### WHAT DO YOU THINK THESE MEAN? SCAN IT IN!



1. A plethora of individuals with expertise in culinary techniques vitiate the potable concoction produced by steeping certain comestibles.

2. Neophyte's serendipity





# It's Not Them, It's Us: Health Literacy in EHDI

Maternal and Child Health Bureau | National EHDI Conference | March 18, 2024

### **Presenters**

MDH Office for Children and Youth with Specific Health Care Needs (OCYSHCN)

Tameka Thomas, MPH Program Manager Early Hearing Detection and Intervention Noadya Legrand Coordinator Children and Youth with Specific Health Care Needs



### **Activity:** Answers

- 1. A plethora of individuals with expertise in culinary techniques vitiate the potable concoction produced by steeping certain comestibles.
  - a. Too many cooks spoil the stew.

- 1. Neophyte's serendipity.
  - a. Beginners luck.



### **Objectives:**

Participants will be able to:

- 1. Define health literacy
- 2. Identify areas in their own work where they could assess health literacy
- 3. Apply one or more health literacy assessment tools to their outreach materials



## What is Health Literacy?

Several Definitions, but guidance is in accordance with "Healthy People 2030"

Originating from the Office of Disease Prevention and Health Promotion in 1979, Healthy People is a comprehensive plan of evidence based practices that identifies areas of improvement for the overall betterment of public health for individuals, organizations and communities.

Health Literacy - Healthy People 2030, Health.gov, n.d.



## What is Health Literacy?

Healthy People 2030 categorizes Health Literacy into two subsections: Personal Health Literacy and Organizational Health Literacy.

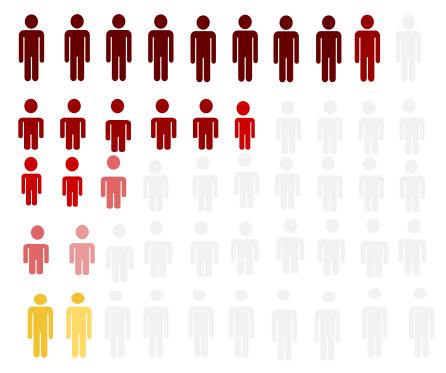
**Personal Health Literacy:** is the degree to which **individuals** have the ability to **find**, **understand**, and **use** information and services to inform health-related decisions and actions for **themselves** and **others**.



**Organizational Health Literacy:** is the degree to which **organizations** equitably enable individuals to **find**, **understand**, and **use** information and services to inform health-related decisions and actions for **themselves** and **others**.



## Health Literacy in the U.S., 2022



Total % of adults living in the US that have health literacy inadequate to navigate the healthcare system and promote their well-being **Below Intermediate** 55%

Proficiency

22% **Basic Proficiency** 

**Below Basic Proficiency** 14%



88%

**Proficient Health Literacy** 

laryland DEPARTMENT OF HEALTH

https://milkeninstitute.org/sites/default/files/2022-05/Health Literacy United States Final Report.pdf

### Drumroll...

### "It's me. Hi! I'm the problem, it's me"

-Anonymous



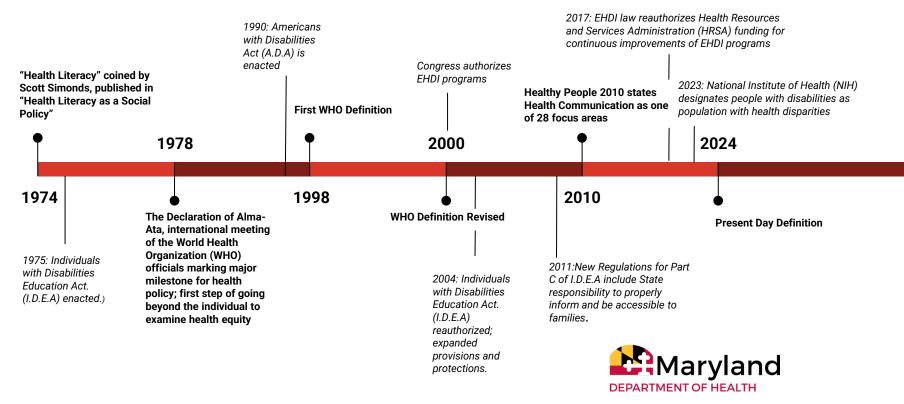
### **EHDI Accountability**

"Public health and social service organizations are responsible for promoting health literacy and providing equitably accessed services and information."

-Trezona et al., 2017



### Why It's Important: Health Literacy Version Health Equity



## Why It's Important

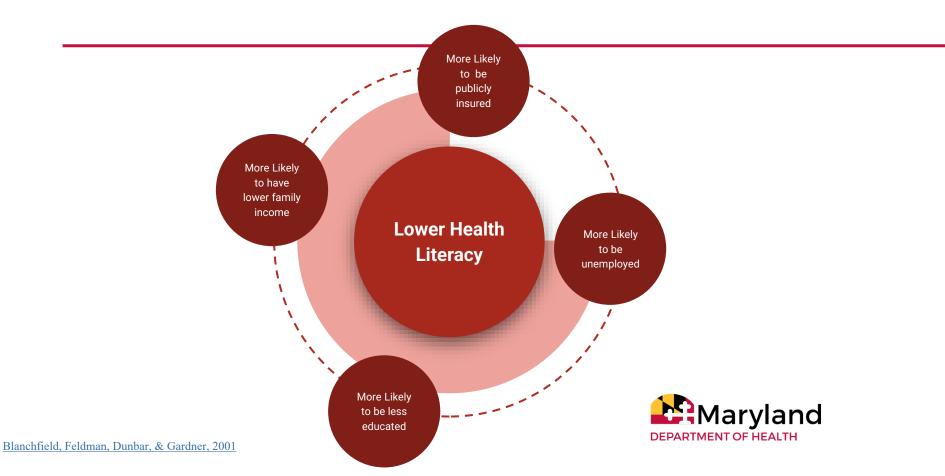


OPENING DOORS. Removing Barriers.

VS



### Health Literacy Intersectionality Study



## Why is it important?

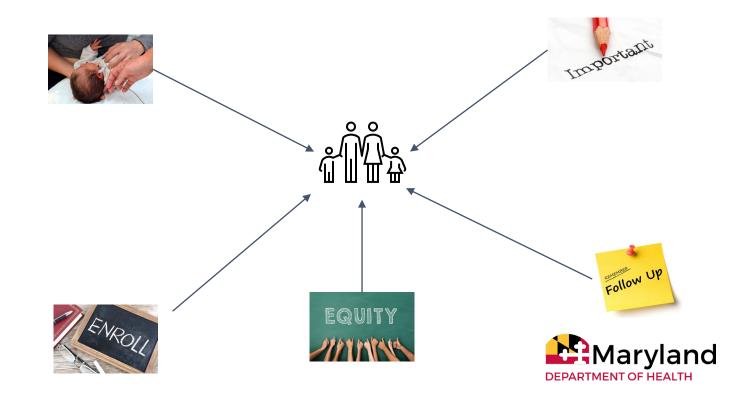
Adults with lower health literacy are more likely to return incomplete medical forms/assessment tools, miss appointments with health providers, and neglect follow-ups to required medical procedures.(Lopez et al., 2022)

• Low caregiver literacy is common and associated with poor preventive care behaviors and poor child health outcomes (Sanders, et al., 2009)

• There is a clear link between parental health literacy, health behaviour and health outcomes for children with chronic disease. (Zaidman et al. 2023)



### **Health Literacy and EHDI**



### **Materials Assessed**

- Maryland EHDI Website
- MD EHDI Resources, including:
  - 1. Developmental Milestones
  - 2. Letters to Parents
  - 3. Helpful Hints for Parents



## Areas of difficulty

### **Original MD EHDI Website:**

- Not easily accessible (difficult to find the website)
- Hard to navigate website to retrieve information
- Minimal visuals

### **Developmental Milestones Handout**

- Wordy language
- Needed main message
- Limited language offerings



## Areas of difficulty

### **Helpful Hints Handout**

- Hard to find on the website
- Only offered in English
- Communication unclear

### **Letters to Parents Handout**

- Limited language offerings : English and Spanish
- Lack of a focus audience

**ALL had HIGH reading levels** 



### **Assessment Tool: CDCCCI**

$\leftrightarrow$ $\rightarrow$ C is cdc.gov/ccindex/widget.html		$\dot{\mathbf{x}}$		I	s s	Ď	۵	
Intro Questions Part A: Part B: Part C: Part D: Final Score Behavior Numbers Risk Final Score							1	
intro Q1 Q2 Q3 Q4								
Welcome to the CDC Clear Communication Index The CDC Clear Communication Index is a research-based tool to plan and assess public communication materials. It includes 4 open-ended questions, and 20 scored items grouped into 4 parts. At the end, the material will get a final score and explanation. You will get more information about each part and how to score once you begin. You can find more guidance in the CDC Clear Communication Index User Guide. Fill in the information below to start:								
Name of Material Type in the name of the material.								
	Example: Cancer fact sheet							
Material Type	Print and web							

**CDCCCI**: Center for Disease Control Clear Communication Index

Tool used to create and evaluate communication material using research pulled from scientific literature.

 <u>https://www.cdc.gov/ccin</u> <u>dex/widget.html</u>



### Assessment Tool: PEMAT(Understandability)

Understandability

Onderstandability					
ltem #	ltem	Response Options	Rating		
	Content				
1	The material makes its purpose completely evident.	Disagree=0, Agree=1			
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1			
Topic: Word Choice & Style					
3	The material uses common, everyday language.	Disagree=0, Agree=1			
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1			
5	The material uses the active voice.	Disagree=0, Agree=1			

### PEMAT: Patient Education Materials Assessment Tool

A guide designed to determine how well and if patients will understand and act on health information materials. Two types and two sections: **understandability** and **actionability** 

- P: Print/Downloadable materials
- A/V: audio/visual materials
  - <u>https://www.ahrq.gov/h</u> <u>ealth-literacy/patient-</u> <u>education/pemat-p.html</u>

### Assessment Tool: PEMAT (Actionability)

### Actionability

ltem #	Item	Response Options	Rating
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=NA	
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	
26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	

Total Points:

Total Possible Points: \_\_\_\_\_

Actionability Score (%):

(Total Points / Total Possible Points x 100)

### PEMAT: Patient Education Materials Assessment Tool

A guide designed to determine how well and if patients will understand and act on health information materials. Two types and two sections: **understandability** and **actionability** 

- P: Print/Downloadable materials
- A/V: audio/visual materials
  - <u>https://www.ahrq.gov/h</u> <u>ealth-literacy/patient-</u> <u>education/pemat-p.html</u>

### **Assessment Tool: SMOG**

### SMOG Readability

### Using the SMOG Calculator

The easiest way to establish the readability level of a text is to use the SMOG calculator developed by Harry McLaughlin PH.D. Click on the link below to access the calculator, which was adapted from:

National Literacy Trust 2008. Readability - how to test how easy a text is to read. London, England.

### http://www.niace.org.uk/misc/SMOG-calculator/smogcalc.php

There is an alternative method you can use to determine the reading level of your written materials. This method is especially useful when you are revising existing patient/family education materials and may not have access to the original Microsoft Word document. This document was adapted from:

University of Wisconsin Hospital and Clinics. (1996). Developing health facts for you: An author's guide. Madison, WI: Author.

### Using the SMOG Formula:

- Count 10 consecutive sentences near the beginning, middle, and end of your material (30 total sentences).
- Count every word with three or more syllables in the 30 sentences, even if the same word appears more than once.
- Add the total number of words counted. Use the SMOG Conversion Table to find the grade level.
- 4. If your material has fewer than 30 sentences, follow the instructions for "SMOG on Shorter Passages" and use SMOG Conversion Table II.

### Word Counting Rules

- A sentence is any string or words ending in a period, exclamation point or question mark.
- Words with hyphens count as one word.
- Proper nouns are counted.
- Read numbers out loud to decide the number of syllables.
- In long sentences with colons or semicolons followed by a list, count each part
  of the list with the beginning phrase of the sentence as an individual sentence.
- Count abbreviations as if they were not abbreviated.
- Do not count verbs ending in "ed" or "es" that make the word have a third syllable.

# SMOG: Simple Measure of Gobbledygook

### Formula used to determine reading levels of printed/ written materials

• chrome-

extension://efaidnbmnnnibpcajpcglclefindmkaj/<u>https://ww</u> w.aspiruslibrary.org/literacy/SMOG%20 Readability%20Formula.pdf

### **MDH Benchmarks**

### Tool Score Goal:

CDCCCI: 90% or higher

This level indicates message presented to audience is clear

PEMAT: 90% in both understandability and actionability.

*Higher Score in either understandability and actionability indicates higher chances of comprehension. Ex. 90% in understandability means the document is likely to be more clear than an document scored at 60%.* 

SMOG: 4th-6th grade reading level

Scores indicate reading/age level required to comprehend the document. The lower the reading level, the higher number of people able to read it.



### **Baseline Assessment Scores**

Materials	PRE-REVISION				
	CDCCCI Benchmark: 90%	PEMAT Benchmarks: U: 90% A: 90%	SMOG Benchmarks: 4th- 5th grade reading level		
MD EHDI Website	26.7%	Understandability: 60% Actionability: 0%	13		
Developmental Milestones	21.40%	Understandability: 88% Actionability: 0%	6		
Helpful Hints Handout	50%	Understandability: 62% Actionability: 100%	12		
Letters to Parents	56%	Understandability: 54% Actionability: 100%	11		

### What was done to improve

- Revised materials internally with OCYSHCN.
- Revised materials with Dr. Lindsay Rosenfeld, and graduate students.
- Edited materials went through several revisions by OCYSHCN.
- Finalized materials were re-assessed using Health Literacy Tools for a second time.



### **Assessment Scores**

Materials		PRE-REVISION POST-REVISION				
	CDCCCI Benchmark: 90%	PEMAT Benchmarks: U: 90% A: 90%	SMOG Benchmarks: 4th- 5th grade reading level	CDCCCI Benchmark: 90%	PEMAT Benchmarks: U: 90% A: 90%	SMOG Benchmarks: 4th- 5th grade reading level
MD EHDI Website	26.7%	Understandability: 60% Actionability: 0%	13		Understandability: 58% Actionability: 33%	5
Developmental Milestones	21.40%	Understandability: 88% Actionability: 0%	6		Understandability: 69% Actionability: 40%	7
Helpful Hints Handout	50%	Understandability: 62% Actionability: 100%	12		Understandability: 83% Actionability: 60%	10
Letters to Parents	56%	Understandability: 54% Actionability: 100%	11	71%	Understandability: 62% Actionability: 100%	12



## **MD EHDI Website (Current)**

Maryland.gov	Remove the sideline		Options for different	🔰 🎝 State Directory 🏛 State Agencies   🖶 Translate
	menus to create more		audiences types	
Office of Children Specific Health Ca		aryland Early Heatervention (MD E	aring Detection and	Highlights
A-Z Index				2022 Maryland Early Hearing Detection and Intervention Conference sessions
Birth Defects Repo System	orting Information		Expand space to	Session 1, December 1, 2022 State of the State - Maryland EHDI Program.
Children's Medical	l Services		enlarge the picture	Presenter: Stacy Taylor, JD and Language Deprivation: Old Concept, New Word. Presenter: Dr. Wyatte Hall
Critical Congenital Early Hearing Dete Intervention Prog	ection and	Resource Li	ne: 1-800-633-1316	Session 2, December 8, 2022 New Developments in Diagnosis and Treatment for Hearing Loss. Presenter: Eliot Shearer, MD PhD
Family Professiona	al Partnership		"Detection" and "Intervention" . Add ers (stats, risk,etc.). Emphasize "call to action" language	Session 3, December 15, 2022 Transforming Deaf Education through Critical Self-Reflection, Presenter: Andrea Sonnier, EdS
Health Care Transi Maternal and Chile			Intervention (MD EHDI) Program aims to ensure the newborn hearing screening and that hearing	Best Practices Guidelines for Hospitals and Birthing Center Staff, Midwives, Physicians and Staff, Audiologists and Early Intervention
Medical Home Pro	ogram	status is identified at the earliest age poss	ible, preferably by 3 months of age.	Providers
Newborn Metabol	ic Screening		ceive early intervention services, preferably by 6	Letter sent to parents of babies identified as deaf or hard of hearing (in Generation English and Generation)
				Maryland

**DEPARTMENT OF HEALTH** 

### Activity

# **Rephrase This!**





1. Delays in exposure to language can lead to language deprivation, which could have lifelong impacts on your child's development.





2. While there are many communication options for you and your child to consider later in life, it is critical that your child receives exposure to language immediately.



### **Activity:** Answers

- 1. While there are many communication options for you and your child to consider later in life, it is critical that your child receives exposure to language immediately.
  - a. It is important for your child to learn language early. Thankfully, there are many different communication types to choose from.
- 2. Delays in exposure to language can lead to language deprivation, which could have lifelong impacts on your child's development.
  - a. If your child does not learn language early, their development can have long term effects.



## **Health Literacy and Your EHDI Work**

### **Identifying Assessment Areas**

- Outreach materials
- Online resources
- Telephone and in-person communication



## What Did We Learn?

- 1. Team Effort
- 2. Cultural Humility
- 3. Continuous Process



## **Special Thanks**

Special thanks to **Lindsay Rosenfeld**, ScD, ScM, Brandeis University, Heller School for Social Policy & Management, Institute for Child, Youth, & Family Policy; Harvard T.H. Chan School of Public Health

Contact: Irosenfeld@hsph.harvard.edu



## **QR Codes for Tools**











### **Works Cited**

- 1. Declaration of Alma-Ata. (n.d.). https://www.who.int/teams/social-determinants-of-health/declaration-of-alma-ata
- DeWalt, D. A., & Hink, A. (2009). Health Literacy and Child Health Outcomes: A systematic review of the literature. *Pediatrics*, 124(Supplement\_3). <u>https://doi.org/10.1542/peds.2009-1162b</u>
- Early Hearing Detection and Intervention Act (EHDI) Hearing Loss Association of America. (2021, August 18). Hearing Loss Association of America. https://www.hearingloss.org/programsevents/advocacy/know-your-rights-archived/early-hearing-detection-intervention-act-

ehdi/#:~:text=Congress%20first%20authorized%20the%20EHDI,them%20to%20early%20intervention%20services.

- 4. Healthy People HP2010 Focus areas. (n.d.). https://www.cdc.gov/nchs/healthy\_people/hp2010/hp2010\_focus\_areas.htm
- 5. Healthy People HP2020 Topic Areas. (n.d.). https://www.cdc.gov/nchs/healthy\_people/hp2020/hp2020\_topic\_areas.htm
- 6. Health Literacy in healthy people 2030. Health Literacy in Healthy People 2030 Healthy People 2030. (n.d.). https://health.gov/healthypeople/priority-areas/health-literacy-healthypeople-2030
- 7. Health literacy in the United States: Enhancing assessments and reducing disparities | Milken Institute. (2022, May 17). Milken Institute. https://milkeninstitute.org/report/health-literacy-

### us-assessments-disparities

8. Impact of health literacy of parents on the health outcomes of children with chronic disease: A systematic review. (2019). Journal of Paediatrics and Child Health, 55(S2), 14–14. https://doi.org/10.1111/jpc.14467\_5



### Works Cited (cont'd)

1. Individuals with Disabilities Education Act. (2024, February 16). A history of the Individuals With Disabilities Education Act. Individuals With Disabilities Education Act.

### https://sites.ed.gov/idea/IDEA-History

2. Individuals with Disabilities Education Act (IDEA) Services / CDC. (2018, March 9). Centers for Disease Control and Prevention.

https://www.cdc.gov/ncbddd/cp/treatment.html#:":text=Part%20C%20of%20IDEA%20deals,be%20eligible%20for%20IDEA%20services.

- 3. Lopez, C., Kim, B., & Sacks, K. (2022). Health Literacy in the United States: Enhancing assessments and reducing disparities. SSRN Electronic Journal. https://doi.org/10.2139/ssrn.4182046
- 4. McKee, M., Paasche-Orlow, M. K., Winters, P., Fiscella, K., Zazove, P., Sen, A., & Pearson, T. A. (2015). Assessing health literacy in deaf American sign language users. Journal of Health

Communication, 20(sup2), 92-100. https://doi.org/10.1080/10810730.2015.1066468

5. NIH designates people with disabilities as a population with health. (2023, September 26). National Institutes of Health (NIH). <u>https://www.nih.gov/news-events/news-releases/nih-</u>

### designates-people-disabilities-population-health-disparities

6. New law to strengthen early hearing screening program for infants and children. (2017, October 23). NIDCD. https://www.nidcd.nih.gov/news/2017/new-law-early-hearing-screening-

### infants-and-children

- 7. Piao, Z., Lee, H., Mun, Y., Lee, H., & Han, E. (2023). Exploring the health literacy status of people with hearing impairment: A systematic review. Archives of Public Health, 81(1). https://doi.org/10.1186/s13690-023-01216-x
- 8. Simonds, S. (1974). Health education as social policy. https://www.semanticscholar.org/paper/Health-Education-as-Social-Policy-Simonds/e22b29742e85089b4308e57a953937a747434f24



# **Questions or Comments?**





