia to help other parents” (moderate effect size), “I have an adequate amount of knowledge of dyslexia to actively participate in IEP meetings” (moderate effect size), “I have an adequate amount of knowledge

about dyslexia to encourage my child” (moderate effect size), “I have an adequate amount of knowledge about dyslexia to advocate at the state level” (moderate effect size), and “I have an adequate amount of knowledge about my child to get them the services needed” (moderate effect size). All other comparisons generated statistically nonsignificant findings at the probability level of $p < 0.05$ and weak to moderate effect sizes.

Table 6
Parent Advocacy and Confidence: Chi Square (X^2) and Cramer's V (ϕ_c)

Variables of Interest	X^2	df	p	ϕ_c	Effect size
I have an adequate amount of knowledge about dyslexia to help other parents.	23.8	9	0.005	0.329	Moderate
I have an adequate amount of knowledge of dyslexia to actively participate in Individualized Education Program (IEP) meetings.	38.3	9	<0.001	0.418	Moderate
I have an adequate amount of knowledge about dyslexia to encourage my child.	18.4	6	0.005	0.355	Moderate
I have an adequate amount of knowledge about dyslexia to advocate at the state level.	19.2	9	0.023	0.296	Moderate
I have an adequate amount of knowledge about my child to get them the services needed.	22.2	9	0.008	0.318	Moderate
I use/used an advocate/attorney to attend an IEP meeting.	3.06	6	0.801	0.147	Weak
I have/had someone else (not an advocate) attend an IEP meeting.	3.56	6	0.736	0.158	Weak
I attended a workshop about special education rights.	5.82	3	0.121	0.286	Moderate
I have called an agency to ask about special education rights.	5.75	6	0.451	0.201	Moderate
I have searched the internet for special education rights.	1.23	3	0.747	0.131	Weak
I read a copy of special education rights or procedural safeguards.	5.22	6	0.516	0.192	Weak
I have talked with another parent or professional about special education rights.	2.62	6	0.854	0.136	Weak
I have advocated at the District or State level for dyslexia services.	5.06	9	0.829	0.154	Weak

Aim #3. Parent Advocacy and Impact

In Aim # 3, we sought to explore the personal socioemotional, financial (etc.) impact afforded by parents who advocate for their children who are struggling to read. As shown in Table 7, for parents who agreed or neither agreed/disagreed that they understood dyslexia enough for advocacy purposes, the majority reported having adequate funds to afford dyslexia

services (66.1% and 60% respectively), while the majority of those who disagreed with respect to understanding for advocacy purposes reported they did not have adequate funds to afford dyslexia services (54.5%), and those who did not know whether or not they understood enough to advocate did not know if they had adequate funds to afford dyslexia services (100%). Further, for parents who agreed with respect to understanding for advocacy purposes, the majority had enough time to advocate (66.1%). Conversely, the majority of those who disagreed, neither agreed/disagreed, and did not know whether or not they understood dyslexia enough for advocacy purposes, reported that they did not have enough time to advocate (81.8, 60.0%, and 100% respectively). All parents reported that they were currently advocating for their child (78.6% who agreed, 90.9% who disagreed, 60% who neither agreed/disagreed, and 100% who did not know whether or not they understood enough for advocacy purposes). Parent responses also varied such that the majority of those who agreed, disagreed, and neither agreed/disagreed that they understood enough to advocate, reported that going through the experience of advocating for their child did, or would have a positive impact on their child's ability to succeed academically (85.5%, 63.6%, and 100% respectively). The majority of those who did not know if they knew enough to advocate, on the other hand, also reported not knowing whether or not the experience of advocating would have a positive impact on their child (100%). Regardless of advocacy status, the majority of respondents agreed that advocating for their child was demanding with respect to one or all of the following: their mental health, family relationships, friendships, job security/ability to work, and finances (89.0%). Parents also indicated that they had to fund their child's assessment (72.6%), that going through the experience of advocating did not have a negative impact on their child's ability to succeed academically (67.1%), that they had a good relationship with personnel at their child's school (63.01%), that a negative and/or

positive experience with the school was a motivator to work harder as an advocate (68.1% and 53.5% respectively), and that advocating for their child either negatively or positively impacted them (57.53% and 58.9% respectively).

Table 7
Parent Advocacy and Impact: Descriptive Statistics

Parent Advocacy: I have enough understanding of dyslexia to advocate for my child.								
	Agree		Disagree		I don't know		Neither	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Advocating for my child with dyslexia was demanding with respect to one or all of the following: my mental health, family relationships, friendships, job security/ability to work, and finances.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Agree	48	85.7	11	100.0	1	100.0	5	100.0
Disagree	4	7.1	0	0.0	0	0.0	0	0.0
Neither	4	7.1	0	0.0	0	0.0	0	0.0
I had to fund my child's assessment.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	39	69.6	8	72.7	1	100.0	5	100.0
No	17	30.4	2	18.2	0	0.0	0	0.0
I don't know	0	0.0	1	9.1	0	0.0	0	0.0
I had adequate funds to afford my child's needed dyslexia services.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	37	66.1	5	45.5	0	0.0	3	60.0
No	16	28.6	6	54.5	0	0.0	1	20.0
I don't know	3	5.4	0	0.0	1	100.0	1	20.0
With advocacy defined as wanting an equal opportunity and services for my child, advocating for my child negatively impacted me.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	31	55.4	6	54.5	1	100.0	4	80.0
No	19	33.9	3	27.3	0	0.0	0	0.0
I don't know	6	10.7	2	18.2	0	0.0	1	20.0
With advocacy defined as wanting an equal opportunity and services for my child, advocating for my child has positively impacted me.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	37	66.1	4	36.4	0	0.0	2	40.0
No	13	23.2	3	27.3	0	0.0	2	40.0
I don't know	6	10.7	4	36.4	1	100.0	1	20.0
I had enough time to advocate for my child with dyslexia.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	37	66.1	1	9.1	0	0.0	2	40.0
No	17	30.4	9	81.8	1	100.0	3	60.0
I don't know	2	3.6	1	9.1	0	0.0	0	0.0
I am currently advocating for my child with dyslexia.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	44	78.6	10	90.9	1	100.0	3	60.0

No	12	21.4	1	9.1	0	0.0	1	20.0
I don't know	0	0.0	0	0.0	0	0.00	1	20.0
I feel that going through this experience will have (or having gone through this experience has had) a positive impact on my child's ability to succeed academically.								
(N=72)	(n = 55)		(n = 11)		(n = 1)		(n = 5)	
Yes	47	85.5	7	63.6	0	0.0	5	100.0
No	1	1.8	4	36.4	0	0.0	0	0.0
I don't know	7	12.7	0	0.0	1	100.0	0	0.0
I feel that going through this experience will have (or having gone through this experience has had) a negative impact on my child's ability to succeed academically.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	10	17.9	4	36.4	0	0.0	0	0.0
No	38	67.9	7	63.6	1	100.0	3	60.0
I don't know	8	14.3	0	0.0	0	0.0	2	40.0
I have/had a good relationship with personnel at my child's school.								
(N=73)	(n = 56)		(n = 11)		(n = 1)		(n = 5)	
Yes	36	64.3	7	63.6	1	100.0	2	40.0
No	11	19.6	2	18.2	0	0.0	0	0.0
I don't know	9	16.1	2	18.2	0	0.0	3	60.0
The negative experience with the school was a motivator to work harder as an advocate.								
(N=72)	(n = 56)		(n = 11)		(n = 1)		(n = 4)	
Yes	41	73.2	5	45.5	1	100.0	2	50.0
No	11	19.6	5	45.5	0	0.0	0	0.0
I don't know	4	7.1	1	9.1	0	0.0	2	50.0
The positive experience with the school was a motivator to work harder as an advocate.								
(N=71)	(n = 55)		(n = 11)		(n = 1)		(n = 4)	
Yes	31	56.4	6	54.5	0	0.0	1	25.0
No	12	21.8	4	36.4	1	100.0	0	0.0
I don't know	12	21.8	1	9.1	0	0.0	3	75.0

The statistical relationships between respondent impact and level of agreement with statements related understanding of dyslexia for advocacy purposes are listed in Table 8. Statistically significant differences in levels of agreements between groups were present for the statements, “I had adequate funds to afford my child's needed dyslexia services” (moderate effect size), “I had enough time to advocate for my child with dyslexia” (moderate effect size), “I am currently advocating for my child with dyslexia” (moderate effect size), and “I feel that going through this experience will have (or having gone through this experience has had) a positive impact on my child's ability to succeed academically” (moderate effect size). All other

comparisons generated statistically nonsignificant findings at the probability level of $p < 0.05$ and weak to moderate effect sizes.

Table 8
Parent Advocacy and Impact: Chi Square (X^2) and Cramer's V (ϕ_c)

Variables of Interest	X^2	df	p	ϕ_c	Effect size
Advocating for my child with dyslexia was demanding with respect to one or all of the following; my mental health, family relationships, friendships, job security/ability to work, and finances.	2.73	6	0.842	0.137	Weak
I had to fund my child's assessment.	8.55	6	0.201	0.242	Moderate
I had adequate funds to afford my child's needed dyslexia services.	18.7	6	0.005	0.358	Moderate
With advocacy defined as wanting an equal opportunity and services for my child, advocating for my child negatively impacted me.	3.71	6	0.716	0.159	Weak
With advocacy defined as wanting an equal opportunity and services for my child, advocating for my child has positively impacted me.	11.2	6	0.083	0.277	Moderate
I had enough time to advocate for my child with dyslexia.	14.5	6	0.025	0.315	Moderate
I am currently advocating for my child with dyslexia.	15.0	6	0.020	0.321	Moderate
I feel that going through this experience will have (or having gone through this experience has had) a positive impact on my child's ability to succeed academically.	26.8	6	<0.001	0.431	Moderate
I feel that going through this experience will have (or having gone through this experience has had) a negative impact on my child's ability to succeed academically.	7.30	6	0.294	0.224	Moderate
I have/had a good relationship with personnel at my child's school.	6.65	6	0.354	0.213	Moderate
The negative experience with the school was a motivator to work harder as an advocate.	12.5	6	0.052	0.295	Moderate
The positive experience with the school was a motivator to work harder as an advocate.	11.4	6	0.076	0.284	Moderate

Discussion

The purpose of this project was to explore the knowledge and confidence that parents of children with dyslexia have to advocate, as well as the impact advocacy has on the parent's well-being. Specifically, we explored the differences in demographics, knowledge of dyslexia, confidence to advocate, and impact of advocacy as compared to understanding of dyslexia for advocacy purposes.

Characteristics of Parent Respondents

Parent Advocacy and Demographics

Respondents differed regarding highest level of education, with a majority of parents reporting having obtained a professional degree or a 4-year degree. A small percentage of respondents reported having some college or an associate degree, and two responded having a doctorate degree. All respondents received education higher than a high school degree. The majority of respondents were married and employed full-time. A small percentage included parents working part-time or other, which is assumed to be a stay-at-home-parent, and two respondents reported being a student or seeking a work opportunity. Income level differed significantly, with majority of parents reporting an income more than \$100,000. Of all the respondents making over \$150,000, 92% were confident in advocating for their child. Out of the 50 respondents who reported having enough understanding to advocate for their child, almost half of them (46%) earn more than \$150,000. Conversely, respondents who disagreed in understanding enough to advocate for their child, only 18.2% earn more than \$150,000. The geographic location of respondents varied greatly across the United States, but was equally distributed throughout the regions, excluding the Midwest region.

The majority of respondents had a family history of reading disabilities and reported that their child had received a formal diagnosis of dyslexia or a reading disability with the diagnosis being from a private practice. Only 11 out of the 72 respondents indicated their child's assessment and formal diagnosis was obtained in the school setting. This high occurrence of the need to seek a diagnosis outside the school setting exemplifies the need of parent advocacy to acquire a diagnosis as the first step in the advocacy journey.

Out of the parents who agreed to understanding dyslexia enough for advocacy purposes, the majority of respondents reported having advocated for a year or more, while the majority of

respondents who disagreed to understanding dyslexia enough for advocacy purposes received a diagnosis within the last 6 months. This response could indicate that it may take about a year to gain enough knowledge and confidence (or understanding of dyslexia) to advocate for a child.

Aim #1. Parent Advocacy and Knowledge

We sought to compare parent knowledge of dyslexia with understanding of dyslexia for advocacy purposes. Most respondents demonstrated a consistent overall knowledge of dyslexia, as only two questions (of 24) demonstrated a significant relationship between parent knowledge and understanding of dyslexia to advocate (see Table 9). Between respondents who reported having enough understanding to advocate and those who did not, knowledge of dyslexia was not a differentiating factor: both groups typically chose the same, correct responses. This lack of difference may be due to research design. People who do not have much knowledge of dyslexia may have been intimidated and not responded to the survey, resulting in those who filled out the survey to demonstrate a skewed amount of knowledge.

There was 100% agreement from all the respondents with the statement that dyslexia can contribute to low self-esteem. This overwhelming majority could demonstrate a trend that parents recognize the deeper impact of dyslexia on their child. The published literature has stated that low self-esteem is one of the hallmarks of undiagnosed dyslexia in school-aged children that parents often recognize when their child is struggling. The survey results validated that there is a correlation between self-esteem and dyslexia. In addition to academic related difficulties, the survey clearly indicated that dyslexia causes impacts beyond academic. Only 1 out of 72 respondents disagreed with the statement that dyslexia often causes social, emotional, and/or family problems (and 10 respondents indicated they did not know). Further, 85% of the respondents indicated that many different areas of life (social, emotional, and economic)

Table 9

Summary of Parent Responses from Table 3 (highlighting correct responses and demonstrating respondent knowledge about dyslexia)

Total # of Applicable Survey Questions: 22 (1581 total responses)
 Total Correct Responses: 1342
 Total Incorrect or No Response – Responses: 239
 Percent of Total Responses that were correct: 84.88%

Survey Question	Correct	Incorrect / No Response	% Correct
In school, dyslexia only affects a student's performance in reading (not in math, social studies, etc.).	69	2	97.18%
People with dyslexia often excel in science, music, art, and/or technical fields.	49	22	80.32%
Individuals with dyslexia have trouble understanding the structure of language.	60	12	83.33%
Individuals with dyslexia are usually extremely poor spellers.	63	9	87.50%
Readers with dyslexia experience deficits in their ability to break words down, resulting in difficulty identifying printed words.	65	7	90.28%
Some indirect impacts of dyslexia include reduced reading comprehension and reduced reading experience.	70	2	97.22%
Dyslexia can be cured with intervention.	59	13	81.94%
Most students with dyslexia have difficulties with listening comprehension.	52	20	72.22%
Dyslexia is usually outgrown.	68	4	94.44%
Dyslexia can contribute to low self-esteem.	72	0	100%
If parents read to their children, then their children will likely not develop dyslexia.	72	0	100%
Most pediatricians perform diagnostic evaluations to determine if a child has dyslexia.	66	6	91.67%
In most cases it is not possible to diagnose a child with dyslexia until the third grade.	58	14	80.56%
An individual can be dyslexic and gifted.	69	3	95.83%
Multisensory instruction is absolutely necessary for students with dyslexia to learn.	55	17	76.39%
Dyslexia often causes social, emotional, and/or family problems.	61	11	84.72%
Difficulty with phonological processing is a major contributing factor to dyslexia.	60	12	83.33%
Phonological awareness is another term for phonics.	37	35	51.39%
Phonemic awareness is the ability to recognize and manipulate speech sounds in words.	63	8	87.50%
Reading instruction should include lessons in all of the following: phonemic awareness, phonics, reading fluency, vocabulary, and reading comprehension.	65	7	90.28%
Phonics is how letters correspond to speech sounds.	67	5	93.06%
Spelling practice is important for reading improvement.	42	30	58.33%

When hearing about dyslexia or a reading disability, it is sometimes assumed that this disability would only affect reading. All but two respondents disagreed with the statement that dyslexia only affects a student's performance in reading (not in math, social studies, etc.).

Dyslexia impacts all areas of schooling, either directly or indirectly. Academic tasks can take longer and become overwhelming when reading comprehension is impaired. Further, 97% of respondents agreed that dyslexia has an indirect impact on reading comprehension and reduces the reading experience.

Parents demonstrated that they knew that having a child with dyslexia was not something that they could have prevented as a parent. All but one respondent disagreed with the question “if parents read to their children, then their children will likely not develop dyslexia”. The one respondent who did not disagree with the statement, indicated they did not know. Through the advocacy process, it is important that parents do not blame themselves. Knowing that reading to their child more would not have changed the outcome of their child’s difficulties is an encouraging fact. The vast majority of respondents also recognized that dyslexia cannot be cured with intervention and that dyslexia is not outgrown. This supports the need for parents to advocate, as it is a lifelong job.

Aim #2. Parent Advocacy and Confidence

We sought to explore parent confidence in advocating for their child with dyslexia. This survey showed that parents equipped with knowledge of dyslexia have a greater capacity to be an encouraging influence on their child. Of the respondents, the more understanding parents indicated they had of dyslexia, directly corresponded to their ability to encourage their child. Specifically, those who indicated that they had knowledge of dyslexia felt confident in encouraging their child, while those with no, or limited understanding of what it means to be dyslexic, indicated they did not feel they had enough knowledge to adequately encourage their child. The importance of parent knowledge about dyslexia also appears to transcend into the community, as parents who felt they had a good understanding of dyslexia indicated that they

had the confidence to lend support to other parents of dyslexic children. On the other hand, those that did not have the confidence to help their own child, did not feel like they had the ability to support others struggling with the journey of encouraging a dyslexic child. These survey results are important because having the support of a community to help navigate the trials of supporting a dyslexic can be a very valuable asset. Those who have the confidence to make connections will benefit from the community support, while those who do not, can feel isolated in their struggles to support or encourage their child. Further, this confidence to support the child extends beyond the home and into the school through navigating the IEP process.

Navigating the IEP process requires strong advocacy from the parents. The respondents that understood dyslexia reported actively participating in IEP meetings, while respondents who indicated a lack of understanding of dyslexia reported not actively participating. Advocating in IEP meetings is very important to acquire adequate services and accommodations to meet the needs for children with dyslexia. If parents are not speaking out for their children, then many opportunities to help said children navigate the educational system may be missed. Those who indicated that they were not active participants in IEP meetings, also disagreed to utilizing an advocate, an attorney, or anyone else to help support them in IEP meetings. With the survey responses indicating very few parents take advantage of additional resources in IEP meetings, this may suggest why only a slight majority of these respondents (54.5%) agreed to having an adequate amount of knowledge to get their dyslexic child the needed services.

Trying to get the services a child needs in an IEP meeting can be challenging, and that is why advocacy for children with dyslexia is important at the state level. Responses indicated that only those with an understanding of dyslexia committed time to advocate at the state level. This further supports the importance of providing resources for educating parents about dyslexia as

the fight for support of dyslexic children begins in the home and extends to the school and state level.

In Table 10, the survey responses clearly show how a gap in the education of parents about dyslexia can impact their ability to advocate for their child.

Table 10

Summary of Parent Responses from Table 5 (highlighting parent confidence level in ability to advocate for their child)

Total # of Applicable Survey Questions: 5 (365 total responses)			
Total Number of Responses Showing Advocacy Confidence: 265			
Total Other Responses: 100			
Percent of Total Responses Showing Advocacy Confidence: 72.60%			
Survey Question	Agree	Disagree / No Response	% Agree
I have an adequate amount of knowledge about dyslexia to help other parents.	55	18	75.34%
I have an adequate amount of knowledge of dyslexia to actively participate in Individualized Education Program (IEP) meetings.	54	19	73.97%
I have an adequate amount of knowledge about dyslexia to encourage my child.	64	9	87.67%
I have an adequate amount of knowledge about dyslexia to advocate at the state level.	39	34	53.42%
I have an adequate amount of knowledge about my child to get them the services needed.	53	20	72.60%

Aim #3. Parent Advocacy and Impact

No matter what understanding the parent felt they had of dyslexia for advocacy purposes, a vast majority agreed that advocating for their child was demanding in at least one or more of the following areas: mental health, family relationships, friendships, job security/ability to work, and finances. For parents who take on the additional role of being an advocate, we expected to find such an impact. It is unmistakable that advocating has an impact on daily living for these parents, especially financially. The majority of parents reported having to pay out of pocket for their child's assessment, which means the assessment is not happening at the school. Parents have to take extra time out of their day to schedule and get their child assessed. To go to a private practice for assessment, and then obtain services, takes substantial money and time away from the already busy schedule of a parent. The majority of parents who agreed with

understanding dyslexia enough for advocacy purposes, responded they had both adequate funds to afford services for their child, and enough time to advocate. Conversely, the majority of those who reported not understanding dyslexia enough for advocacy purposes, responded they had neither adequate funds for services nor enough time to advocate. This seems to link parent's confidence in their advocacy abilities with their available time and money. It seems logical that parents would learn more about their child's dyslexia and therefore be more confident in advocating if they experience less stress about money and have more time to care for their kids. There would also seem a direct correlation between a parent's available time and their willingness to advocate as advocacy at any level requires a lot of time.

Interestingly, when asked if advocating for their child negatively or positively impacted the respondent, some respondents answered that advocating both positively and negatively impacted them. These responses highlight the complex nature of parent advocacy. While advocating can be an all-consuming, full-time job, some parents find positive value in this form of helping their child.

Implications

This study highlights the importance of knowledge when stepping into the role of a parent advocate for a child with dyslexia. We found that parent knowledge about dyslexia in this sample, had a direct impact on their ability to support their child. This is important because the first line of defense for a child struggling with dyslexia is typically the parents. In addition, results indicated that parent knowledge about dyslexia also has a direct impact on their ability to make connections with other parents struggling with a dyslexic child. Parents with knowledge about dyslexia in this study indicated that they were willing to support other parents advocating for their dyslexic child, thus building a support group for parents in their community.

Responses appear to indicate that parents with higher incomes (>\$150,000) had more confidence in advocating for their child than those with lower incomes. Thus, the confidence to advocate among parents appears to be skewed toward those with higher incomes. If a parent's advocacy solely impacts their child, this suggests children of higher household incomes would receive greater dyslexia accommodations and services. However, if the parents who advocate for their children are also successful in improving the greater educational system, all children with dyslexia would benefit.

This study implies, unfortunately, factors that can help children with dyslexia be successful are directly related to a parent's ability to adequately advocate for and support their child. This survey found that parents with knowledge about dyslexia indicated that they felt confident in their ability to encourage their struggling child, while parents without knowledge of dyslexia felt ill equipped. It is logical to think that a child who receives encouragement and support has a greater chance of student success than a child who does not receive the same level of advocacy or encouragement. The results also showed that a parent's financial means has an impact on their ability to provide strong advocacy for their child. The fact that a dyslexic student's success is contingent on factors like a parent's ability to become knowledgeable about dyslexia, or their financial wealth means that we have to do more as a society to help students succeed who do not have the same level of advocacy and financial means from their parents.

Study Limitations

Based on review of the methods used in the study, several potential flaws and limitations were discovered that may have an impact on the results that were found. The first thing to consider is that survey studies are by definition volunteer-based, which may lead to response biases. For this survey specifically, parents that feel strongly about their experiences with

dyslexia may have felt more compelled to respond. This could have skewed the results due to the possibility that the parents who are more passionate about advocating for dyslexia have more drive to fill out a survey related to parent advocacy. Those who are passionate about a topic typically have an increased amount of knowledge than those who are not, which could have had an impact on the responses we obtained.

The sample size of responses analyzed was small, especially when compared to the prevalence of dyslexia and reading disabilities within the United States. The survey was advertised via social media and word of mouth. The most indirect distribution was via email to all 50 state chapters of Decoding Dyslexia. Although reminders were sent to the chapters, it is unclear if the survey was further distributed to the chapter members. Given the non-random sampling approach, there are reasonable questions regarding the generalizability of the sample.

When analyzing the demographics, 93% of respondents were married, 61% of respondents had incomes over \$100,000, and only one respondent was seeking employment opportunity. These demographics are not an adequate representation of the population, again limiting the generalizability of the results.

With the use of a survey, question formulation can have several potential limitations. Question formulation may lead to unreliable or swayed responses, which would limit findings of the study. The phrasing of the questions had the potential to encourage or discourage a response. This question design can inaccurately represent the respondents true understanding and answer to the given question. Question responses that may have an impact on the internal validity of the study were under the parent advocacy and impact aim. For example, respondents were asked if there was a negative or positive impact on both the child's ability to succeed academically and if a positive or negative experience with the school was a motivator to work harder as an advocate.

The majority of responses contradicted one another, decreasing survey validity and pointing to a problem in question phrasing. Further, the study demonstrated ambiguity in defining the respondent's current job classification by offering the choice of "other". To reduce ambiguity, we could have included the option of "stay at home parent".

The data was collapsed into fewer categories. This collapse could result in the loss of information and can impact the patterns within the data. Due to this collapse, variability in responses between groups may have been reduced.

Future Directions

This study revealed several opportunities to enhance the ability of schools and professionals to support children with dyslexia, and the families that support them. First of all, one interesting thing the respondents of this study indicated was that often a child with dyslexia presents with an additional diagnosis like attention deficit disorder (ADD), attention deficit/hyperactivity disorder (ADHD), anxiety, auditory processing disorder, autism spectrum disorder (ASD), disruptive mood dysregulation disorder (DMDD), dysgraphia, dyscalculia, intellectually gifted, obsessive-compulsive disorder (OCD), sensory processing, social communication disorder, and visual communicative disability. It may be valuable to gain insight into the percentage of the co-occurrence of dyslexia and other formal diagnoses. Additional research should be done to specifically investigate more details on the existence of these additional diagnoses. In addition, providing more awareness to educators and support professionals that many times dyslexic students may also present with another diagnosis would help to ensure that all the needs of a child struggling with dyslexia are met.

One of the key findings in this study was the impact that knowledge of dyslexia has on a parent's ability to encourage and advocate for their child. Early education to parents on how to

identify the signs of dyslexia, as well as how to support their child at home and in the educational system could make a real impact on the ability of parents to support their children and on student success in the classroom. It would be beneficial to provide education in kindergarten to parents to explain the signs, symptoms, and presentation of dyslexia to increase parental awareness of how to recognize if their child is struggling with dyslexia. Providing this information for parents in the public-school setting would hopefully offset some of the findings of this survey that indicated that children of parents with higher financial means understood more about dyslexia and felt more equipped to advocate for their child.

Conclusions

Through this study, we aimed to identify the relationship between (a) a parent's knowledge of dyslexia, (b) their confidence to advocate for their child, or others impacted by dyslexia, and (c) the impact of advocating for a child with dyslexia. In conclusion, research has shown that a parent's knowledge about dyslexia has a positive effect on the parent's ability to serve a child struggling with the social, emotional, and educational effects of dyslexia. Parents who have knowledge about dyslexia are more confident in encouraging their child. In addition, a parent's knowledge about dyslexia also was an indicator of whether a parent played an active role in the child's IEP process. Parents with knowledge about dyslexia actively participated in IEP meetings. The research further showed that parents with knowledge about dyslexia were more likely to participate in state level advocacy. This study also found that having a child with dyslexia impacts a family socially, emotionally, and financially. By promoting education about dyslexia for all parents, parents who discover they have a child struggling with the impacts of dyslexia may feel more equipped to encourage and advocate for their child. A parent's role in the educational IEP process is imperative to identify and execute proper intervention techniques.

Providing education about dyslexia for parents will make them a more active participant in the IEP process, and therefore make the IEP process more successful at identifying interventions for the child. While there are limitations in this study, such as sample size, volunteer bias, and diversity of demographics, we can confidently argue that promoting education about dyslexia is of vital importance in helping parents fill the role of support and advocate for their child with dyslexia.

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Appendix

The Demanding Nature of Advocating for Dyslexia Services Survey

Demographics

1. Are you the caregiver of a child with dyslexia?
 - a) Yes
 - b) No
2. Do you have a child you are concerned about or that has been diagnosed with dyslexia?
 - a) No
 - b) Yes concerned
 - c) Yes diagnosed
 - d) Both concerned and diagnosed
3. Do you have a family history of reading disabilities?
 - a) Yes
 - b) No
 - c) Unknown
4. What is your highest level of education?
 - a) High School Diploma
 - b) Some college
 - c) Associate degree
 - d) Bachelor's Degree
 - e) Master's Degree
 - f) Ph.D. or higher
 - g) Other doctoral degrees
 - h) Trade School
 - i) Other
5. What is your current employment status?
 - a) Full-time
 - b) Part-time
 - c) Seeking Opportunity
 - d) Student
 - e) Other
6. Income
 - a) Less than \$15,000
 - b) \$15,000-29,999
 - c) \$30,000-49,999
 - d) \$50,000-69,999
 - e) \$70,000-99,999
 - f) More than \$100,000
7. Marital status
 - a) Single
 - b) Married
 - c) Never married
 - d) Separated/divorced/widowed
8. In what geographic region do you currently live?

- a) New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont)
 - b) Middle Atlantic (New Jersey, New York, Pennsylvania)
 - c) East North Central (Indiana, Illinois, Michigan, Ohio, Wisconsin)
 - d) West North Central (Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota)
 - e) South Atlantic (Delaware, District of Columbia, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia)
 - f) East South Central (Alabama, Kentucky, Mississippi, Tennessee)
 - g) West South Central (Arkansas, Louisiana, Oklahoma, Texas)
 - h) Mountain (Arizona, Colorado, Idaho, New Mexico, Montana, Utah, Nevada, Wyoming)
 - i) Pacific (Alaska, California, Hawaii, Oregon, Washington.)
9. How long ago was your child's reading disability diagnosed?
- a) They do not have a formal diagnosis
 - b) Within the last 6 months
 - c) 6 months – 12 months
 - d) 1 – 3 years ago
 - e) 3 – 6 years ago
 - f) 6+
10. If a formal diagnosis was given, where was the assessment conducted?
- a) School
 - b) Private Practice
 - c) Both
 - d) Does not apply

All remaining responses (unless otherwise noted) will be reported on a “level of agreement” Likert scale such that 1 = strongly disagree, 2 = disagree, 3 = somewhat disagree, 4 = neither disagree nor agree, 5 = somewhat agree, 6 = agree, 7 = strongly agree, and 8 = I don't know.

Knowledge of Dyslexia

- 11. I knew about dyslexia before it was a concern for me or my child.
- 12. I have been doing research on my own to understand dyslexia.
- 13. In school, dyslexia only affects a student's performance in reading (not in math, social studies, etc.).
- 14. People with dyslexia often excel in science, music, art, and/or technical fields.
- 15. Individuals with dyslexia have trouble understanding the structure of language, especially phonics.
- 16. Individuals with dyslexia are usually extremely poor spellers.
- 17. Readers with dyslexia experience deficits in their ability to break words down, resulting in difficulty identifying printed words.
- 18. Some indirect impacts of dyslexia include reduced reading comprehension and reduced reading experience.
- 19. Individuals with dyslexia may comprehend a passage read to them very well but be unable to read the words independently.

- 20. People with dyslexia have below average intelligence.
- 21. Dyslexia can be cured with intervention.

QUESTIONS 22-44 RELATED TO SELF-EFFICACY (RAINSDON'S Thesis)

Confidence to Help Child

- 45. With advocacy defined as wanting an equal opportunity and services for my child, I have enough understanding of dyslexia to advocate for my child.
- 46. I have an adequate amount of knowledge about dyslexia to help other parents.
- 47. I have an adequate amount of knowledge of dyslexia to actively participate in Individualized Education Program (IEP) meetings.
- 48. I have an adequate amount of knowledge about dyslexia to be an encourager for my child.
- 49. I have an adequate amount of knowledge about dyslexia to advocate at the state level.
- 50. I have an adequate amount of knowledge about your child to get the services needed.

QUESTIONS 51-53 RELATED TO SELF-EFFICACY (RAINSDON'S Thesis)

Personal Cost

- 54. I had adequate funds to afford my child's needed dyslexia services.
- 55. I had enough time to advocate for my child with dyslexia.
- 56. Advocating for my child negatively impacted my mental health.
- 57. Advocating for my child has positively impacted my mental health.
- 58. If not necessary, I would choose not to be an advocate for my child.
- 59. I have/had a good relationship with personnel at my child's school.
- 60. The negative experience with the school was a motivator to work harder as an advocate.
- 61. The positive experience with the school was a motivator to work harder as an advocate.

The following statements will be presented in a five-point Likert format, in which the respondent must rate the extent of occurrence, 1- never, 2- occasionally, 3- sometimes, 4- often, 5- very often.

- 62. I use/used an advocate/attorney to attend an IEP meeting.
- 63. I have/had someone else (not an advocate) attend an IEP meeting.
- 64. I attended a workshop about special education rights.
- 65. I have called an agency to ask about special education rights.
- 66. I have searched the internet for special education rights.
- 67. I read a copy of special education rights or procedural safeguards.
- 68. I have talked with another parent or professional about special education rights.