# Pediatric Early Analysis of Risk for Literacy Problems: Draft (PEARL-D)

Eric Q. Tridas <sup>1</sup> , Yaacov Petscher <sup>2</sup>	, Christopher Stanley <sup>2</sup> , Jose	ph Sanfilippo³, and Nadine Gaab⁴
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<u>Disclaimer</u>: This is a newly created checklist for use in a pediatric medical practice. The authors are currently in the process of further developing and refining the scoring criteria. We strongly encourage the clinical and scientific communities to provide feedback in order to help us with the further development of the checklist and its validation.

## Correspondence

Nadine Gaab, PhD
Associate Professor of Education
Harvard Graduate School of Education
Harvard University
Larsen Hall (Office 504)
14 Appian Way, Cambridge, MA 02138
nadine gaab@gse.harvard.edu
www.gaablab.com

<sup>&</sup>lt;sup>2</sup>Florida Center for Reading Research, Florida State University, Tallahassee, Florida

<sup>&</sup>lt;sup>3</sup>School of Medicine, Faculty of Health Sciences, Queen's University, Kingston, Ontario

<sup>&</sup>lt;sup>4</sup>Harvard Graduate School of Education, Cambridge, Massachusetts

#### Introduction

The identification of children at risk for reading difficulty in the pediatric primary care setting represents an opportunity to address a crucial but often-overlooked social determinant of health. The development of literacy in childhood is associated not only with academic success, but also with longer-term economic and vocational success as well as physical and mental health outcomes. The While reading difficulties may be a consequence of socioeconomic disadvantage or a lack of opportunity, 5-10% of children have a specific learning disorder with impairment in reading (known more commonly as developmental dyslexia as in previous editions of the DSM) which has a known neurobiological basis. Regardless of etiology, however, children who struggle with reading have been shown to be subjected to the same adverse health consequences and respond equally well to the same interventions. 11,12

Besides the risk of academic failure, of most immediate concern to the physician are the consistent bidirectional associations between learning disorders and mood and anxiety disorders<sup>13</sup>, behavioral disorders<sup>14</sup>, and comorbid learning disorders<sup>15</sup> among children. As a child's first point of routine contact for developmental surveillance prior to and upon entering the school system, pediatricians and other child-facing physicians are uniquely situated to identify risk for reading difficulty, refer for further evaluation when necessary, and advocate for expeditious intervention and ongoing supports for the child.<sup>16</sup>

Developmental research has demonstrated that early identification of learning disorders and subsequent intervention have a profoundly positive effect on outcomes. <sup>17,18</sup> As many as 92% of at-risk beginning readers who receive appropriate intervention go on to achieve expected reading ability. <sup>19</sup> Unfortunately, however, children with language-based learning disorders are not typically identified until well into elementary school or later <sup>18</sup>, predisposing them to academic failure, psychosocial stressors, and psychiatric sequelae. <sup>20,21</sup> It is thus imperative that our approach to reading difficulty be a proactive one, rather than a reactive one. A proactive approach demands a systematic method by which to identify children at risk.

Of course, pediatricians and other primary care providers are well-acquainted with the use of screening tools as a means of secondary prevention, as well as with the long-established and widely accepted Wilson and Jungner criteria<sup>22</sup> which stipulate the requisite components of an appropriate screening regimen in clinical medicine. While short, quick, validated screening tools have been developed and implemented for other neurodevelopmental and mental health diagnoses (e.g., depression<sup>23</sup> and ADHD<sup>24</sup>), no such tool yet exists for reading disabilities, despite the fact that a screening tool for reading disabilities would certainly satisfy the Wilson and Jungner criteria. Children can be screened for reading disabilities feasibly through a consideration of their personal and family history and through a short clinical assessment of cognitive-linguistic precursors that are known to be associated with subsequent reading difficulty.<sup>25,26</sup> These precursors can be identified during a latent pre-literacy stage, when interventions are more likely to be protective against subsequent reading difficulties.<sup>18,27</sup> The economic cost of screening as well as the risk to patients are both negligible, especially when considered against the significant personal and economic burden of illiteracy. While the means of management of reading disorders is ultimately outside the scope of a physician's practice, physicians are nonetheless crucial in the process by which these disabilities are

identified, through the facilitation of diagnostic testing and intervention with appropriate referrals to allied health and the education system.

To that end, we have developed a draft of the Pediatric Early Analysis of Risk for Literacy Problems (PEARL-D), which is a brief checklist which requires two-to-three minutes to administer and is designed to assess early markers of reading disabilities/dyslexia in children from pre-K to second grade. It is important to note that this tool is not yet a scientifically validated screening instrument (nor is it a diagnostic instrument), but it is an evidence-based checklist designed in the interest of practical rigor for clinicians. The goal of the checklist is to provide a formative assessment that will identify children at risk for these challenges who require further investigation in the context of a busy pediatric practice. As the PEARL-D is not yet validated or normed, our goal with this first version of the tool was to optimize the instrument's sensitivity with conservative thresholds for follow-up and referral as indicated in the preliminary scoring tables.

The PEARL-D consists of two sections: a history and brief assessment. There are five different forms of the assessment based on the child's educational experience (from no early childhood educational experience to the second grade). The first section of the instrument is the history, which focuses on risk factors such as family history, developmental language delay and phonemic awareness challenges. The second section, which is a brief clinical assessment, consists of five-to-eight items (depending on the child's educational experience) that briefly evaluate literacy precursors, including phonemic awareness (rhyming, letter identification, phoneme matching, sound/symbol association, sound/syllable deletion, phoneme blending, nonsense word decoding) and working memory. The PEARL-D is not a validated instrument, and normative scores are not yet available. We are sharing this first version of the PEARL-D and invite researchers and clinicians to review it, use it, and provide comments on it. Further development of the tool will involve validation and the authors are seeking clinical partners for this next step (please email <a href="mailto:gaablab@gse.harvard.edu">gaablab@gse.harvard.edu</a> if interested). For this phase we encourage researchers to share normative data with us. Once these findings are available, they will be incorporated and shared with the research and clinical communities.

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#### Instructions for Administration of the PEARL-D

### Selecting a Form

The checklist forms are based on the student's educational experience to ensure that the instrument items match the expected exposure to instruction. There are five different checklist forms:

Form A: 4 Years Old with No Formal Schooling

Form B: Mid-Late Pre-Kindergarten to Early Kindergarten

Form C: Mid-Late Kindergarten to Early 1st Grade Form D: Mid-Late 1st Grade to Entering 2nd Grade

Form E: Mid-Late 2nd Grade

#### Scoring

Preliminary scoring instructions are described below. Definitive cut-off scores have not been ascertained as more clinical experience with the instrument is needed. We encourage other researchers who may wish to develop normative data to share their findings.

To determine a patient's score, sum the number of "yes" and "incorrect" responses from the history and brief clinical assessment sections; this is the number in the box at the bottom of each Form. This number is the total score and can be compared to the rows in the respective table below to offer a corresponding "level of concern" and "potential action." Please note percentages are approximate and attempt to reflect this scale:

Green: < 20% (No concern)
Yellow: 21-60% (Mild concern)
Orange: 60-80% (Moderate concern)
Red: 80+ % (Significant concern)

Form A: 4 Years Old, No Formal Schooling (TOTAL = 17)

History (7 items) and brief clinical assessment (10 items)

Total Score	Level of Concern	Potential Action
0-3 (< 18%)	Green - None	Re-check next well visit
4 – 10 (23 – 59%)	Yellow - Mild	Re-check in 6 months
11 – 13 (65 – 76%)	Orange - Moderate	Re-check in 3 months
14 – 17 (> 82%)	Red - Significant	Refer

### Form B: Mid-Late Pre-Kindergarten to Early Kindergarten (TOTAL = 22)

History (10 items) and brief clinical assessment (12 items)

Total Score	Level of Concern	Potential Action
0 – 4 (< 18%)	Green - None	Re-check next well visit
5- 12 (22 - 55%)	Yellow - Mild	Re-check in 6 months
13 – 17 (59 – 77%)	Orange - Moderate	Re-check in 3 months
18 – 22 (> 82%)	Red - Significant	Refer

## Form C: Mid-Late Kindergarten to Early 1st Grade (TOTAL = 34)

History (13 items) and brief clinical assessment (21 items)

Total Score	Level of Concern	Potential Action
0 – 6 (< 18%)	Green - None Re-check next well vi	
7 – 19 (21 – 56%)	Yellow - Mild Re-check in 6 months	
20 – 26 (59 – 76%)	Orange - Moderate	Re-check in 3 months
27 – 34 (> 79%)	Red - Significant	Refer

## Form D: Mid-Late 1<sup>st</sup> Grade to Early 2<sup>nd</sup> Grade (TOTAL = 22)

History (10 items) and brief clinical assessment (12 items)

Total Score	Level of Concern	Potential Action
0 – 4 (< 18%)	Green - None	Re-check next well visit
5-12 (22 - 55%)	Yellow - Mild	Re-check in 6 months
13 – 17 (59 – 77%)	Orange - Moderate	Re-check in 3 months
18 – 22 (> 82%)	Red - Significant	Refer

## Form E: Mid-Late 2<sup>nd</sup> Grade (TOTAL = 22)

History (10 items) and brief clinical assessment (12 items)

Total Score	Level of Concern	Potential Action
0 – 4 (< 18%)	Green - None	Re-check next well visit
5-12 (22 - 55%)	Yellow - Mild	Re-check in 6 months
13 – 17 (59 – 77%)	Orange - Moderate	Re-check in 3 months
18 – 22 (> 82%)	Red - Significant	Refer

# PEARL-D Form A: 4 Years Old: No Formal Schooling

HIS	STORY STORY	NO	YES
1.	Has anyone in your family had trouble with reading, or learning to read or spell?		
2.	Has anyone in your family been diagnosed with dyslexia?		
3.	Did your child		
	<ul><li>speak less than 50 words at 2 years of age in any language?</li></ul>		
	<ul> <li>have no two-word combinations at 2 years of age (ex. go car, want cookie)?</li> </ul>		
	<ul> <li>ever have a diagnosis of a language or articulation (speech) delay?</li> </ul>		
4.	Does your child speak another language at home?		
5.	Do you have any concern about how your child speaks or communicates?		
<u>BR</u>	IEF CLINICAL ASSESSMENT	CORRECT	INCORRECT
1.	Letter naming (use following letters for items below)		
	Tell me the name of these letters:		
	• C		
	• D	H	
	• A	H	H
	<ul> <li>B (or first letter in their name)</li> </ul>	H	H
2.	Rhyming		
	I am going to say 3 words and I want you to tell me which 2 sound most alike. For		
	example if I say 'tab','big', and 'dig', 'big' and 'dig' are the two words that sound		
	alike.		
	• cat, rat, <i>log</i>	H	H
2	• pot, <i>men</i> , rot		
3.	Syllable deletion		
	I am going to tell you a word and I want you to take part of the word away to make a new word. For example, I say the word FIRETRUCK. Now I say FIRETRUCK		
	but I don't say FIRE. What is left is the word TRUCK.		
	<ul> <li>Say the word ICECREAM. Now say it but don't say ICE. What word is left? (cream)</li> </ul>		
	<ul> <li>Say the word BASEBALL. Now say it but don't say BASE. What word is left? (ball)</li> </ul>		
		NO	YES
4.	Hearing screening concern?		
5.	Clinician concern?		
		TOTAL YES/	INCORRECT:

# PEARL-D Form B: Mid-Late Pre-Kindergarten to Early Kindergarten

HIS	<u>FORY</u>	NO	YES
1.	Has anyone in your family had trouble with reading, or learning to read or spell?		
2.	Has anyone in your family been diagnosed with dyslexia?		
3.	Did your child		
	<ul><li>speak less than 50 words at 2 years of age in any language?</li></ul>		
	<ul><li>have no two-word combinations at 2 years of age (ex. go car, want cookie)?</li></ul>		
	<ul> <li>ever have a diagnosis of a language or articulation (speech) delay?</li> </ul>		
4.	Does your child speak another language at home?		
5.	Do you have any concern about how your child speaks or communicates?		
6.	Does your child have difficulty identifying rhyming words (ex. run/fun)?		
7.	Is your child unable to name any letters?		
8.	Has anyone expressed concerns about how your child is learning letters and their sounds?		
BRII	EF CLINICAL ASSESSMENT	CORRECT	INCORRECT
1.	Letter recognition (use following letters for items below)	COMMECT	IIICOMILE
	Tell me the names of these letters:		
	A		
	F	H	
	M	H	H
	P	H	H
2.	Rhyming		
	I am going to say 3 words and I want you to tell me which 2 sound most alike. For example f I say 'tab', 'big', and 'dig', 'big' and 'dig' are the two words that sound alike.		
	• cat, rat, <i>log</i>		
	• pot, <i>men</i> , rot	H	$\vdash$
3.	Syllable deletion		
	I am going to tell you a word and I want you to take part of the word away to make		
	a new word. For example, I say the word FIRETRUCK. Now I say FIRETRUCK, but I		
	don't say FIRE. What is left is the word TRUCK.		
	<ul> <li>Say the word RAINBOW. Now say RAINBOW but don't say RAIN. What word is left? (bow)</li> </ul>		
	• Say the word <i>CARTOON</i> . Now say <i>CARTOON</i> but don't say <i>CAR</i> . What word is		
	left? (toon)		
4.	Multistep directions		
	<ul> <li>Point to your nose then tap your knee.</li> </ul>		
	<ul> <li>Touch your ear two times, then point to your elbow.</li> </ul>		
		NO	YES
5.	Hearing screening concern?		
6.	Past/current clinician concern?		
		TOTAL YES/	NCORRECT:

# PEARL-D Form C: Mid-Late Kindergarten to Early 1st Grade

HIS	STORY STORY	NO	YES
1.	Has anyone in your family had trouble with reading, or learning to read or spell?		
2.	Has anyone in your family been diagnosed with dyslexia?		
3.	Did your child		
	<ul><li>speak less than 50 words at 2 years of age in any language?</li></ul>		
	<ul> <li>have no two-word combinations at 2 years of age (ex., go car, want cookie)?</li> </ul>		
	<ul> <li>ever have a diagnosis of a language or articulation (speech) delay?</li> </ul>	Ī	
4.	Does your child speak another language at home?	Ī	
5.	Do you have any concern about how your child speaks or communicates?	Ħ	一
6.	Does your child have difficulty		
	<ul><li>identifying rhyming words (ex. run/fun)?</li></ul>		
	<ul> <li>recognizing most of the English alphabet letters and their sounds?</li> </ul>	H	H
	<ul> <li>sounding out simple words while reading (ex., mom, cat, hot)?</li> </ul>	H	H
	<ul><li>spelling simple words (ex., hot, dad, cub, etc.)?</li></ul>	H	H
	<ul> <li>retelling stories or events accurately?</li> </ul>	H	H
7.	•	H	H
	, ,		Ш
BR	IEF CLINICAL ASSESSMENT	CORRECT	INCORRECT
1.	Letter/Sound Naming: Tell me the names and the sounds of these letters:		
	S		
	A	H	H
	T	H	H
	P	H	H
	0	H	H
	M	H	
	G	H	H
2.	Word Parts		
	Sounds: I will say 3 words and I want you to tell me which 2 words start with the		
	same sound. For example, if I say cat, luck, and coat, cat and coat start with the		
	same sound. Now, I want you to tell me which 2 words start with the same sound:		
	<ul> <li>bed, mouse, book (bed, book)</li> </ul>	H	님
	• cape, pain, pen (pain, pen)		
	Phoneme Deletion: I am going to tell you a word and I want you to take part of the		
	word away to make a new word. For example, if I say the word MOTEL and I take		
	MO out I am left with the word TEL		
	<ul> <li>Say the word feet. Now say feet but don't say /f/. (eat)</li> </ul>		
	<ul> <li>Say the word like. Now say like but don't say /k/. (lie)</li> </ul>		
	Phoneme segmentation: I am going to say a word. Tell me each sound in the word.		
	For example, if I say "dog", you would say /d/ /o/ /g/. Now say each sound in:		
	• to = /t//oo/		
	<ul><li>pot = /p//o//t/</li></ul>		
	• fish = /f/ /i/ /sh/		
	Non-word Reading: I want you to read these made-up words.	_	
	• tep = /t//e//p/		
	• lat = /l//a//t/		
	<ul><li>nog = /n//o//g/</li></ul>		

3.	Multistep directions: I am going to give you some instructions for you to follow, but I want you to wait until I have finished saying them before you start.	CORRECT	INCORRECT
	<ul> <li>Point to your nose then tap your knee twice.</li> <li>Touch your ear two times, then point to you elbow.</li> </ul>		
4. 5.	Hearing screening concern? Past/current clinician concern?	<b>NO</b>	YES
		TOTAL Y	ES/INCORRECT:

# PEARL-D Form D: Mid-Late 1st Grade to Entering 2nd Grade

<u>HIS</u>	STORY  Has anyone in your family had trouble with reading, or learning to read or spell?	NO	YES
2.	Has anyone in your family been diagnosed with dyslexia?		
3.	Did your child	_	_
	<ul><li>speak less than 50 words at 2 years of age in any language?</li></ul>		
	<ul> <li>have no two-word combinations at 2 years of age (ex., go car, want cookie)?</li> </ul>		
	<ul><li>ever have a diagnosis of a language or articulation (speech) delay?</li></ul>		
5.	Does your child speak or read another language at home?		
4.	Do you have any concern about how your child speaks or communicates?		
5.	Do you have any concern about the way your child reads and spells?		
6.	Can your child have difficulty retelling stories or events accurately?		
7.	Has anyone expressed concerns about the way he or she speaks or learns?		
BR	IEF CLINICAL ASSESSMENT	CORRECT	INCORRECT
1.	Reading Single Words		
	I want you to read these words.	_	
	• fine		
	• turn		
	• stove		
	• bait		
2.	Reading Nonsense Words		
	I want you to read these made-up words.		
	• <i>tope</i> (3) /t//oe//p/		
	• glish (4) /g/ /l/ /i/ /sh/		
	• <i>creb</i> (4) /c/ /r/ /e/ /b/		
	• <i>sprad</i> (5) /s/ /p/ /r/ /a/ /d/		
3.	Multistep directions: I am going to give you some instructions for you to follow,		
	but I want you to wait until I have finished saying them before you start.		
	Point to your nose after you tap your knee twice.	H	
	Touch your ear two times, then point to you elbow.		
		NO	YES
4.	Hearing screening concern?		
5.	Past/current clinician concern?		
		TOTAL YE	S/INCORRECT:

# PEARL-D Form E: Mid-Late 2<sup>nd</sup> Grade

HIS	STORY STORY	NO	YES
1. 2.	Has anyone in your family had trouble with reading, or learning to read or spell? Has anyone in your family been diagnosed with dyslexia?		
<ol> <li>4.</li> </ol>	<ul> <li>speak less than 50 words at 2 years of age in any language?</li> <li>have no two-word combinations at 2 years of age (ex., go car, want cookie)?</li> <li>ever have a diagnosis of a language or articulation (speech) delay?</li> <li>Does your child speak or read in another language at home?</li> </ul>		
5. 6.	Do you have any concern about how your child speaks or communicates?  Do you have any concern about the way your child reads and spells?		
7. 8.	Does your child have difficulty retelling stories or events accurately?  Has anyone expressed concerns about the way he or she speaks or learns?		
BR	IEF CLINICAL ASSESSMENT	CORRECT	INCORRECT
1.	Reading Single Words  I want you to read these words.  tunnel athlete pending thankful		
2.	Reading Nonsense Words  I want you to read these made-up words.  • shobe (3) /sh/ /oe/ /b/  • twaze (4) /t/ /w/ /ae/ /z/  • croast (5) /c/ /r/ /oe/ /s/ /t/  • flepping (6) /f/ /l/ /e/ /p/ /i/ /ng/		
3.	Multistep directions: I am going to give you some instructions for you to follow, but and I want you to wait until I have finished saying them before you start.  • Before you point to your nose tap your elbow 3 times.  • After you touch your head two times, stick out your tongue and then point to		
4. 5.	you elbow.  Hearing Screening Past/Current Clinician Concern	<b>NO</b>	YES
		TOTAL Y	ES/INCORRECT: