



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

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Presenters

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

2. Neophyte's Serendipity

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.

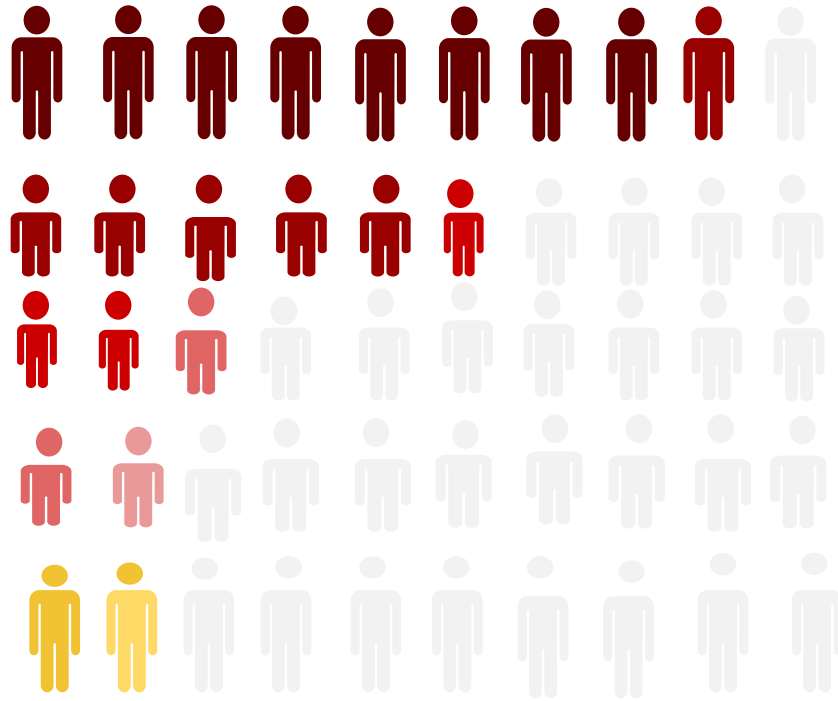
What is Health Literacy?

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



88%

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

55%

Below Intermediate Proficiency

22%

Basic Proficiency

14%

Below Basic Proficiency

12 %

Proficient Health Literacy



Drumroll...

“It’s me. Hi! I’m the problem, it’s me”

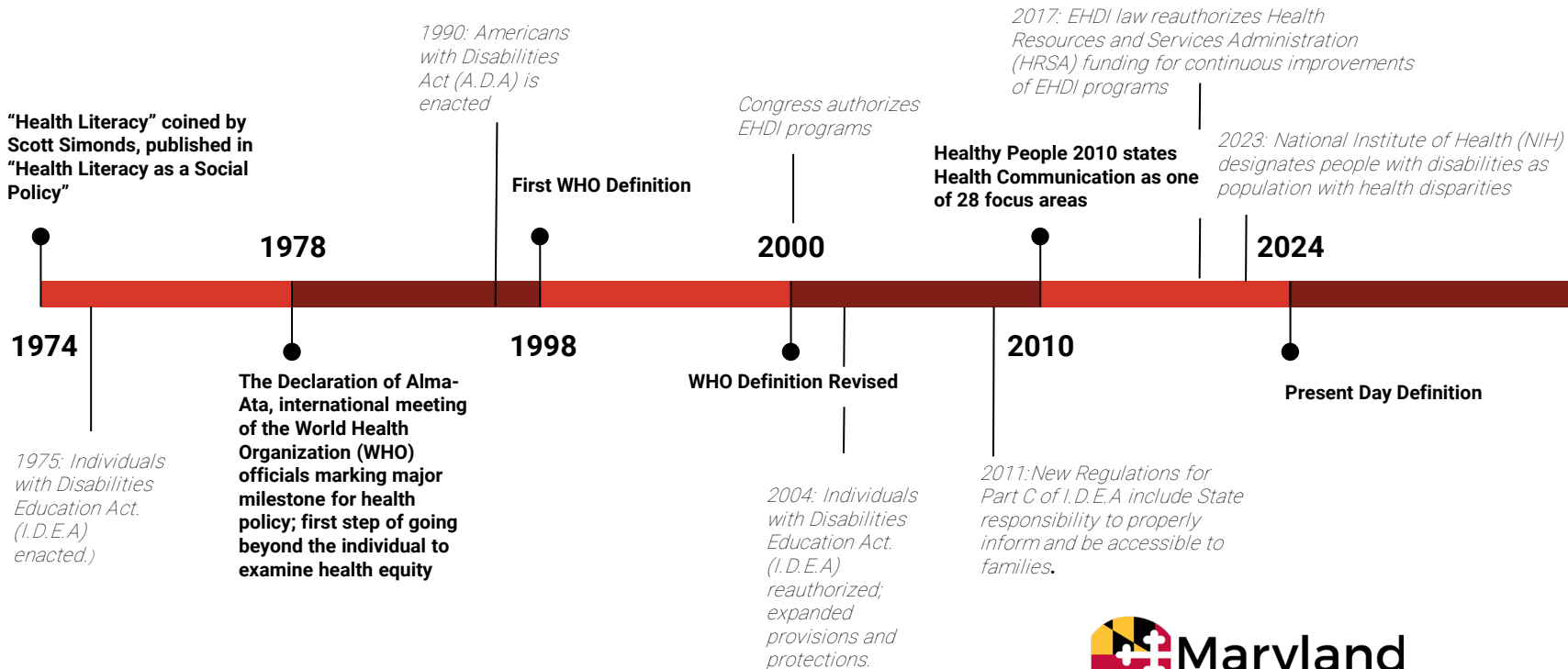
-Anonymous

EHDI Accountability

“Public health and social service organizations are responsible for promoting health literacy and provide equitably accessed services and information.”

-Trezona et al., 2017

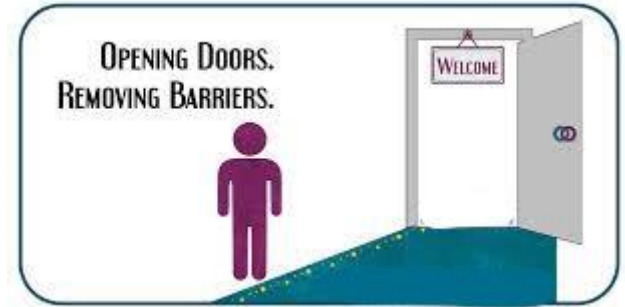
Why It's Important: Health Literacy Health Equity



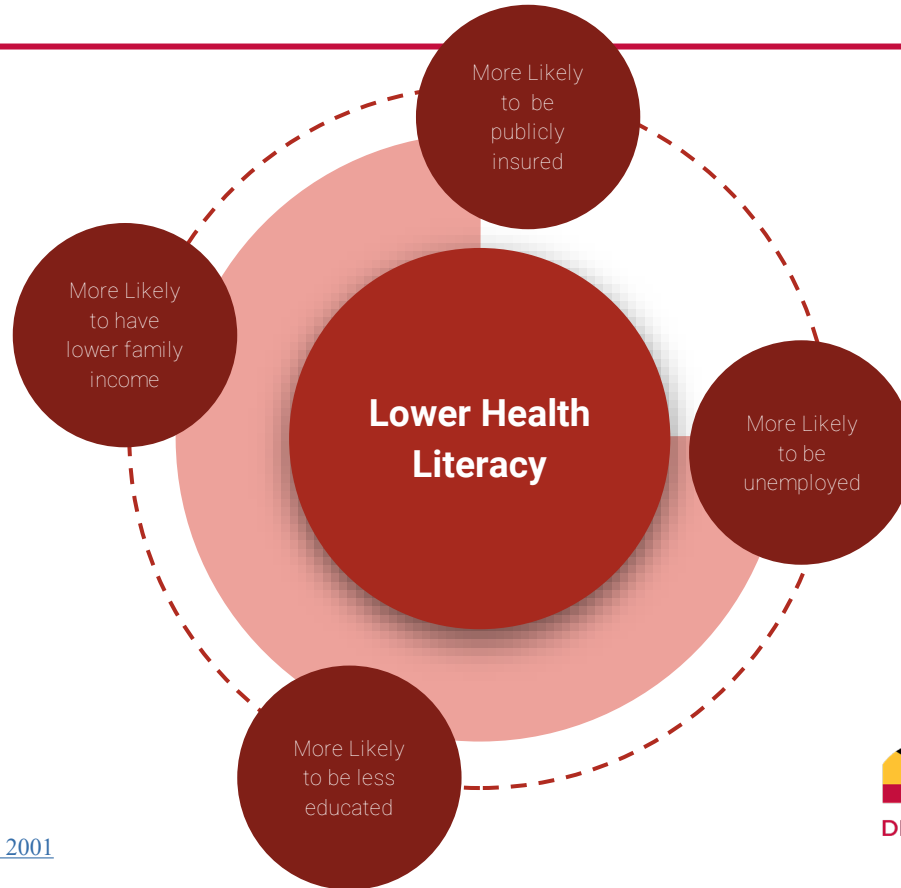
Why It's Important



VS



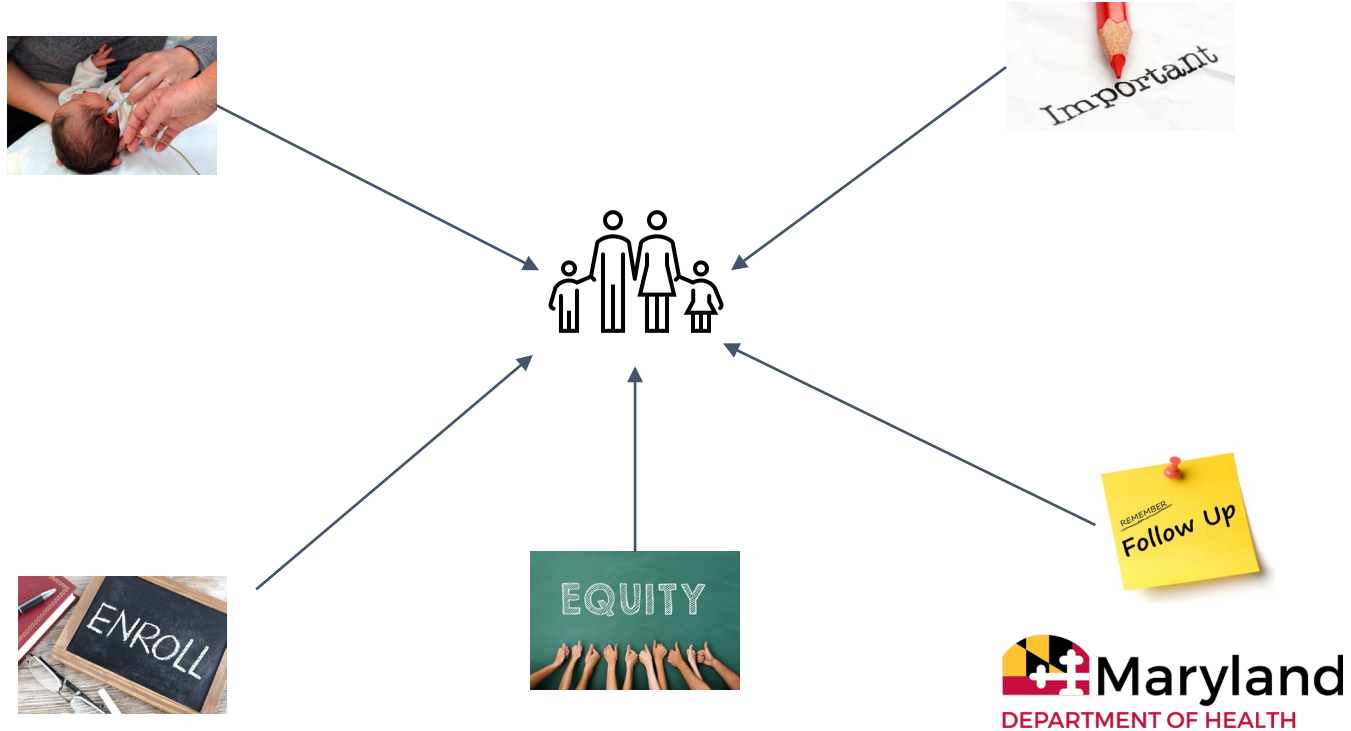
Health Literacy Intersectionality Study



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

The screenshot shows the CDC Clear Communication Index (CCICI) assessment tool interface. The browser address bar displays "cdc.gov/ccindex/widget.html". The navigation bar includes "Intro Questions", "Part A: Core", "Part B: Behavior", "Part C: Numbers", "Part D: Risk", and "Final Score", with a "Reset" button on the right. Below the navigation bar, a progress indicator shows "Intro" selected, followed by "Q1", "Q2", "Q3", and "Q4". The main content area contains the following text:

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

CDCCCI: Center for Disease Control Clear Communication Index

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

- <https://www.cdc.gov/ccindex/widget.html>

Assessment Tool: PEMAT(*Understandability*)

Understandability

Item #	Item	Response Options	Rating
Topic: 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
 - <https://www.ahrq.gov/health-literacy/patient-education/pemat-p.html>

Assessment Tool: PEMAT (*Actionability*)

Actionability

Item #	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)

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- P: Print/Downloadable materials
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 - <https://www.ahrq.gov/health-literacy/patient-education/pemat-p.html>

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.nlace.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:

1. Count 10 consecutive sentences near the beginning, middle, and end of your material (30 total sentences).
2. Count every word with three or more syllables in the 30 sentences, even if the same word appears more than once.
3. 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://efaidnbnmnnibpcajpcgiclfefindmkaj/<https://www.aspiruslibrary.org/literacy/SMOG%20Readability%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 EHDl 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		
	CDCCI Benchmark: 90%	PEMAT Benchmarks: U: 90% A: 90%	SMOG Benchmarks: 4th- 5th grade reading level	CDCCI Benchmark: 90%	PEMAT Benchmarks: U: 90% A: 90%	SMOG Benchmarks: 4th- 5th grade reading level
MD EHDl Website	26.7%	Understandability: 60% Actionability: 0%	13	65%	Understandability: 58% Actionability: 33%	5
Developmental Milestones	21.40%	Understandability: 88% Actionability: 0%	6	47%	Understandability: 69% Actionability: 40%	7
Helpful Hints Handout	50%	Understandability: 62% Actionability: 100%	12	64%	Understandability: 83% Actionability: 60%	10
Letters to Parents	56%	Understandability: 54% Actionability: 100%	11	71%	Understandability: 62% Actionability: 100%	12

MD EHDI Website (Current)

The screenshot shows the Maryland EHDI website with several annotations in green callout boxes:

- Remove the sideline menus to create more space:** Points to the left sidebar menu.
- Options for different audiences types:** Points to the top navigation links: State Directory, State Agencies, and Translate.
- Expand space to enlarge the picture:** Points to the image of a baby being screened.
- Define "Detection" and "Intervention". Add numbers (stats, risk, etc.). Emphasize "call to action" language:** Points to the "About" section header.

Website Content:

- Header: Maryland.gov
- Page Title: Maryland Early Hearing Detection and Intervention (MD EHDI) Program
- Left Sidebar: Office of Children and Youth with Specific Health Care Needs; A-Z Index; Birth Defects Reporting Information System; Children's Medical Services; Critical Congenital Heart Disease; Early Hearing Detection and Intervention Program; Family Professional Partnership; Health Care Transition Program; Maternal and Child Health; Medical Home Program; Newborn Metabolic Screening.
- Right Sidebar: Highlights; 2022 Maryland Early Hearing Detection and Intervention Conference sessions; Session 1, December 1, 2022; Session 2, December 8, 2022; Session 3, December 15, 2022.
- Main Content: Resource Line: 1-800-633-1316; About section with text: "The Maryland Early Hearing Detection and Intervention (MD EHDI) Program aims to ensure that every baby born in Maryland receives the newborn hearing screening and that hearing status is identified at the earliest age possible, preferably by 3 months of age." and "The MD EHDI Program coordinates with providers statewide to help ensure that babies who are identified as deaf or hard of hearing receive early intervention services, preferably by 6 months of age."

Activity

Rephrase This!

slido



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

slido



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

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QR Codes for Tools

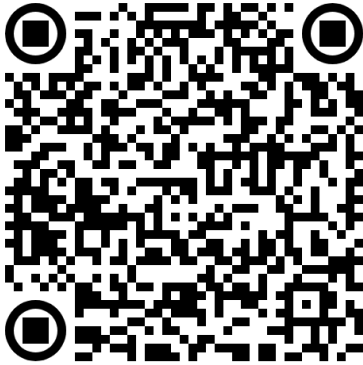
CDCCCI



PEMAT



SMOG



Works Cited

1. *Declaration of Alma-Ata*. (n.d.). <https://www.who.int/teams/social-determinants-of-health/declaration-of-alma-ata>
2. DeWalt, D. A., & Hink, A. (2009). Health Literacy and Child Health Outcomes: A systematic review of the literature. *Pediatrics*, 124(Supplement_3). <https://doi.org/10.1542/peds.2009-1162b>
3. *Early Hearing Detection and Intervention Act (EHDI) - Hearing Loss Association of America*. (2021, August 18). Hearing Loss Association of America. <https://www.hearingloss.org/programs-events/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-healthy-people-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). <https://www.nih.gov/news-events/news-releases/nih-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?



Audience Q&A Session