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Barriers To Identifying Learning Disabilities: A Qualitative Study Of Clinicians And Educators

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BARRIERS TO IDENTIFYING LEARNING DISABILITIES: A QUALITATIVE STUDY OF

CLINICIANS AND EDUCATORS

A Thesis Submitted to the Yale University School of Medicine

in Partial Fulfillment of the Requirements for the Degree of Doctor of Medicine

by

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Abstract

BARRIERS TO IDENTIFYING LEARNING DISABILITIES: A QUALITATIVE STUDY OF

CLINICIANS AND EDUCATORS

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The estimated prevalence of learning disabilities (LDs) is nearly 8% of all children. Yet

fewer than 5% of all children are diagnosed in public schools — jeopardizing

remediation. The specific aims of this study were as follows: 1) To perform a qualitative

study involving individual interviews with front-line child-facing professionals to identify

barriers to detecting school-aged children with LDs and 2) To utilize results to suggest

improvements to pediatric clinical care, as pediatricians are often initial responders for

families when children experience academic difficulties.

We conducted a qualitative study with individual interviews of 40 professionals from

different areas of the United States identified through theoretical sampling (20

educators, 10 pediatricians, and 10 child mental health clinicians). Clinicians

represented academic and community settings, and educators represented public,

private, and charter schools. Twenty had expertise in assessing LDs; 20 were generalists

without specific training. We also endeavored to maximize representation across age,

gender, race/ethnicity, and location. We analyzed transcripts utilizing grounded theory and identified themes reflecting barriers to detection.

Themes (and sub-themes) included: 1) areas requiring improved professional education (misconceptions that may hinder detection, confounding factors that may mask LDs, and need for increasing engagement of parents or guardians in identifying LDs) and 2) systemic barriers (time constraints that limited professionals' ability to advocate for children and to delve into their emotional experiences, inconsistent guidelines across institutions and inconsistent perceptions of professional responsibility for detection, and confusion surrounding screening tools and lack of screening by some professionals in the absence of overt problems).

Clinicians and other child-facing professionals may benefit from augmented training in screening and identification and enhanced evidence-based and institutional guidance. Future quantitative research could investigate whether these efforts could increase efficiency and perceived responsibility for recognition and improve earlier detection.

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Finally, I would like to thank my classmates, whose brilliance inspired me, and whose friendship kept me grounded. Most importantly, I have deep gratitude for my parents and younger brother for all of their affection and encouragement.

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Introduction

Academic achievement is critical for wellbeing and is associated with health outcomes in adulthood.[1] Individuals with learning disabilities (LDs) typically exhibit normal levels of intelligence and adaptive functioning but experience particular academic deficits that precipitate a mismatch between intellectual capacity and academic achievement.[2] The onset and presentation of LDs can be heterogeneous. For instance, while some children may manifest with overt issues at school (e.g. academic failure, disengagement, or disruptive behaviors), others may demonstrate signs of greater learning effort (e.g. investing greater amounts of time compared with peers to complete assignments).[2] Some children may compensate for their weaknesses and mitigate or delay evidence of impairment, sometimes even into adulthood.[2-5] When professionals notice suggestive signs, they may refer children to members of the school district or private psychologists for formal diagnostic evaluation that involves academic and cognitive testing.[2,3]

LDs are common, with an estimated prevalence of nearly 8% in children aged 3-17 between 2009 and 2017 in the United States.[6] Yet, over the same time period in the country fewer than 5% of all children were identified and received services in public schools.[7] Over the past decade, many states have passed legislation designed to improve the identification of dyslexia, but this did not impact the detection rate in the years following enactment.[8] These findings represent a critical gap, as LDs are associated with profound consequences — such as mental illness and an increased risk

of suicide attempts,[9] and failure to complete educational programs with subsequent difficulty in earning sufficient income.[10] Moreover, later diagnosis is correlated with an even greater self-perception of incompetence.[11] Furthermore, academic remediation is most effective when commenced before second grade.[12]

To date, research on under-identification has been narrowly focused on select groups, such as highly intelligent children or those who compensate for their disability,[4] those who display disruptive behaviors,[13] or students learning English as a second language (ESL) who may be over- or under-identified.[14,15] To our knowledge, no study has investigated under-identification from the vantage point of child-facing professionals tasked with detection, such as educators, pediatricians, and child mental health clinicians who are critical for recognition.[16]

Statement of Purpose

The specific aims of this study were as follows:

- **Specific Aim 1:** To perform a qualitative study involving individual interviews with these front-line professionals to identify barriers to diagnosing school-aged children with LDs.

- **Specific Aim 2:** To utilize our results to suggest improvements to pediatric clinical care, given that pediatricians are often initial responders for families when children experience academic difficulties.[3,16]

Methods

Ethics Statement

The Institutional Review Board of Yale University deemed this study exempt from
ongoing formal review (Protocol #2000030062). This research is reported in adherence
with the Standards for Reporting Qualitative Research (SRQR).[17]

The funders of the study 1) the James G. Hirsch Endowed Medical Student Research
Fellowship and Yale School of Medicine Fellowship for Medical Student Research 2)
Qua*Lab* — the Qualitative & Mixed Methods Lab, a collaboration between the Yale Child
Study Center and the Centre de Recherche en Epidémiologie et Santé des Populations
(CESP, Paris) and 3) the Riva Ariella Ritvo Endowment at the Yale Child Study Center, had
no role in the design and conduct of the study, nor in the collection, management,
analysis, and interpretation of the data, nor in the writing of the thesis or related
scholarly work.

Setting and Study Population

We adopted a constructivist grounded theory approach to develop the methodology for
this qualitative study.[18-20] Grounded theory studies may begin with purposive sampling
to yield initial data believed to provide insights relevant to the research question and to
maximize variation in the early stages. Inclusion of different types of sub-groups is
integral to generating varied data for creation of the theory. Accordingly, we first used
purposive sampling to generate diversity with respect to self-reported age, gender,

race/ethnicity, location within the United States, type of professional, and practice setting (academic or community-based for clinicians, or public, private, or charter schools for educators). We also recruited elementary educators, to ensure sufficient representation during a critical period for screening, and middle and high school educators, to include perspectives on the later presentation of undiagnosed LDs.

Subsequently, the sampling strategy may transition to theoretical as the theory begins to emerge to corroborate, repudiate, and develop ideas. Grounded theory is iterative and entails analysis (further described below in "Qualitative Analysis") that occurs simultaneously with data collection and that drives it. Thus, after several interviews we subsequently utilized theoretical sampling to seek additional data to explore initial concepts — namely that there were not clear differences in perspectives, knowledge, and practices between clinicians versus educators nor experts versus generalists. This warranted further study. Therefore, we continued to maintain diversity with respect to the above categories, but proceeded to recruit the same number of clinicians and educators, and specifically included an expert clinician to match each generalist clinician, and an expert educator to match each generalist educator in pairs, to ensure equal representation. Experts were formally trained in the recognition, assessment, and remediation of LDs (developmental pediatricians, neuropsychologists, school psychologists, or special educators) and generalists did not have specialized training in LDs (general pediatricians, general psychologists or psychiatrists, and general educators, some of whom had ESL training).

We initially contacted professionals by e-mail and phone. We obtained verbal informed consent to record interviews and to publish de-identified excerpts. Interviewees did not receive a stipend for participating.

Interview Procedures

Multiple co-authors have experience with qualitative research and pediatric clinical care (L.B., A.M., and J.H.) and with education (J.H.). All of the investigators jointly developed an interview guide based on a literature review and broadly focused the questions on identification practices and attitudes toward LDs (**Table 1**) for a targeted duration of 60 minutes. The student author collected self-reported demographic data as indicated above and conducted semi-structured individual interviews between March and June of 2021 via Zoom video conference software. We audio- and video-recorded interviews, professionally transcribed them, and de-identified the transcripts.

Table 1. Interview Guide

1. Please tell us about your professional background.

   a. How did you choose your position?

   b. What are the biggest challenges associated with your job? What are the most gratifying aspects?

2. Please tell us about your experience with LDs.

3. What are the most and least common LDs you see?

4. How do you identify LDs?

5. Do you do any screening for LDs? If so, how?

6. What do you do if you suspect a child may have an LD?

7. How do you start a conversation with a child if you suspect an LD?

8. Do you screen for other conditions in the children you work with? If so, how?

9. In your opinion, why do we miss LDs in children?

   a. Whose responsibility is it to detect them?

10. Do you have any personal or family experience with LDs?

11. What makes children who are gifted with an LD seem gifted?

12. Why do you think some people have difficulty believing a successful person can have an LD?

13. What is your perspective on the etiology of an LD?

14. Do you feel there is stigma associated with an LD?

15. Do you have experience with LDs in English language learners?

Abbreviations: LD, learning disability.

Qualitative Analysis

We managed transcripts using NVivo software version 12 (QSR International) and maintained an audit trail. We analyzed data using a constructivist grounded theory approach.[18-20] Through the constant comparative method, the student author and L.B. independently coded the transcripts line-by-line, as follows: They each open-coded the first 5 transcripts and subsequently met to achieve consensus and developed a codebook in conjunction with the other investigators. The student author and L.B. iteratively coded the remaining interviews and refined the codebook through regular meetings for triangulation with the other investigators. Interviews continued until we reached theoretical saturation in the overall sample — defined as the point at which no new codes were generated.[18] All investigators consolidated the codes into categories, and categories into themes, through consensus.

Student Contributions

The student author conceived of the project idea and research question and performed all aspects of the study — under the supervision of faculty mentors through regular meetings. The student author: 1) designed the study and data collection instruments utilizing qualitative research resources that the faculty mentors supplied 2) generated the Institutional Review Board application 3) performed the study (recruited all professionals and performed all qualitative interviews) 4) conducted all data analyses, including coding all interview transcripts (as indicated above, in keeping with established qualitative research methods, L.B. also coded all interview transcripts for

consistency, and the study team had regular meetings for triangulation and refinement of the codebook) and 5) independently wrote the thesis and all related scholarly work (under the mentorship of the thesis advisor).

Results

Forty child-facing professionals (20 educators, 10 pediatricians, and 10 child mental health clinicians) participated (**Table 2**). Professionals were diverse with respect to age, gender, race/ethnicity, location, and practice setting. Twenty were experts and 20 were generalists. Sixteen reported having family members with LDs and 2 were diagnosed themselves.

We identified 2 overarching themes (each with sub-themes), common to both clinicians and educators, and reflecting barriers to detecting LDs in school-aged children.

Table 2. Demographic Characteristics

Characteristic	Educator (N=20)	Pediatrician (N=10)	Child/adolescent mental health clinician (N=10)	Total (N=40)
	Number	Number	Number	Number
Age, years				
20-30	3	0	0	3
31-40	3	3	2	8
41-50	3	1	1	5
51-60	7	3	5	15
61-70	3	1	2	6
71-80	1	2	0	3
Gender				
Male	6	3	4	13
Female	14	7	6	27
Self-identified race/ethnicity				
Asian, non-Latinx	2	2	1	5
Black, Latinx	0	1	0	1
Black, non-Latinx	2	0	1	3
White, Latinx	1	0	3	4
White, non-Latinx	14	7	5	26
Decline to provide race/ethnicity	1	0	0	1
Professional expertise in LD				
Yes	10	5	5	20

Characteristic	Educator (N=20)	Pediatrician (N=10)	Child/adolescent mental health clinician (N=10)	Total (N=40)
	Number	Number	Number	Number
No	10	5	5	20
Grades worked with (educators)[A]				
Elementary	7	--	--	--
Elementary and middle	5	--	--	--
Elementary, middle, and high	4	--	--	--
Middle	1	--	--	--
Middle and high	3	--	--	--
Educational setting (educators)[A]				
Charter	2	--	--	--
Private	4	--	--	--
Public	14	--	--	--
Practice setting (clinicians)[B]				
Academic	--	5	4	--
Academic and community	--	1	1	--
Community	--	4	5	--
Personal experience with LD				
Family member	8	3	5	16
Self	0	0	1	1

Characteristic	Educator (N=20)	Pediatrician (N=10)	Child/adolescent mental health clinician (N=10)	Total (N=40)
	Number	Number	Number	Number
Self and family member	0	0	1	1
Region of practice				
Northeast United States	8	7	7	22
Southern United States	4	1	2	7
Northwest United States	8	2	1	11

Abbreviations: LD, learning disability.
[A] Applies to educators and not clinicians.
[B] Applies to clinicians and not educators.

Theme 1: Areas Requiring Improved Professional Education

Under this first theme, we identified 3 sub-themes: misconceptions that may hinder detection, confounding factors that may mask LDs, and need for increasing engagement of parents or guardians in identifying LDs. **Table 3** summarizes the sub-themes alongside representative quotations.

Table 3. Theme 1: Areas Requiring Improved Professional Education

Barrier (sub-theme/code)	Representative quotation (professional)
Misconceptions that may hinder detection	
Belief that children with LDs are unintelligent, lazy, or to blame for their struggles	"[T]hey're not as smart as the person next to them." (general educator)
	"[W]e've got to get out of this idea that if someone just tried harder, that they would then miraculously do better…" (expert psychologist)
Belief that LDs must involve academic failure, behavioral challenges, work avoidance, or reports of concerns from other professionals or parents or guardians	"[B]efore a kid is identified with learning disabilities, they are failing in the classroom environment. They're failing tests. And it's consistent. They are not performing in parallel with their peers in their classroom. Another thing that shows up oftentimes with students with disabilities is behavior challenges. Because they can't catch up or keep up with the general ed classroom, they'll do things to distract." (expert educator)
Confounding factors that may mask LDs	
Confusion between struggles resulting from LDs versus other factors (e.g. growing up, lack of access to academic content, or poor attendance)	"[I]n pediatrics in general we tend to assume everybody's going to grow out of whatever kind of developmental difference they have, and that's just not the case…" (expert pediatrician)
	"[With] a certain amount of [poor] attendance … I see something that is now totally different. It's not a learning disability, that kid is just behind." (general educator)
Failure to identify LDs when there are co-occurring health issues	"[J]ust because you have one thing or three things doesn't mean you can't also have a learning disability. But at some point, it feels like you're almost layering on these labels and it's like, 'Oh God, that's a lot.'" (general pediatrician)
	"[A] lot of times I'll get a referral for an evaluation. [Psychologists] want to know, 'Well, why is she so anxious, and can you find the underlying causes, or the psychoanalytic perspective?' She can't read. That's going

	to make everybody anxious. Think about if you had to do your job, and weren't taught the skillset to do that. You'd be anxious every day of your life." (expert psychologist)
Failure to identify LDs in English language learners	"'[Y]ou have to wait a year or two [to evaluate for LDs].' Who has that time? … they have barriers that impede their learning, how are you expecting them to learn?" (general educator)
Need for increasing engagement of parents or guardians in identifying LDs	
Professionals could offer instruction on the range of presentations of LDs	"[P]arents [say], 'Oh, definitely not dyslexia. She doesn't turn her letters around…' [W]e're not very well educated as a public. It's partly [professionals] like my fault…" (expert psychologist)
	"The answer I get is, 'oh no, he's very bright, he can't have a learning disability.'" (expert pediatrician)
Professionals could explain that struggle does not equate with lack of capacity or motivation	"In about two year I grabbed [English] … my daughter have to struggle and I was thinking, 'oh my god, my daughter is dummy…' I feel so bad [now] … My daughter was diagnosed with dyslexia and I didn't know what was dyslexia [*sic*]." (general educator)
	"'[W]e just thought he wasn't as smart as his older sister…'" (expert pediatrician)
	"[S]he had lost interest in reading … she just needed a lot of help and support for this nonspecific, what is it? Laziness? And here I am. Why am I calling my daughter names?" (general psychiatrist)
Professionals could offer instruction on progress-monitoring	"[T]hey just didn't really bring it up with me because they didn't think it really had anything to do with their pediatrician and it was a school issue." (general pediatrician)

Professionals could help address misconceptions to reduce perception of stigma	"I think sometimes parents see a learning disability … as a failure on their part, and they work to correct it rather than understand and support the child. So sometimes there can be a lot of tension between parents and kids where parents might be honestly thinking that they're trying their best and doing what they need to be doing for their child. But the way that they're supporting their kid is toxic." (expert pediatrician)

Abbreviations: LD, learning disability.

Misconceptions That May Hinder Detection

Some experts and generalists across fields interviewed felt that professionals in pediatrics, mental health, and education could succumb to the belief that children struggling with undiagnosed LDs are either not intelligent or lazy or that they should be able to overcome their difficulties through hard work. Several experts and generalists from these professions interviewed seemed to share these misapprehensions. For instance, one expert pediatrician felt that everyone must expend great effort to advance, with or without an LD: "I don't have any learning disabilities that I know of. And I worked really, really hard, and it affected my social life." Those who cited the misconceptions explained that the confusion often led professionals either to blame children for the academic difficulties or to regard them as unintelligent. As a consequence, they would sometimes diminish the degree of difficulty of the workload, thereby humiliating children. In turn, students often disengage which could further hide

the LD. In addition, children may actively go to great lengths to mask their struggles to avoid stigmatization.

Certain expert and general pediatricians, mental health clinicians, and educators interviewed said they understood that children with LDs can perform at a satisfactory level, often with extraordinary effort, yet they noted that professionals in their fields may have inaccurate preconceptions in that they expect academic failure, behavioral challenges, work avoidance, or reports of concerns from other professionals or parents or guardians. In fact, a number of other interviewed expert and general professionals from these fields themselves believed those problems were the principal signs of an LD. As a result of this misconception, LDs could remain unidentified for years in students who did not evidence these overt issues — potentially "feeling a little bit of academic post-traumatic stress disorder from years of just not understanding why it is that they're learning differently than their peer group or feeling really overwhelmed [and] frustrated…" (expert educator).

Confounding Factors That May Mask LDs

Some expert and general pediatricians, mental health clinicians, and educators interviewed cited factors that may obscure LDs for professionals in these fields. For instance, they said there was a common misconception that struggles associated with LDs were merely a by-product of development and that children would outgrow them. They also encountered the misunderstanding that children eventually diagnosed with

LDs were struggling in school simply because they were not exposed to enough academic content at home. For example, an expert pediatrician said a school principal thought that one child performed poorly because "'he was watching too many cartoons.'" Another problem is that affected children could be either transient or frequently absent, which might make detection even more difficult because professionals may not be able to monitor progress over time. Furthermore, co-occurring health issues could obscure LDs. Finally, there could be challenges in the setting of cultural assimilation. In particular, it might be difficult to identify LDs among ESL students for a number of reasons. For instance, it may be hard to determine whether their continuous silence stems from language-learning or LDs.

Need For Increasing Engagement of Parents or Guardians In Identifying LDs

Many general and expert pediatricians, mental health clinicians, and educators interviewed felt that professionals could better engage parents or guardians in the effort to identify LDs. That might begin with better instruction on the range of presentations. For instance, parents or guardians may mistakenly believe that LDs manifest themselves only early in elementary school. Furthermore, some parents or guardians "never expected anything" from under-performing children because they attributed their struggles to a lack of intelligence or motivation, but professionals could explain that they may be grappling with LDs instead. Moreover, instruction on progress-monitoring might be useful. Even parents or guardians who had sufficient time outside of work did not always know how to "help [children] with their work" and observe

them. They also did not always know whom to consult to address concerns. Finally, encouraging parents or guardians to discuss their apprehensions helped uncover misconceptions and reduce both stigma and resistance to evaluation. Such reluctance can take many forms: For instance, embarrassment can be a factor, sometimes causing parents or guardians to attempt to hide children's struggles by using additional supports such as tutoring. That approach only delays diagnosis and proper treatment. Other parents or guardians fretted about career implications and worried whether LDs would "show up on their transcripts."

Theme 2: Systemic Barriers

Under this second theme, we identified 3 sub-themes: time constraints that limited professionals' ability to advocate for children and to delve into their emotional experiences, inconsistent guidelines across institutions and inconsistent perceptions of professional responsibility for detection, and confusion surrounding screening tools and lack of screening by some professionals in the absence of overt problems. **Table 4** summarizes the sub-themes alongside representative quotations.

Table 4. Theme 2: Systemic Barriers

Barrier (sub-theme/code)	Representative quotation (professional)
Time constraints that limited professionals' ability to advocate for children and to delve into their emotional experiences	
Completion of documentation required unpaid personal time	"[S]ometimes I would call the schools or write a letter, or sometimes participate in [meetings] depending on timing and my energy level, [but] that was all on my own time." (expert pediatrician)
	"[I]t's just demanding. There's no fixed days, or there are no fixed hours, right?" (expert psychologist)
Some professionals were too busy to engage with children, yet others believed conversation was invaluable	"[I]f you don't have an aid and you have a challenging classroom, you're [concerned] with one of 23, 24 [students], it could just be the shutters are blind … You can miss things … I just can't do it." (general educator)
	"[F]inally, the school picked up [the disability] and I didn't pick up on it, but it was a lesson to me. You've got to get the child maybe get her alone in the room so that you can really draw her out and figure out what's going on. But I was very embarrassed at myself for missing that because I shouldn't have missed that." (general pediatrician)
Inconsistent guidelines across institutions and inconsistent perceptions of professional responsibility for detection	
Some institutions did not prioritize identification or did not have clear policies for doing so	"[I]t's not something they tell me I need to do as a teacher … 'You need to pick out students that you think have these certain indications and refer.' It's not promoted. There's not systematic promotion of identifying learning disabilities." (expert educator)
	"[W]e don't do anything for learning disabilities within our own clinic setting." (general pediatrician)

	"Everyone who's involved in the children's life needs to be aware of what this little person is struggling with and try to support them and figure out a way to help them and give them resources they need." (general psychologist)
Some professionals simply absolved themselves of responsibility to detect, yet others accepted the responsibility	"We can say that the parents should be the one to observe or to get those things first…" (expert educator)
	"Well, [the responsibility is] mine, primarily." (general educator)
	"There's no way we're going to pick it up in the office. So I think it's a combination of parental concern for thinking something is different about how their child is learning or ultimately the school." (general pediatrician)
	"So that is a huge part of my role as a pediatrician is being able to assess … and also to address that when it's brought up as an issue from the parents and also from the teachers." (general pediatrician)
Confusion surrounding screening tools and lack of screening by some professionals in the absence of overt problems	
Some professionals did not attempt to identify LDs if children were not obviously struggling	"And sometimes when they said things were going great, I just assumed that was true … I often did wait until there were problems, I would say, or until somebody expressed something, or until I had a definite sense that this kid was not performing…" (expert pediatrician)
	"[I]f the parent doesn't have a reason to be concerned, if the teacher doesn't have a reason to be concerned and therefore the doctor has no reason to be concerned, it's never going to come up." (general pediatrician)

Abbreviations: LD, learning disability.

Time Constraints That Limited Professionals' Ability to Advocate For Children and to Delve Into Their Emotional Experiences

A number of expert and general pediatricians, mental health clinicians, and educators interviewed said they were under time pressure on a day-to-day basis, sometimes affecting their ability to detect LDs. They cited frustration because they had to utilize personal time to complete extensive documentation to support the need for evaluations or to interface with other professionals in caring for a given child. They often lacked sufficient time to spend with children to hear their perspectives. As one general pediatrician explained, "[D]uring a doctor visit for 30 minutes, we might not get to, 'How is he doing in school,' or, 'How is she doing in school?'" Several expert psychologists and educators interviewed said that more time for conversation may be necessary since they found that socio-emotional observations of children were highly predictive in identifying LDs.

Inconsistent Guidelines Across Institutions and Inconsistent Perceptions of Professional Responsibility For Detection

Expert and general pediatricians, mental health clinicians, and educators interviewed noted variability in their institutions' guidance on identifying LDs. Some said there were procedures for detection, whereas others received little direction. Several general educators reported confusion about the management of struggling children who had received targeted interventions without formal testing. Their schools had no clear policy about when to test these children, and as a result LDs might remain undiagnosed. As

one general educator explained, "[W]hen many kids if they enter [intervention] they doesn't have a way to go to another path … It never change [*sic*]."

Some of the expert and general pediatricians, mental health clinicians, and educators interviewed said they absolved themselves or their field of the responsibility to detect LDs in the first place. In contrast, others said they accepted the responsibility and believed that identification is a teamwork effort. As one general pediatrician explained, if professionals do not feel a sense of obligation, cooperation among them may be difficult as children are passed from person to person: "[T]here's this bouncing back and forth … [S]ometimes I'm not really sure if children have a learning disability, whether it's been adequately assessed…"

Confusion Surrounding Screening Tools and Lack of Screening by Some Professionals in the Absence of Overt Problems

Other than collecting data from routine academic screening and generalized monitoring of all children, there were no standardized procedures professionals regularly employed to identify either children at risk for LDs or those silently struggling with them (**Table 5**). For instance, those expert and general pediatricians, mental health clinicians, and educators interviewed, who believed that LDs must present with overt academic or behavioral challenges or reports of concerns from others, did not seek to identify in the absence of these signs. Few of them reported personal or family experience with LDs. In contrast, the rest of those interviewed, most of whom did report personal or family

experience, said they utilized additional strategies to screen regardless of performance,

both inside and outside the classroom, because LDs are "ever present." As a general

psychiatrist from this group explained, "If they're struggling in school, I always make a

recommendation for testing and if they're not, it's something that's always on my

mind…" As displayed in **Table 5**, the strategies of this group included: seeking additional

profiles they felt suggested risk, prioritizing time alone with children and utilizing their

intuition, evaluating work processes to identify evidence of greater learning effort, or

administering self-made academic assessments.

Table 5. Variation In Methods of Identification

Method of identification	Characteristics of professionals		
	Number, expertise, field	**Number reporting personal or family experience with LDs[A]**	**Total number**
I. **Considered LDs only when there were academic performance deficits, behavioral challenges, work avoidance, or concerns from other professionals or parents or guardians**	**3** general pediatricians **1** expert pediatrician **1** general psychiatrist **1** expert psychologist **5** general educators **5** expert educators	**3**	**16**

Method of identification	Characteristics of professionals		
	Number, expertise, field	Number reporting personal or family experience with LDs[A]	Total number
II. Utilized the following additional strategies to detect LDs:		15[B]	24[C]
A. *Considered LDs when observing one or more of the following additional profiles suggesting risk:*			
• Child who is described as intelligent but whose performance is not commensurate and may be thought of as lazy	**1** expert pediatrician **1** general psychiatrist **1** general educator	2	3
• Child who reports more effort to complete tasks	**1** general pediatrician **1** general psychiatrist **1** expert educator	1	3
• Child who does not like school	**1** general pediatrician **1** expert pediatrician	0	2
• Child with unexplained struggles	**1** expert psychologist **1** expert educator	1	2

Method of identification	Characteristics of professionals		
	Number, expertise, field	Number reporting personal or family experience with LDs[A]	Total number
• Child with mental health issues	**1** expert psychologist **1** general educator	2	2
• Child with difficulty following directions	**1** general pediatrician **1** expert educator	0	2
• Child with difficulty observing social cues or exhibiting social extremes, such as self-isolating	**2** general educators	1	2
• Child with working memory deficits	**1** general educator	0	1
B. *Utilized intuition as a strategy by prioritizing time alone with the child, to elicit the emotional experience with school*	**1** general pediatrician **1** expert pediatrician **1** general psychiatrist **4** expert psychologists **1** general educator **2** expert educators	8	10

Method of identification	Characteristics of professionals		
	Number, expertise, field	**Number reporting personal or family experience with LDs[A]**	**Total number**
C. *Developed informal questions to ask the child to probe work process (versus work product), such as how much time they spent on homework, did they feel they worked differently than peers, how much help they received from others*	**2** expert pediatricians **1** general psychologist **1** general psychiatrist **1** expert psychologist **1** expert educator	4	6
D. *Developed informal academic assessments:*			
• Observed child and parents or guardians interacting with books and toys	**1** general pediatrician **2** expert pediatricians	2	3
• Evaluated what the child had learned at different stages through self-made assessments	**1** general pediatrician **1** general psychiatrist **1** general educator **1** expert educator	2	4

Abbreviations: LD, learning disability.
[A] Self and/or family member with diagnosed LDs.
[B] Below totals sum to greater than 15 because professionals could employ multiple strategies.
[C] Below totals sum to greater than 24 because professionals could employ multiple strategies.

Several factors could have contributed to lack of standardization. First, many general pediatricians, mental health clinicians, and educators interviewed said they received either inadequate or even negligible training on LDs. Some turned to the internet or expert colleagues, capitalized on their experiences as parents, or considered additional certifications. Others admitted that they over-diagnosed attention-deficit/hyperactivity disorder (ADHD), a related condition they felt was easier to identify using the Vanderbilt assessment tool, which follows the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*).[21] On the other hand, they said LDs are less visible and that there are no clear criteria for recognizing those who should be formally tested. As one general pediatrician explained, "I can look at the *DSM* and say, 'Okay, ADHD or no ADHD.'" Several expert pediatricians said that expert and general pediatricians alike may grapple with this issue. As one expert pediatrician said, "[T]here's not an easy, pull-off-the-rack, one-or-two-minutes screen for learning disabilities. You have to know what you're looking for, even as a developmental behavioral pediatrician." Several expert pediatricians and educators said they had trialed brief formal aptitude tests for screening, but found that they were unhelpful in part because they could lead to overestimation of children's abilities. Moreover, personal or family experience with LDs could have enhanced the motivation to consider LDs in all children regardless of performance (**Table 6**).

Table 6. Influence of Personal or Family Experience with Learning Disabilities on Perspectives of Those who Screened

Insight	Representative quotation (professional)	Experience with LD
Understanding that LDs were often hidden	"I always try not to make assumptions about kids because I think a lot of the times students with learning disabilities get the reputation that they're lazy, and it's the complete opposite. They have to work so much harder to do anything that everyone else can do. So I think always just keeping that in the back of my mind, just how hard my sister has had to work to get what she has." (expert educator)	Family member
	"But then as she went into college and she started getting really challenged much more academically, then you started seeing the symptom … she just needed to work 10 times more." (general psychiatrist)	Family member
Understanding that LDs could afflict any child	"I wish I could shut it off sometimes … I can just look at them and it's like my super disability powers connect with their super disability powers without us talking. So there's this energy of, 'I get you. Is it this?' And they're like, 'Oh my God, you get it.'" (expert psychologist)	Self and family member
	"…I never had a learning disability and things always came easy to me and [my niece with a reading disability] just worked her tail off … She's at the top, she went to the top college, the top medical school, top residency so there you have it…" (general psychiatrist)	Family member

Insight	Representative quotation (professional)	Experience with LD
Understanding that test scores did not always explain experience	"[My son] was kind of low average. And [teachers were] like, 'Do you think that's accurate? I mean look at these scores, they're kind of all over the place.' But they were focused on the number, and I'm like, 'I don't think you can focus on the final number. I think you got to look at the sub scores, and I think you have to look at where he is.' … [this experience has] been kind of that guiding light about advocacy. And it's kind of rearranged my thinking around how the education system really treats kids…" (expert pediatrician)	Family member

Abbreviations: LD, learning disability.

Discussion

To our knowledge, this study is the first to identify barriers to detecting LDs in school-aged children from the perspective of front-line pediatric clinicians and educators, and the similarity of their views on the nature or extent of those barriers was enlightening. In turn, our results illuminated opportunities for improvement in early intervention, in particular for pediatric practice.

A key finding was that professionals disagreed about the degree of their responsibility to detect LDs in the first place. This was striking because clinicians, especially general pediatricians who interface regularly with families, are thought to serve a central role as

key advocates for facilitating assessment in conjunction with schools.[3,16] Although the

American Academy of Pediatrics (AAP) provides recommendations to integrate

developmental monitoring into practice (e.g. [16]), pediatricians might not envision a role

for themselves in the effort to detect LDs. One survey demonstrated that 91% believed

they should be responsible for identifying ADHD, versus only 59% for LDs.[22] Surveys

from 2004 versus 2013 among exclusively general pediatricians exhibited no increase in

the percentage who self-reported screening for learning problems, versus an increase of

nearly 9% for ADHD.[23] In the last few decades the estimated prevalence of ADHD, but

not LDs, has increased.[6,24,25] Clinicians may have paid greater attention to ADHD because

of continuing medical education, availability of pharmacological treatments,

development of practice guidelines from the AAP and the Society for Developmental

and Behavioral Pediatrics,[25-27] and access to the Vanderbilt assessment tool.[21]

Our study showed that there may be opportunities for augmented professional

education on LDs, as there have been for ADHD, which could especially benefit general

pediatricians, mental health clinicians, and educators, many of whom felt under-trained.

Previous research suggested that educators are unprepared with regard to LDs in part

due to ineffective instruction[28] and that many clinicians lack sufficient comfort and

preparation with LDs but not with ADHD.[29-31] Even pediatricians who had received

greater developmental and behavioral training relative to their peers were no more

likely to screen for LDs[32] — implying that their instruction may be inadequate. We

added to this literature with suggestions for potential areas of focus for future

educational efforts, such as instruction on misconceptions and confounding factors that could interfere with detection, and training with regard to signs of LDs. An additional topic could be better engagement of parents or guardians. This could involve addressing their misunderstandings we identified, some of which have been reported (e.g. the assumption that struggling children are unintelligent or unmotivated),[2,3] and teaching them to detect key concerns, which may inform risk prediction.[33]

Our results highlighted several other systemic barriers to detection. Interviews revealed that some institutions did not provide professionals with guidance regarding processes for identification of LDs nor did they emphasize the importance of doing so. Outside of routine monitoring of all children, approaches to screening and identification were not standardized and there was confusion surrounding reliable screening tools. To our knowledge, there are no evidence-based clinical practice guidelines in use in the United States designed to screen at-risk school-aged children specifically for LDs or to determine who should be referred for formal evaluation. An AAP book addresses identification,[34] however clinicians have found the recommendations difficult to institute in practice and they cite the dearth of evidence-based support in the book.[35] There is only one AAP clinical report or policy statement on LDs and academic problems that reviews brief screeners feasible for generalist use, and it cites only one screener that is psychometrically assessed and specific to LDs (The Einstein Assessment of School-Related Skills).[3] Although new laws concerning dyslexia mandate screening, identification did not improve in the years following enactment, in part because

educators may also face confusion regarding the nature of the process.[8] Expanded

screening tools and formal recommendations could catalyze greater involvement of

professionals in identification, particularly for children without overt problems, might

encourage enhanced standardization of processes across institutions, and improve

efficiency given the issue of time constraints. Guidelines for ADHD may be a fruitful

example to follow because they target both clinicians and collaborative professionals,

such as educators.[27]

Enhancement of cross-professional partnerships in other ways may further address

knowledge and systemic barriers we identified. For instance, when mental health

providers are integrated into pediatric primary care, youth behavioral health outcomes

improve.[36] Those collaborations could have potential to augment care for children with

LDs. They might have multiple benefits: increasing physicians' understanding of

behavioral health conditions, alleviating time pressure, enhancing psychoeducation for

parents or guardians, and helping them advocate for children in schools.[37]

Challenges and Limitations

We encountered several challenges over the course of this research. For instance,

interviews could precipitate discussion of sensitive topics, which professionals may not

have always felt comfortable addressing in a recorded interview. Similarly, they could

have offered socially desirable answers to interview questions for fear of highlighting

their own shortcomings. To address these related challenges we reassured professionals

of confidentiality, specifically that 1) data were stored securely and accessible only to the research team 2) research staff were conducting interviews from private locations and 3) transcripts were de-identified. Moreover, incomplete reporting of essential features of qualitative research studies may reduce transparency and lead to difficulties with evaluation of the research; we addressed this challenge by reporting our research in adherence with established standards (the SRQR), as indicated in our Methods.[17] Finally, bias may be a challenge in qualitative analysis if one individual performs all coding, thus we utilized multiple methods from the literature to reduce bias in this regard.[18] As indicated in our Methods, two members of the study team (the student author and L.B.) independently coded all interview transcripts and all investigators held regular meetings for triangulation.

In addition, this study has limitations. The qualitative research design aimed to be descriptive, not to make causal claims regarding associations between barriers and detection of LDs. Moreover, the findings are not generalizable beyond the experiences of our sample, and several additional limitations pertain to its composition: Further research would be necessary to determine if results are generalizable to other professionals. For instance, 16 professionals reported family experience with LDs. Although greater than half of the sample did not report this experience, a study encompassing fewer professionals reporting LDs in their families as a proportion of the sample might yield different themes. In addition, a majority of pediatricians and mental health clinicians hailed from the Northeast United States. Though we did not observe

significant differences in responses across geographic areas, our themes may be less reflective of experiences of professionals from other regions. Furthermore, our overall percentages of Black and Latinx professionals are above census estimates from physicians,[38] mental health providers,[39] and educators,[7] however an even more diverse sample could yield different themes.

Finally, in terms of limitations, we interviewed clinicians and educators, some of whom were parents, but future research should incorporate additional perspectives from other professionals and non-professional parents or guardians who may also be involved in identification of LDs.

Future Directions

Our study illuminated several opportunities for further research in this field. First and foremost, researchers could perform similar qualitative studies with different compositions of professionals. As noted in the Limitations, our findings are not generalizable beyond the experiences of our sample and further research would be necessary to determine whether our results may apply to other groups. For instance, different themes could emerge from samples composed of fewer professionals reporting LDs in their families, those hailing from other geographic regions beyond those represented in our study, or a greater percentage of professionals self-identifying as racial or ethnic minorities.

Moreover, the areas of focus for future educational efforts that we identified could form the basis of related quantitative studies. For example, we could survey a larger sample size of professionals regarding their perceived deficits in knowledge in the area of LD identification, and subsequently work toward development of novel educational programs to be pilot tested among child-facing trainees, in particular clinicians. Perhaps, such efforts could improve comfort with recognition of LDs and/or enhance earlier detection.

Finally, our analysis implied that professionals might benefit from expanded screening tools and suggested a specific line of questioning that could be investigated in the development of future instruments. Some professionals stated that taking a child's perspective into account and probing the work process yielded insights, above and beyond measurement of academic skills. Though The Behavior Assessment System for Children is a rating instrument that features a few questions about perspective and process, it was not designed specifically for LDs.[40] Informed by our qualitative data, we developed a draft list of potential questions that child-facing professionals could employ, which will be tested in future quantitative studies for utility in identifying children who may benefit from formal evaluation (**Table 7**). To begin the process, we would perform a confirmatory expert review, during which we would invite experts trained in the development of psychometric instruments and expert clinicians and educators to assist with writing of the questions prior to pilot testing.[41]

Table 7. Identification Challenges That Could Inform Questions to Ask Children

Relevant sub-theme	Identification challenge	Potential questions based on the qualitative data that could be used to assess children
Time constraints that limited professionals' ability to advocate for children and to delve into their emotional experiences	Some professionals believed that asking children about their feelings related to school could be informative for detection of struggle but not all professionals devoted time to doing so	Professionals could ask children about their socioemotional experience and perceptions of academic challenges: • Many children struggle with school. Do you think you are more stressed by schoolwork than your peers? • Do you feel that certain classes are harder for you than others? • Do you feel stressed when writing papers? • Does the thought of starting a project make you feel stressed? • Do you worry about how you might sound when you read out loud? • Do you feel that you have a hard time finding the right word to say? • Do you avoid speaking up in groups because you worry about looking dumb? • Do you find it hard to enjoy reading because it is difficult? • Do you feel it takes you a long time to get through a chapter book? • Do you feel that you need to reread things multiple times to understand them?

Relevant sub-theme	Identification challenge	Potential questions based on the qualitative data that could be used to assess children
		- Do you prefer graphic novels over books because they are easy for you to understand? - Do you feel that you have trouble summarizing? - Do you feel that you have trouble understanding what other people say to you? - Do you feel that you have trouble remembering what other people say to you?
Confusion surrounding screening tools and lack of screening by some professionals in the absence of overt problems	Children without academic performance deficits or behavioral challenges may escape detection	Professionals could ask children about the amount of effort they expend to complete their work: - Do you feel that your brain works differently relative to your peers? - Do you feel that things are harder for you than for your peers? - Do you feel that you take longer to do schoolwork than your peers? - Do you feel that you need more time to study for tests than your peers? - Do you feel that you have to put in more effort than your peers to ensure that grades show what you know? - Do you often need help from others to get your schoolwork done?

Relevant sub-theme	Identification challenge	Potential questions based on the qualitative data that could be used to assess children
	There may be evidence of LDs in experiences outside of school, but looking only for issues in the setting of academics may mask them	Professionals could ask children about difficulties in settings outside of school: • Do you feel that you take longer to do things other than school relative to your peers? • Do you avoid spending time with peers or family because you worry about looking dumb? • Do you feel that you have trouble recounting the plot of movies? • Do you feel that you have trouble keeping track of characters in movies?

Abbreviations: LD, learning disability.

Conclusion

We identified barriers affecting front-line clinicians and educators in the detection and the timely remediation of LDs in school-aged children. Our results suggested that augmented education for professionals in these fields, coupled with greater evidence-based and standardized institutional guidelines, might be warranted. Future quantitative research could investigate whether these efforts could improve the quality of child health care with earlier detection, potentially by increasing efficiency in the face of time pressures, and by fostering greater collective professional responsibility to identify LDs in all children routinely.

Dissemination

The student author first-authored two abstracts stemming from distinct analyses from this project, and she presented those data in poster form at The American Psychiatric Association Annual Meeting (2022) and The American Academy of Pediatrics National Conference & Exhibition (2022). Moreover, the student author also submitted this work as a first-author manuscript to *Academic Pediatrics* and the journal has accepted the paper for publication.[1]

Moreover, recognizing that medical students could either suffer from undiagnosed learning disabilities or experience shame surrounding disclosure of known disabilities, the student author delivered an oral presentation (2022) to students currently on clerkships at the Yale School of Medicine. The student author discussed the possibility of overlooked learning disabilities — sharing research from this thesis — and attempted to reduce perceptions of stigma surrounding disclosure.

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[1] This thesis was published in *Academic Pediatrics*, Lauren A. Stone, Laelia Benoit, Andrés Martin, Janet Hafler, Barriers to Identifying Learning Disabilities: A Qualitative Study of Clinicians and Educators, Copyright Elsevier and Academic Pediatric Association (2022). DOI: https://doi.org/10.1016/j.acap.2022.12.008

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