

INTRODUCTION

A child who experiences difficulty learning how to read goes through many struggles and exhibits a myriad of symptoms and emotions. This response affects not only the individual child, but greatly impacts the entire family (Snowling et al., 2007). Watching as your child struggles to learn how to read and not being able to help them can be a devastating feeling. Receiving the news that your child has dyslexia may trigger feelings of frustration, fear, sadness, or helplessness. Additionally, ongoing needs for advocacy, support, effective interventions, and appropriate accommodations for a child with dyslexia can cause continued family stress.

Current literature regarding parental perspectives of disability diagnoses has primarily addressed children with the diagnosis of autism (e.g., Howlin, 1997; Mansell & Morris, 2004) and diagnosis in Europe and Asia (e.g., Brogan & Knussen, 2003; Crane et al., 2016; Long & McPolin, 2009; Rimkute et al., 2014; Soriano et al., 2015). Evaluation of parental perspectives of children with dyslexia located in the United States represents an internationally under-researched area in the field of special education.

A multidisciplinary team of researchers from the fields of school psychology, literacy education, educational diagnostics, special education, and counseling came together to investigate parents' experiences and perspectives regarding their child's diagnosis and treatment of dyslexia. The primary goal of the study was to determine how parental perspectives of a child with dyslexia change during the cycle of identification. The findings from this research study provide insights into the lived experiences of the children and their families with dyslexia; including those who suspect a reading problem, those who are currently going through the assessment process, or those who have already received a diagnosis of dyslexia. From preliminary data analyses, we will present some significant findings gleaned from data collected from this under-researched population. Outcomes from this research study include providing valuable information to the fields of education, special education, and dyslexia intervention.

PARTICIPANTS

Data was collected from across the United States from a total of 601 parents of 653 children with suspected or diagnosed dyslexia, recruited through emails and posts to various professional organizations, educational agencies, and parent support groups for dyslexia and learning disabilities. The parent respondents were primarily female (84.6%), married (88%), and had a bachelor's degree or higher (75%). Reported parents' and children's races were very similar, with 89% of parents and 83.4% of children identified as White. About a third (32.5%) were parents of at least one other child with a disability.

METHODS

Data collection for the mixed methodology study was completed electronically through a Qualtrics survey link which was shared with prospective participants through a wide variety of electronic platforms. Participants completed a survey with screener questions to identify only U.S. parents of children ages 4-22 with difficulties in learning to read. If a participant met the specific inclusion criteria for the study, they were then prompted to respond to the survey questions.

Questions were either developed by the researchers to address issues specific to U.S. parents or adapted from previous studies that were reviewed to reflect similar factors in parent perceptions (some referenced above). The survey included demographics and questions related to parental experiences surrounding the assessment/diagnosis of their child. The survey was designed to collect information from three sections of parents: suspected dyslexia/pre-assessment, current/ongoing assessment, or post-assessment/diagnosis. Respondents received different blocks of questions depending on their previous answers. Before recruitment and collection of survey responses, the survey was reviewed by professionals in the field to ensure understanding and relevance, through a process of expert panel evaluation (Presser & Blair, 1994). The research team then qualitatively analyzed participants' responses regarding their experiences throughout the diagnosis process and verified the responses through quantitative data analysis of participants' satisfaction with and stress related to the dyslexia diagnosis process.

RESULTS

Parents reported that the children with dyslexia or suspected dyslexia had an average age of about 9 years, 11 months (118.56 months). The average age of dyslexia diagnosis, if already given, was about 8 years, 3 months (99.41 months). Of the children indicated in the survey, 74 were suspected of dyslexia but not yet evaluated, 29 were undergoing an evaluation, and 552 were diagnosed with dyslexia.

Parents also reported several changes throughout the process of seeking a diagnosis for their children. In addition to those listed in Table 1, 30.7% of parents reported needing to travel more than 20 miles to receive an evaluation.

Table 1
Parent Responses to Multiple-Selection Survey Items

Items	n	%
Reported Lifestyle Changes (n = 414)		
Feelings about a dyslexia diagnosis	193	46.6
Expectations for child's college education	162	39.1
Expectations for child's future work/career	127	30.7
Family relocation or different school	165	39.9
Parent career or lifestyle	125	30.2
Why did you seek an evaluation or diagnosis? (n = 583)		
School informed parent of needs	80	13.7
Parent had suspicion of problems	387	66.4
Seek guidance on interventions/remediation	97	16.6
Seek additional services	127	2.2
Other	98	16.8
What professional performed the evaluation? (n = 478)		
Physician	23	4.8
Educational Diagnostician/Psychometrician	131	27.4
Psychologist	132	27.6
School Psychologist	95	19.9
Dyslexia Specialist	123	25.7
Reading Interventionist	36	7.5
Other	80	16.7

One parent reported of these changes and concerns:

"Since this diagnosis my ability to work has been limited due to increased requirements of me getting [my child] to and from dyslexia therapy 45 miles away after school during the week as well as helping with homework."

Scores on the Likert survey items regarding parent perceptions (Table 2) reveal generally positive views of the process, with some exceptions. The lowest average ratings were related to stress and the timeline of the evaluation. 5-point Likert items were also rated for satisfaction with the timeline of evaluation ($M = 2.59$, $SD = 1.55$) and satisfaction with the results of the evaluation ($M = 3.70$, $SD = 1.41$), and ages for first requesting an evaluation were recorded. The time between first request and diagnosis predicted satisfaction with the evaluation timeline, $b = -.35$, $t(377) = -7.17$, $p < .001$, and satisfaction with the evaluation results, $b = -.21$, $t(380) = -4.24$, $p < .001$. This also accounted for a significant proportion of the variance in satisfaction, although the total explained variance was small ($R^2 = .12$ and $R^2 = .04$, respectively).

Table 2
Parent Responses (%) to Likert Survey Items Regarding the Dyslexia Diagnosis Process (n = 517)

	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree	Mean (SD)
Adequate support from family or (close) others	29.6	29.0	15.5	15.3	10.6	3.52 (1.34)
Adequate support from teachers or education professionals	13.0	25.7	8.5	27.1	25.7	2.73 (1.42)
Adequate support from therapists or interventionists	26.7	26.9	18.4	14.1	13.9	3.38 (1.38)
Support from other parents who also have a child with a dyslexia or suspected dyslexia	25.9	24.6	29.0	8.1	12.4	3.44 (1.29)
Appropriate support for family	25.0	27.3	23.6	14.3	9.9	3.43 (1.28)
Appropriate support for child	16.4	29.8	14.1	24.4	15.3	3.08 (1.35)
Evaluation process is stressful for parent*	33.1	34.6	14.9	10.8	6.6	2.23 (1.21)
Evaluation process is stressful for child*	28.4	34.2	18.0	12.8	6.6	2.35 (1.20)
Evaluation process was adequately explained	25.4	32.2	13.6	16.9	12.0	3.42 (1.35)
Appropriate information on what steps to take after the diagnosis/results	21.7	27.5	14.3	20.9	15.5	3.19 (1.39)
Evaluation results have been adequately explained	30.0	36.6	11.1	11.3	10.9	3.64 (1.31)
Evaluation results are useful	31.2	37.6	11.7	9.9	9.7	3.71 (1.27)
Comfortable with the professional who performs the evaluation	48.8	25.3	8.4	8.8	8.6	3.97 (1.31)
Comfortable with the professional who shares the results and/or diagnosis	47.3	26.9	9.3	10.1	6.4	3.99 (1.25)
Child should have received assessment and/or diagnosis earlier*	66.5	14.5	8.1	6.2	4.7	1.68 (1.15)
Hopeful for child's future	54.5	30.4	4.7	9.5	1.0	4.28 (0.99)
Confident that parent can help child succeed	51.9	29.8	6.6	9.7	1.9	4.20 (1.05)
A diagnosis of dyslexia is accurate for child	89.7	7.0	2.1	0.6	0.6	4.85 (0.53)

*Items reversed for mean calculations.

In reference to the diagnosis experience, one parent stated:

My son's dyslexia is so profound and so intertwined with other issues... We knew he was dyslexic by the time he was six, but it took nearly eight years to get the other items addressed by medical professionals. He lost a lot of his life because of these other factors."

IMPLICATIONS FOR STAKEHOLDERS

- Children are suspected of reading difficulties and recommended by parents for evaluation by about 2nd grade age (i.e., average 8 years, 3 months). This is consistent with previous literature and continued need for early identification, referral, and evaluation of students with reading difficulties.
- Data indicated a relationship between parent satisfaction with the timeline of the evaluation and results of the evaluation, with a direct relationship to the request for diagnosis and evaluation completion. This strongly suggests a need for advocacy surrounding the time it takes to complete referral and evaluation processes.
- Educators play a critical role and bear the responsibility of informing parents of legally compliant evaluation processes and timelines. Conversely, parents play a critical role in monitoring evaluation processes through ongoing and continuous communication with evaluation personnel and school leaders from the initial request for diagnosis.
- Parent suspicions and referrals were the most common reason for an evaluation, and schools were the most common source of dyslexia evaluations. However, parents largely felt a lack of support from educators, but were largely comfortable with evaluation personnel.
- Parent reports reveal several changes throughout the diagnostic process, for both individuals and families. Data indicates that improved, early access to evaluation and services may improve parent satisfaction as well. In particular, there is a concern and significant disruption when families need to travel long distances for evaluation and services.
- Parents reported relocating/changing schools due to perceived lack of support or services from the schools because of limited intervention services and/or educational support.
- Parents reported that attending support groups focusing on education, acceptance, and advocacy needs in their area can help with advocating for their needs and learning from each other's experiences. There is a need for ongoing school-wide or community support for parents to answer questions and talk about services available to them.
- Despite reported concerns, parent ratings were largely positive regarding their children's future and education. This seems especially true for parents after receiving a diagnosis and services.

KEY REFERENCES

Click on hyperlink or QR code for references



<https://bit.ly/3q6QpYm>

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ACKNOWLEDGEMENTS

We appreciate the generous financial support provided by the West Texas A&M University Department of Psychology, Sociology, & Social Work.

We would like to acknowledge the contributions and support of the West Texas A&M University research collaborators and graduate assistants: Yvette Castillo,



Parent Perspectives of the Dyslexia Diagnosis Process

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We appreciate the partnership and support of the West Texas A&M University Center for Learning Disabilities for this project.