



HASSENFELD
CHILDREN'S
HOSPITAL
AT NYU LANGONE

Health Literacy in Youth

Milestones and Development

H. Shonna Yin, MD, MS

Departments of Pediatrics and Population Health
NYU School of Medicine

Collaborators: Benard P. Dreyer, MD, Alan L. Mendelsohn, MD, Alexander Glick MD, MS,
Tiffany A. Williams, BA, BS

Developing Health Literacy Skills in Youth: A Workshop
Roundtable on Health Literacy -- National Academies of Sciences, Engineering, and Medicine
November 19, 2019

Outline

Stages of Child Development & Health Literacy

Child Development Milestones / Frameworks

- Literacy Development – Speech / language Milestones

- Numeracy Development

- Cognitive Development – Piaget

- Vygotsky Framework for Learning

- Neurocognitive Perspectives

- Media Literacy / eHealth Literacy

Health Literacy Development and Chronic Disease Management

Health Literacy Development in the Educational Context

Consent / Assent

Final Thoughts

Stages of Child Development & Health Literacy

Stages of Child Development & Health Literacy

Early childhood (0-8y)

Middle childhood (6-12y)

Adolescent (10-19y)

Young adult (teens to 20s or 30s)

Stages of Child Development & Health Literacy

Early childhood (0-8y)

Middle childhood (9-12y)

Adolescent (10-19y)

Parent / Caregiver Health Literacy

Young adult (teens to 20s or 30s)



TABLE 3. Low Health Literacy and Relationship with Pediatric Health-Related Knowledge, Behaviors, and Outcomes

	CATEGORY OF ISSUE AFFECTED BY LOW HEALTH LITERACY	DETAILS OF IMPACT OF LOW HEALTH LITERACY
Outcomes	Greater prevalence of disease	Obesity: ↑ child obesity if parent with low health literacy; ↑ obesity if adolescent has low health literacy
	Worse child disease-specific outcomes	Depression: ↑ depression rate (worse child school readiness if parent has low health literacy and depression)
	Greater health-care utilization	Behavior: ↑ behavior problems
	Worse health-care access	Asthma: ↑ school days missed, ↓ asthma control
		Diabetes: ↓ glycemic control
		Epilepsy: ↑ seizure frequency
		Nephrotic Syndrome: ↑ relapse rate, ↓ complete remission rates
		General population: ↑ ED visits, ↑ nonurgent ED visits (among children without chronic illness)
		Asthma: ↑ ED visits and ↑ hospitalizations in children with asthma, ↓ rates of child health insurance

Stages of Child Development & Health Literacy

Early childhood (0-8y)

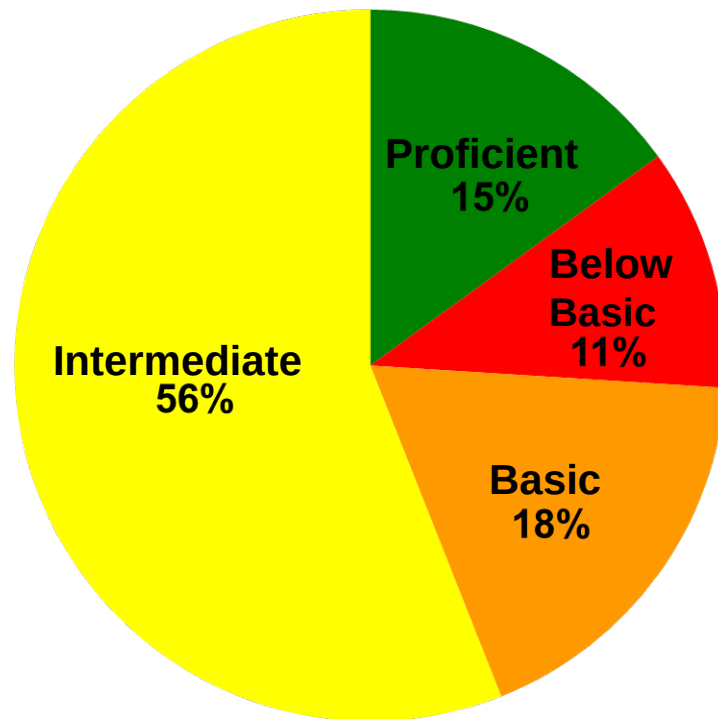
Middle childhood (9-12y)

Adolescent (10-19y)

Young adult (teens to 20s or 30s)

↑ Responsibility for health
↑ Reliance on own health literacy

Health Literacy of Parents in the US



Data from 2003
National Assessment of
Adult Literacy (NAAL):
National Center for
Educational Statistics

Over 21 Million Parents with Basic or Below Basic Health Literacy

Prevalence of Low Health Literacy in Children, Adolescents & Young Adults

- Prevalence of low health in **adolescents** (10-19y) and **young adults** (20-29y) variable
 - Most studies report levels of low health literacy between **30-40%** (range ~1% - 60%)^{1,2}
 - Measurement tools include REALM-Teen, STOFHLA, NAAL, Newest Vital Sign
- Few studies have looked at health literacy skills in **younger children**
 - Unclear how to best measure health literacy in children
 - Some have used Newest Vital Sign in children as young as 7 years old³

1. Sansom-Daly UM, Lin M, Robertson EG, et al. Health Literacy in Adolescents and Young Adults: An Updated Review. Journal of Adolescent and Young Adult Oncology. 2016;5(2):106-118.

2. Sanders LM, Federico S, Klass P, Abrams MA, Dreyer B. Literacy and Child Health. Archives of Pediatrics & Adolescent Medicine. 2009;163(2):131.

3. Driessnack M, Chung S, Perkhounkova E, Hein M. Using the "Newest Vital Sign" to Assess Health Literacy in Children. Journal of Pediatric Health Care. 2014;28(2):165-171.

Health Literacy Definition & Competencies

- Health literacy
 - “The degree to which individuals have the capacity to **obtain, process, and understand** basic health information and services needed to **make appropriate health decisions.**”

(Healthy People 2010;
HHS 2000; IOM 2004)

Skill	Constituent Competency and Ability
Literacy	Perform basic reading tasks
Interaction	Engage in communication about health
Comprehension	Understand varied sources of information
Numeracy	Engage in basic numerical and arithmetic tasks and operations
Information seeking	Seek and obtain health-related information
Application/function	Process and use current and evolving health-related information
Decision making/critical thinking	Engage in informed health-related decision making
Evaluation	Filter, interpret, and evaluate information
Responsibility	Take responsibility for health and health-related decision making
Confidence	Have sufficient confidence to improve personal and community health
Navigation	Navigate society and health systems for successful self-care

Table: Magnani JW, Mujahid MS, Aronow HD, et al. Health Literacy and Cardiovascular Disease: Fundamental Relevance to Primary and Secondary Prevention: A Scientific Statement From the American Heart Association. *Circulation*. 2018;138(2).

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Functional
HL

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Child Development Milestones / Frameworks

Literacy Development – Speech / Language Milestones

12m

1 word other than
“mama” “dada”

6m

Babbling

18m

3 body parts
10-25 words

3y

3 step
command;
200 words;
3-4 word
sentence

5y

5000 words;
future tense

7y

Write/print
many words

12y

50,000 words;
increased
reading fluency /
comprehension

9m

“mama”
“dada”
(specific)

2y

2 step command;
50+ words;
2 word sentence

15m

Points to 1 body part;
1 step command; 5 words

4y

Full
sentences;
past tense

5-6y

Tell a
connected
story; read
simple text

Numeracy Development

9m

Begins to understand quantities

3y

Count up to at least 20

5y

Add by counting fingers on both hands

9y

Multiplication and division; solve problems with decimal points

12-14y

Basic algebra; fractions, percentage, and proportions

15-18y

Use graphs, maps, etc. to learn and convey information

15m

Understand that numbers mean “how many”

4y

Understand that numerals stand for number names (5 = five)

6-8y

Basic addition and subtraction up to 20; read and create a simple bar graph

10-11y

Write and compare fractions/decimals; put in order on a number line; use “>” and “<”

Cognitive Development Stages – Piaget

	SENSORIMOTOR STAGE (0-2 YEARS OLD)
COGNITIVE MILESTONE	• Acquires knowledge through physical manipulation and one's senses • Recognition of ability to control object and acts intentionally

Cognitive Development Stages – Piaget

	SENSORIMOTOR STAGE (0-2 YEARS OLD)	PRE-OPERATIONAL STAGE (~2-7 YEARS OLD)
COGNITIVE MILESTONE	• Acquires knowledge through physical manipulation and one's senses • Recognition of ability to control object and acts intentionally	• Symbolic thought develops • Growth in mental reasoning • Egocentric – see things only from their own point of view

Cognitive Development Stages – Piaget

	SENSORIMOTOR STAGE (0-2 YEARS OLD)	PRE-OPERATIONAL STAGE (~2-7 YEARS OLD)	CONCRETE OPERATIONAL STAGE (~7-11 YEARS OLD)
COGNITIVE MILESTONE	• Acquires knowledge through physical manipulation and one's senses • Recognition of ability to control object and acts intentionally	• Symbolic thought develops • Growth in mental reasoning • Egocentric – see things only from their own point of view	• Active use of logic; learn to apply general rules in standard way • Child can take multiple aspects of a new environment into consideration • Child no longer center of the world; can consider preferences / perspectives of others

Cognitive Development Stages – Piaget

	SENSORIMOTOR STAGE (0-2 YEARS OLD)	PRE-OPERATIONAL STAGE (~2-7 YEARS OLD)	CONCRETE OPERATIONAL STAGE (~7-11 YEARS OLD)	FORMAL OPERATIONAL STAGE (~11+ YEARS OLD)
COGNITIVE MILESTONE	- Acquires knowledge through physical manipulation and one's senses - Recognition of ability to control object and acts intentionally	- Symbolic thought develops - Growth in mental reasoning - Egocentric – see things only from their own point of view	- Active use of logic; learn to apply general rules in standard way - Child can take multiple aspects of a new environment into consideration - Child no longer center of the world; can consider preferences / perspectives of others	**Can think abstractly** - Capable of complex, logical thinking - Can think of potential outcomes and hypothesize best solution

Piaget's Stages & Understanding of Health / Illness

	PRE-OPERATIONAL STAGE (2-7 YEARS OLD)
CONCEPT OF HEALTH / ILLNESS	• May associate illness with a vague emotion (“feel sad”) • Believe illness caused by something they do or fail to do • Explain illness based on what they observe (“bumps on body” “feeling like throwing up”) • Believe can recover from illness by adhering to strict “rules” such as staying in bed

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Piaget's Stages & Understanding of Health / Illness

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Piaget's Stages & Health Literacy Skills

	PRE-OPERATIONAL STAGE (2-7 YEARS OLD)
HEALTH LITERACY SKILLS	• Name body parts • Talk with health professionals • Communicate and locate pain • If given assistance, a school-aged child with diabetes might begin learn to monitor his or her own blood sugar levels

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HEALTH LITERACY SKILLS	• Name body parts • Talk with health professionals • Communicate and locate pain • If given assistance, a school-aged child with diabetes might begin learn to monitor his or her own blood sugar levels	• Execute preventive care (e.g. brushing teeth) • Provide history of illness • Assent to treatment • Self-administer medications (e.g. inhaler) • Read and understand health information on a website and incorporate into their daily activities

Piaget's Stages & Health Literacy Skills

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HEALTH LITERACY SKILLS	- Name body parts - Talk with health professionals - Communicate and locate pain - If given assistance, a school-aged child with diabetes might begin learn to monitor his or her own blood sugar levels	- Execute preventive care (e.g. brushing teeth) - Provide history of illness - Assent to treatment - Self-administer medications (e.g. inhaler) - Read and understand health information on a website and incorporate into their daily activities	- Read/use an asthma action plan - Provide past medical history (including family history) - Self-administer medications - Access and understand health information from various sources (school, community, internet) - Read a label on an over-the-counter medication, consider his or her age/weight and measure correct dosage

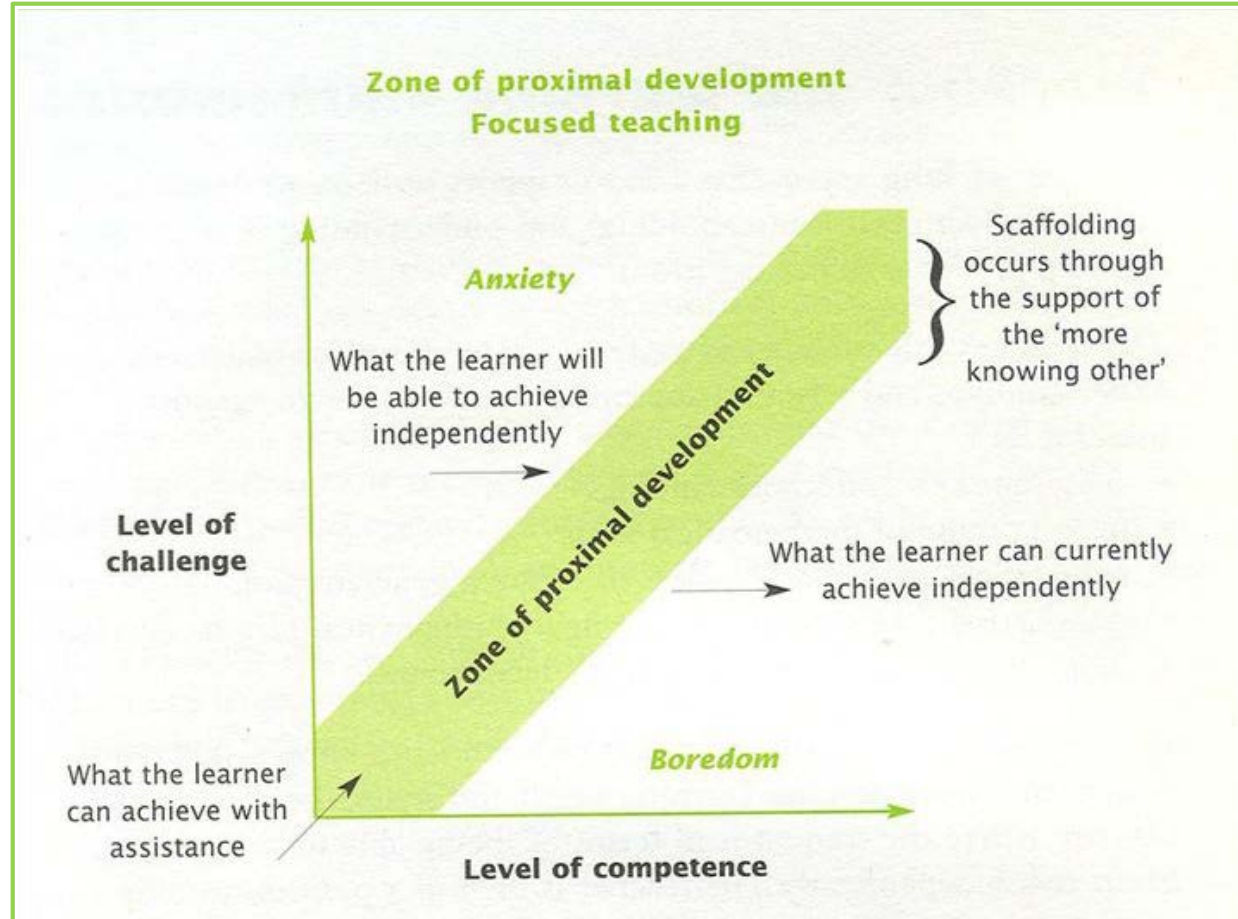
Vygotsky

1. Zone of proximal development (ZPD)

- Between what child can do with help and what child can do on own

2. Scaffolding

- “Knowing other” provides help to child such that he/she can master a new topic or skill
- Optimal = challenge child at “edge” of his/her current understanding



Neurocognitive Perspective on Adolescents and Risk / Sensation-seeking

- Adolescents are prone towards increased risk-taking and this is associated with the development brain structures¹
- Two brain systems are especially important:
 1. **The prefrontal cortex (PFC)** - the control system (impulse control; self-regulation)
 2. **The ventral striatum** - the reward system
- Cross-talk between the control system and the reward system and associated emotional regulation not fully developed before early adulthood^{2,3}

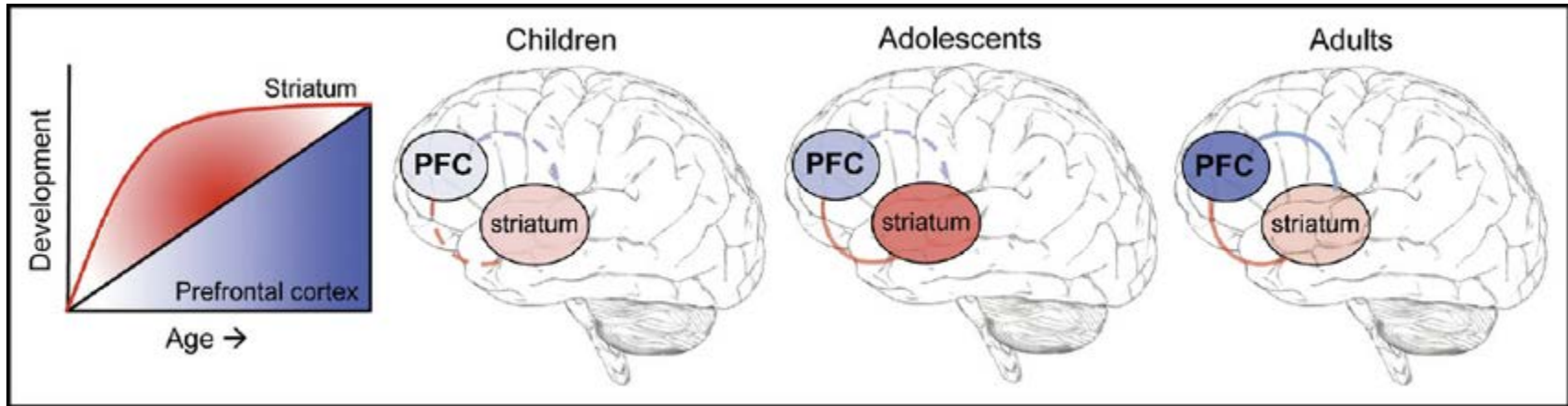
1. Grootens-Wiegers P, Hein IM, Broek JMVD, Vries MCD. Medical decision-making in children and adolescents: developmental and neuroscientific aspects. BMC Pediatrics. 2017;17(1).

2. Steinberg L. Does Recent Research on Adolescent Brain Development Inform the Mature Minor Doctrine? Journal of Medicine and Philosophy. 2013;38(3):256-267.

3. Casey B, Jones RM, Hare TA. The Adolescent Brain. Annals of the New York Academy of Sciences. 2008;1124(1):111-126.

Neurocognitive Perspective on Adolescents and Risk / Sensation-seeking

- During adolescence, reward system becomes hyperresponsive¹
- Nonlinear / mismatched development associated with increased reward-seeking and sensation-seeking²⁻⁴ → risky decisions often observed in adolescents



1. Grootens-Wiegers P, Hein IM, Broek JMVD, Vries MCD. Medical decision-making in children and adolescents: developmental and neuroscientific aspects. BMC Pediatrics. 2017;17(1) (including graphic)

2. Blakemore S-J, Robbins TW. Decision-making in the adolescent brain. Nature Neuroscience. 2012;15(9):1184-1191.

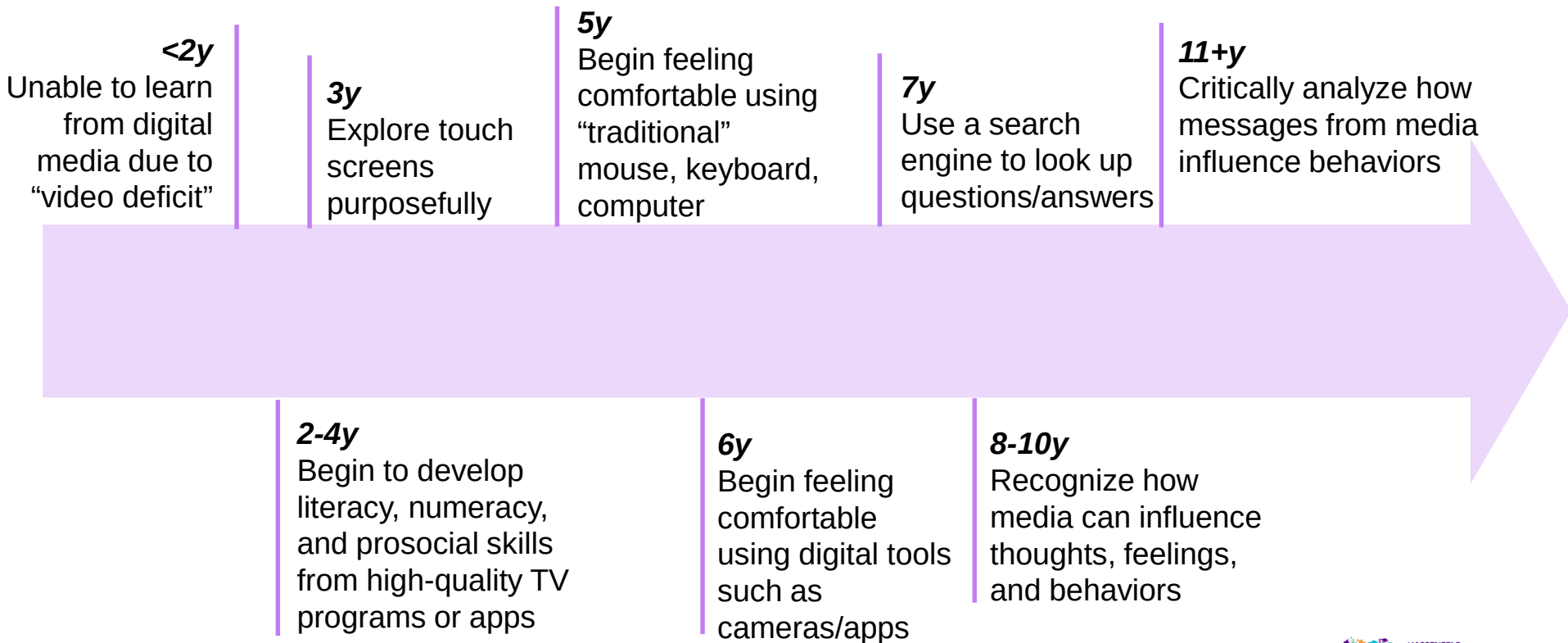
3. Leijenhorst LV, Zanolie K, Meel CSV, Westenberg PM, Rombouts SA, Crone EA. What Motivates the Adolescent? Brain Regions Mediating Reward Sensitivity across Adolescence. Cerebral Cortex. 2009;20(1):61-69.

4. Steinberg L. A social neuroscience perspective on adolescent risk-taking. Developmental Review. 2008;28(1):78-106.

Media Literacy / eHealth Literacy

- Media literacy = “ability to **access, analyze, evaluate, create, and act** using **all forms of communication**”
 - Non-digital → magazines, books, newspapers, and radio
 - Digital → internet, social media, movies, music, video games, television.
- eHealth literacy = “ability to **seek, find, understand, and appraise** health information from **electronic sources** and apply the knowledge gained to addressing or solving a health problem”

Media / eHealth Literacy Development



Health Literacy Development & Chronic Disease Management



THE OFFICIAL NEWSMAGAZINE OF THE AMERICAN ACADEMY OF PEDIATRICS

AAP News

Volume 32 • Number 7
July 2011
www.aapnews.org

Research Update



At what age should children manage their own health?

from the AAP Department of Research

Pediatrician opinion varies concerning when children are old enough to assume primary responsibility for managing various health conditions and preventive care, according to an AAP Periodic Survey of Fellows.

Pediatricians were asked about three chronic health conditions (asthma, diabetes and attention-deficit/hyperactivity disorder [ADHD]) and three preventive care topics (oral health, nutrition and physical activity).

Pediatricians reported that children could assume responsibility for oral health (median age 8) at a younger age than the other topics (see table). ADHD was the condition that pediatricians thought children were less capable of assuming responsibility for at younger ages (median age 14).

In general, pediatricians felt that children should assume responsibility for the preventive care topics at younger ages than the chronic health conditions (11.1 years vs. 13.4 years).

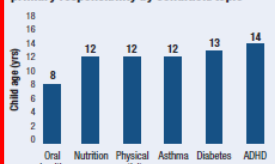
There also was considerable variability in opinion for each of the specific topics. For example, 7% of pediatricians felt that children could assume responsibility for nutrition by age 7, while 23% of pediatricians felt that by 15 years children still were not ready.

A variety of pediatrician characteristics were examined as possible predictors of age estimates. The only factor related was the percentage of a pediatrician's patients who had limited English proficiency. Pediatricians who had more patients with limited English proficiency provided lower age estimates. Pediatricians' communication difficulties with parents who have limited English proficiency may be related to greater openness to having children manage their own care.

Data for this study were collected via AAP Periodic Survey of Fellows #67 conducted in 2007. Surveys were mailed to random samples of roughly 1,600 AAP members, and analyses were limited to pediatricians who reported providing direct patient care. The survey response rate was 56%.

For more information about this survey, contact William Cull, Ph.D., in the AAP Division of Health Services Research, at 800-433-9016, ext. 7628, or wcull@aap.org.

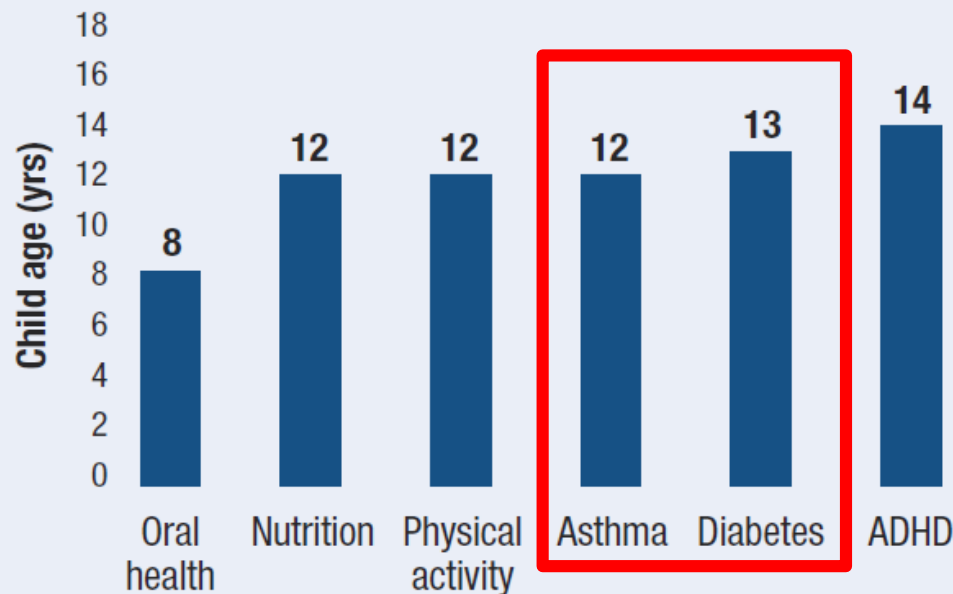
Median reported age that child should assume primary responsibility by condition/topic



RESOURCES

- AAP Health Literacy Project Advisory Committee: Borzekowski D. "Considering Children and Health Literacy: A Theoretical Approach." *Pediatrics*. 2009;124:S282-S288. http://pediatrics.aappublications.org/content/124/Supplement_3/S282.abstract.
- Plain Language Pediatrics: Health Literacy Strategies and Communication Resources for Common Pediatric Topics. Abrams MA & Dreyer BP, eds. https://www.nfaap.org/netforum/eweb/DynamicPage.aspx?webcode=aapbks_productdetail&key=7c5e160d-fa79-468f-8503-20a524bc5ae9

Median reported age that child should assume primary responsibility by condition/topic



Engagement in Chronic Disease - Diabetes

	YOUNG CHILDREN (<5 YEARS OLD)
PIAGET STAGE	PRE-OPERATIONAL
MANAGEMENT OF TASKS	Unable to perform diabetes tasks independently and need adult to provide diabetes care
REPORTING SYMPTOMS	Have difficulty in recognizing hypoglycemia
DECISION- MAKING	Limited; can choose which finger to prick and select an injection site

Engagement in Chronic Disease - **Diabetes**

	YOUNG CHILDREN (<5 YEARS OLD)	ELEMENTARY STUDENTS (5-11 YEARS OLD)
PIAGET STAGE	PRE-OPERATIONAL	CONCRETE OPERATIONAL
MANAGEMENT OF TASKS	Unable to perform diabetes tasks independently and need adult to provide diabetes care	Depending on the duration of diabetes and level of maturity, may be able to perform their own blood glucose checks and self-administer insulin, but usually will require supervision
REPORTING SYMPTOMS	Have difficulty in recognizing hypoglycemia	Usually able to let an adult know when experiencing low blood glucose
DECISION- MAKING	Limited; can choose which finger to prick and select an injection site	Older elementary students are generally beginning to self-administer insulin with supervision and understand the effect of insulin, physical activity, and nutrition on blood glucose levels

Engagement in Chronic Disease - **Diabetes**

	YOUNG CHILDREN (<5 YEARS OLD)	ELEMENTARY STUDENTS (5-11 YEARS OLD)	MIDDLE/HIGH SCHOOL STUDENTS (11-18 YEARS OLD)
PIAGET STAGE	PRE-OPERATIONAL	CONCRETE OPERATIONAL	FORMAL OPERATIONAL
MANAGEMENT OF TASKS	Unable to perform diabetes tasks independently and need adult to provide diabetes care	Depending on the duration of diabetes and level of maturity, may be able to perform their own blood glucose checks and self-administer insulin, but usually will require supervision	Generally able to self-manage their diabetes but will need help when experiencing severe hypoglycemia
REPORTING SYMPTOMS	Have difficulty in recognizing hypoglycemia	Usually able to let an adult know when experiencing low blood glucose	Can recognize hypoglycemia
DECISION-MAKING	Limited; can choose which finger to prick and select an injection site	Older elementary students are generally beginning to self-administer insulin with supervision and understand the effect of insulin, physical activity, and nutrition on blood glucose levels	Independence in older youth should generally be encouraged to enable him/her to engage in decisions about his/her own care

Health Literacy Development in the Educational Context

National Health Education Standards (NHES)

- The NHES are written expectations for what students should know and be able to do by early elementary, late elementary, middle, and high school to promote personal, family, and community health
 - Standard 1** Comprehend concepts related to health promotion and disease prevention
 - Standard 2** Analyze influence of family, peers, culture, media, and technology on health
 - Standard 3** Access valid information, products, and services
 - Standard 4** Use interpersonal communication
 - Standard 5** Use decision-making skills
 - Standard 6** Use goal-setting skills
 - Standard 7** Practice health-enhancing behaviors
 - Standard 8** Advocate for personal, family, and community health

Consent / Assent

Consent, Assent & Permission: Definitions

Consent

Voluntary participation of adults (18+) in research or medical therapies requires informed consent, or an agreement to participate^{1,2}

Two components: disclosing information to patients and obtaining legal authorization before undertaking interventions.

Minors can legally provide informed consent, without parent permission, for many medical therapies related to sexual and mental health³

1. The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research. Washington: Dept. of Health, Education, and Welfare, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research; 1978.

2. Code of Federal Regulations. Protection of human subjects—elements of informed consent, 21 C.F.R. pt. 50.25; 2011.

3. Katz AL, Webb SA. Informed Consent in Decision-Making in Pediatric Practice. Pediatrics. 2016;138(2).

4. Hein IM, Vries MCD, Troost PW, Meynen G, Goudoever JBV, Lindauer RJL. Informed consent instead of assent is appropriate in children from the age of twelve: Policy implications of new findings on children's competence to consent to clinical research. BMC Medical Ethics. 2015;16(1).

Consent, Assent & Permission: Definitions

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Children mature enough to participate in decision making, but not yet legally competent to consent, provide affirmative agreement or assent^{1,2}

Age for assent is controversial, ranging from 7-14 years old⁴

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Consent, Assent & Permission: Definitions

Permission

For minor children, parents must provide permission for their child to participate^{1,2}

Role of parents and guardians in providing informed consent referred to as informed permission, because minors generally can provide assent but not consent

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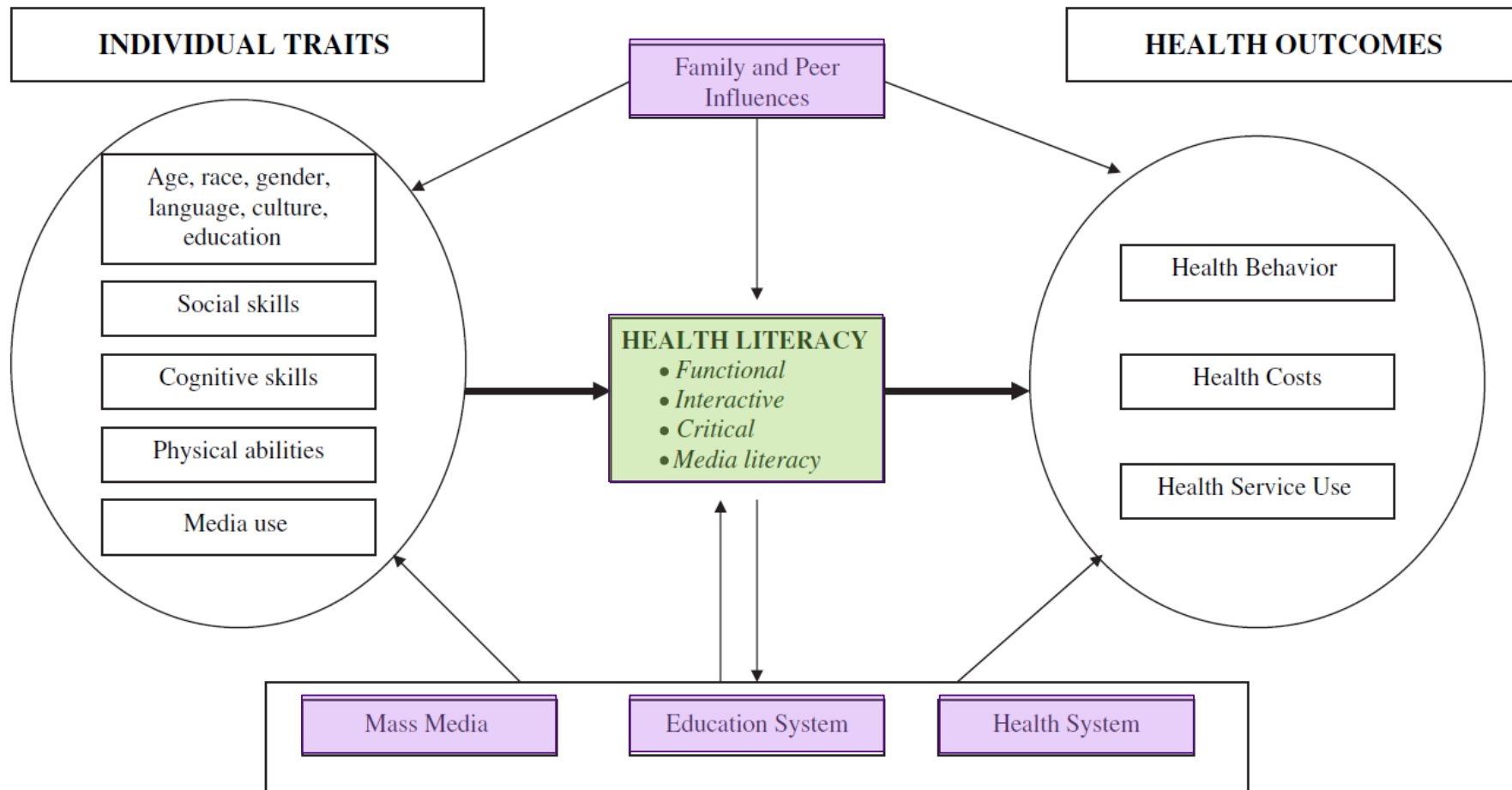
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Final Thoughts

Concluding Thoughts

- To address health literacy in youth important to think about how to support development of health literacy beginning in early childhood
- Many frameworks can be used to think about health literacy development through the lifespan



Thank You

- Questions?