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Developing Health Literacy Skills in Children and Youth

PROCEEDINGS OF A WORKSHOP

Alexis Wojtowicz, Rapporteur

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

Health and Medicine Division

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Acronyms and Abbreviations

ACA	Patient Protection and Affordable Care Act
ACO	accountable care organization
ADAPT	Avoiding Diabetes thru Action Plan Targeting: T2D Prevention
AMHS	August Martin High School
BMI	body mass index
CBO	community-based organization
CCMC	Cohen Children’s Medical Center
CCNY	Child Center of New York
CDC	Centers for Disease Control and Prevention
ECE	early childhood education
ED	U.S. Department of Education
eHEALS	eHealth Literacy Scale
HAS	Health Advocacy Summit
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
IEP	individualized education program
IOM	Institute of Medicine
IRB	institutional review board
KSS	Kids SIPsmartER Study

LTA	less than adequate
NHES	National Health Education Standards
NHW	non-Hispanic white
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Health Disparities
NVS	Newest Vital Sign
PAL	Preparation for Adult Living
PAM	Patient Activation Measure
Pre-K	prekindergarten
QUICCC–R	Questionnaire for Identifying Children with Chronic Conditions–Revised
REALM	Rapid Estimate of Adult Literacy in Medicine
SHCN	special health care needs
SOPHE	Society for Public Health Education
SSB	sugar-sweetened beverage
STEM	science, technology, engineering, and mathematics
TRAQ	Transition Readiness Assessment Questionnaire
W.E.I.G.H.T.	Working to Engage Insulin-Resistant Group Health Using Technology
WSCC	Whole School, Whole Community, Whole Child

1

Introduction¹

Since the publication of *Health Literacy: A Prescription to End Confusion* in 2004, health literacy has become a much more common consideration within the field of public health. However, there is a dearth of research and practice specifically regarding youth health literacy.² As children and youth age, they increasingly interact with the health system, have access to all forms of information, and gradually learn to manage their own health. Higher levels of health literacy will be key for positive health outcomes later in their lives (IOM, 2004; Manganello, 2008). Research has demonstrated that, much like adults, youth may be interested in information about their health but may also find the information difficult to comprehend (Manganello, 2008). Effective health education programs should begin in early childhood and continually build on previous knowledge (IOM, 2004).

Additionally, young people develop health literacy skills in a variety of environments, facing critical thinking challenges about their health from school, home and family life, peers and social life, and online. Accordingly, the Roundtable on Health Literacy convened a workshop on the subject of developing health literacy skills in youth on November 19, 2019, in Washington, DC. An ad hoc planning committee developed the workshop

¹ This Proceedings of a Workshop was prepared by the rapporteur as a factual summary of what occurred at the workshop. The planning committee's role was limited to planning and convening the workshop. The views contained in the proceedings are those of individual participants and do not necessarily represent the views of all workshop participants, the planning committee, or the National Academies of Sciences, Engineering, and Medicine.

² Throughout this proceedings, "youth" refers to young people between the ages of 14 and 26, but in some contexts will include children between the ages of 2 and 13.

agenda around a holistic view of factors related to health literacy skills in youth, and examined places, people, and partnerships involved in such skill development. The planning committee developed the workshop agenda and its objectives, which were as follows:

- To explicate the necessity of developing health literacy skills in youth
- To examine the research on developmentally appropriate health literacy milestones and transitions and measuring health literacy in youth
- To explore how youth learn about health and opportunities to develop health literacy skills through places, people, and partnerships

The planning committee invited expert speakers to discuss their own research, practices, and individual recommendations for best practices for the workshop attendees and broader public. The Statement of Task can be found in Box 1-1, and the agenda can be found in Appendix A.

BOX 1-1 Statement of Task

An ad hoc planning committee will plan and conduct a 1-day public workshop that will feature invited presentations and discussion on developing health literacy skills among youth from early childhood to young adulthood. The workshop discussions may consider all of the settings where youth consume information and misinformation that shape their behaviors and attitudes regarding their health, including the following:

- Schools
- Family
- Clinics/health care settings
- Community
- Media
- Peer groups

The workshop will address the state of the science around programs and interventions to develop health literacy skills in youth from early childhood to young adulthood and may include presentations and discussion related to the following issues:

- What are the developmentally appropriate health literacy milestones for each age?
- What are the individual and population metrics for measuring health literacy in youth?

BOX 1-1 Continued

- What are the challenges of transitioning from one age group to the next in terms of gaining greater responsibility for self-care, healthy behaviors, and managing health conditions?
- What programs/interventions are available to develop youth understanding of their roles and responsibilities in managing their own health?
- What types of programs/interventions should be developed and tested to develop health literacy in youth?
- Where are the opportunities to learn from related disciplines, such as elementary and science, technology, engineering, and mathematics education and transition readiness research?

The planning committee will define the specific topics to be addressed, develop the agenda, select and invite speakers and other participants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

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2

Setting the Stage

In her keynote remarks, H. Shonna Yin, associate professor of pediatrics and population health at the New York University Grossman School of Medicine, explained that she wanted to discuss child development milestones and frameworks. These frameworks would focus on literacy, numeracy, and cognitive development, as well as neurocognitive perspectives, particularly regarding adolescents and risk-taking behaviors. She added that she planned to conclude her keynote by describing health literacy and chronic disease management, health literacy development in the educational context, and consent and assent. Lawrence Smith from Northwell Health moderated the subsequent discussion.

HEALTH LITERACY IN YOUTH: MILESTONES AND DEVELOPMENT

H. Shonna Yin, New York University Grossman School of Medicine

Many terms are used to describe child development, and often with overlap in age range. Some common terms include the following:

- Early childhood: typically refers to the time from birth to 8 years of age
- Middle childhood: typically refers to ages 6 through 12 years
- Adolescence: typically refers to ages 10 through 19 years
- Young adulthood: typically refers to the teens through the early 20s, occasionally the early 30s

When considering health literacy in the context of early and middle childhood, the health literacy of a child's parents or primary caregivers is considered to be most important. In a recent *Pediatrics in Review* article, numerous studies showed that low parent or caregiver health literacy is linked to poorer child health-related knowledge, behaviors, and outcomes, including worse asthma and diabetes-related outcomes (Morrison et al., 2019). During adolescence and young adulthood, a child's own health literacy becomes more important as the child begins to take increasing responsibility for their health, and begins to rely on their own health literacy skills to manage their health. It is important to remember, however, that the building blocks for health literacy are created during early and middle childhood, which is why these early stages are such an important time to begin to foster the development of health literacy skills. Also, as adolescents and young adults grow up, they become parents and caregivers of young children and will take on the role of fostering health literacy skill development for the next generation.

Unfortunately, data collected as part of the National Assessment of Adult Literacy show that about 30 percent of parents in the United States have basic or below-basic health literacy, and only about 15 percent of parents are considered to have proficient health literacy levels (Yin et al., 2009). Most studies of adolescents and young adults report a prevalence of low health literacy that is between 30 and 40 percent, depending on the setting and type of measure used (Driessnack et al., 2014; Sanders et al., 2009; Sansom-Daly et al., 2016). Few studies have looked at health literacy skills in younger children, in part because it is unclear how to best measure health literacy in children. To use a child development lens to examine health literacy skills development, it is helpful to think of health literacy as a set of competencies and skills that can be categorized into three main types (Nutbeam, 2000):

1. **Functional health literacy**, referring to the literacy skills needed to function effectively in everyday situations, including basic reading and speaking skills, and interpreting numbers (also called numeracy)
2. **Interactive health literacy**, referring to more advanced cognitive and literacy skills, which allow someone to actively participate in their health care, often requiring social skills to help individuals interact in ways to promote health
3. **Critical health literacy**, referring to the most advanced cognitive skills, involving the ability to critically analyze information, apply knowledge, make decisions, and evaluate information, leading to greater control over life events and situations

Literacy and Numeracy

Literacy is a key component of functional health literacy, said Yin. Understanding speech and language milestones can help researchers and practitioners think about how to best support the development of a child's health literacy skills. From the first year of life, as language skills begin to develop and children acquire their first words, children can be introduced to concepts of healthy eating and behaviors through the early introduction of books, starting even within the first months of life. At 15 to 18 months, as children start to learn the names of body parts, they begin to acquire the vocabulary they will need to communicate about their health and bodies. Between 2 and 3 years of age, as children begin to follow more complex commands, they are acquiring the foundational steps they will need to follow medical instructions when they are older. At ages 3, 4, and 5, children begin to form complex sentences and become able to describe how they feel when they are sick and the story of how they became sick. Around ages 5 and 6, children are able to read simple text and can start to be able to process information on their own, including information that can be used to promote healthy behaviors. Around age 7, children begin to improve their writing and can begin to make written records of health-related issues. In their teenage years, youth will have advanced their speaking, writing, and language skills in a way that prepares them to take greater responsibility for their own health.

Numeracy development works in a similar way, Yin added. In infancy and childhood, children begin to understand the concept of quantities, and they begin to learn how to count and to understand that numerals stand for number names. This allows them to begin to participate in health numeracy tasks—for example, being able to describe their level of pain as early as 3 or 4 years of age. Children learn basic addition and subtraction around age 5 or 6, and multiplication and division at around age 9. They begin to understand fractions and percentages and proportions at around 10 years old. These milestones set the stage for their ability to participate in health numeracy tasks, such as reading food labels; managing medication use, including measuring medicines and determining timing for taking medicines; interpreting blood sugars or other clinical/lab data; and understanding health risks as well as the risks and benefits of different treatments.

Cognitive Development: Piaget's and Vygotsky's Frameworks

Dr. Jean Piaget, a Swiss psychologist who believed that children's cognitive development moves through a linear set of stages, developed a framework with four major stages: sensorimotor, preoperational, concrete operational, and formal operational (Piaget, 1952).

The sensorimotor stage encompasses the time from birth through the second birthday. During this stage, children learn new knowledge through physical manipulation of their environment and by relying on their senses. They come to recognize that personal actions will lead to certain outcomes. For example, a child will learn how to make a rattle produce sound by shaking it.

In the preoperational stage, which encompasses ages 2 through 7, symbolic thought emerges and mental reasoning grows. For example, a 4-year-old in the preoperational stage will recognize a stop sign, and recognize that their parent will need to stop the car when they see a stop sign while driving. Another feature of the preoperational stage is that children are very egocentric, seeing things only from their own point of view.

The concrete operational stage occurs between ages 7 and 11. In this stage, children actively use logic. They begin to learn to apply general rules in a standard, consistent way, thinking in a more complex way, and taking into account multiple aspects of the environment. Children no longer think of themselves as the center of the world, and they begin to consider the preferences or perspectives of others.

The formal operational stage, occurring in children 11 years and older, is the stage where children start to think in an abstract way. Children at the formal operational stage can think of potential outcomes of different choices that need to be made. They can hypothesize what would be the best solution, and they can deduce what led to a bad outcome.

Using Piaget's theories can help inform how children perceive and think about health and illness. A child in a preoperational stage may associate illness with a vague emotion, like "feeling sad." They might believe that their illness is caused by something they did or did not do. They tend to explain illness based on observations: They have bumps on their body, or they feel like throwing up. They may believe that they can recover from illness by following strict rules like staying in bed.

Meanwhile, a child in the concrete operational stage begins to learn to attribute illness to the concept of germs. They believe that illness can be prevented by avoiding germs, and they may start associating illness with specific consequences. They believe that they can recover from illness by taking care of themselves and by following instructions from their pediatrician, like taking medicine.

In the formal operational stage, where children are typically 11 years old or older, children begin to have a better understanding of the inter-related causes of illness. They can hypothesize that certain situations put people at risk for an illness. They can also understand more advanced concepts like about how their body responds to medicine and how that is important in recovery from an illness.

This framework can also be applied to health literacy skills development. A child in the preoperational stage can name their body parts. They can start communicating with their health care providers, and they can talk about issues like pain and locate where their pain is. With help, they also may be able to perform certain tasks, like monitoring blood sugar levels.

In the concrete operational stage, children can be involved in executing preventive care, like brushing their teeth. They can provide a history of illness. They can begin to assent for treatment. They can start to self-administer medications with supervision, like an inhaler. They can begin to read and understand health information from various sources, including websites, and are able to incorporate this information into their daily life.

In the formal operational stage, teens are able to perform tasks that are more advanced. For example, children with asthma may be able to use an asthma action plan. Children in the formal operational stage may be able to provide a past medical history and family history. They may be able to administer medications themselves, or access information from multiple sources and integrate them. They may be able to perform tasks like interpreting an over-the-counter medication label, navigating a dosing chart, and identifying the right dosage.

Lev Vygotsky, a Russian psychologist, theorized about cognitive development in children and how children learn through social interactions. There are two main concepts that are part of this theory (Borzekowski, 2009). One is the idea of a child's "zone of proximal development," which refers to the difference between what a child can do with help and what a child can do on their own. Vygotsky's theory is that a child's ability is more likely to increase if tasks are presented within this zone of proximal development. The second concept is of scaffolding: Children rely on scaffolding from a "more knowing other," that is, a parent or a teacher, to help guide them. The optimal learning environment is thus one that really challenges the child just at the edge of their current understanding so that the child can then master a new topic or skill.

Neurocognitive Perspectives Regarding Adolescents and Risk-Taking Behavior

A neurocognitive perspective can help explain why adolescents, who are able to think abstractly and are typically more cognitively advanced than young children and preadolescents, sometimes engage in unexpectedly risky behavior. For example, adolescents may engage in behaviors that put them at risk for developing alcohol or substance use disorders, or place them at risk for unplanned pregnancy or sexually transmitted infections. Two brain systems are thought to be especially important: the prefrontal cortex, called the control system, and the ventral system, called

the reward system. The control system is involved in impulse control and self-regulation, whereas the reward system involves a structure that creates dopamine. Because dopamine release causes a feeling of pleasure, it can lead to learning and an urge to repeat a behavior or experience. It is the cross talk between the control system and the reward system that is associated with emotional regulation. This is not fully developed until early adulthood.

During adolescence, the reward system is hyperresponsive such that the dopamine response to reward is much larger. This mismatch in development is associated with increased reward-seeking and sensation-seeking behavior and can account for some of the riskier decision making often seen among adolescents.

Media Literacy and e-Health Literacy

There is potential to leverage different forms of media, including technology, to promote health literacy development among children. Media literacy refers to the ability to access, analyze, evaluate, create, and act on all forms of communication. That could include sources like magazines, books, newspapers, or radio, or digital sources like the Internet, social media, movies, music lyrics, video games, and television. So-called e-health literacy has to do with the ability to seek, find, understand, and appraise health information from electronic sources and then apply that knowledge to addressing a health problem.

Some of the milestones for media and e-health literacy overlap with literacy milestones. Of note, infants and toddlers, early on, experience what is referred to as a “video deficit” (CCM, 2016; Reid Chassiakos et al., 2016). They have difficulty learning from two-dimensional video representations. Per Piaget’s (1952) framework, infants and toddlers are typically in the sensorimotor phase, learning from physically interacting with their environment and from social interactions. After age 2, they can start to develop literacy, numeracy, and other skills from watching high-quality television programs or using apps. They are able to start using touch screens in an intentional way and begin to feel comfortable using computers and other digital tools like cameras. By age 7, children can start to use search engines to look up questions and answers, and from 8 to 10 years old, they can begin to think about how media can impact their thoughts, feelings, and behaviors.

Once they are in their teens, they can think critically about the way media are used to influence behavior. Considering how media, literacy, and e-health literacy skills develop can help researchers think strategically about how to promote the development of health literacy skills in children through media and technology.

Health Literacy and Chronic Disease Management

A 2007 survey revealed that pediatricians' opinions varied when it came to which age a child should assume primary responsibility for managing different health conditions (AAP Department of Research, 2011). For example, the median expected age for assuming primary responsibility for oral health care was 8 years, but for topics or conditions including nutrition, physical activity, or diabetes, pediatricians reported that 12, 13, or 14 years was a more reasonable age range.

To better understand how health literacy skill development can be fostered in young children with chronic diseases, developmental milestones and Piaget's theories can be taken into consideration. In thinking about diabetes and self-management, young children who are in the preoperational phase cannot really function independently. They need an adult to provide their diabetes care. At this stage, a young child with diabetes would have difficulty recognizing that hypoglycemia is occurring. Even though their decision making is quite limited, parents and caregivers can still engage these children in decision making by allowing them to choose which finger to prick to check their blood sugar, or where they should have their medication injected.

When children reach elementary school age, they enter the more concrete operational phase. Depending on the duration of diabetes and the level of the child's maturity, a child may begin to perform their own blood sugar checks, or begin to self-administer insulin but will usually require supervision (Jackson et al., 2015). They can also typically let their parent or caregiver know when they are experiencing issues with hypoglycemia. When it comes to decision making, Yin said, older elementary school children can begin to take on more responsibility regarding when to administer insulin with supervision, "and they begin to understand the effect of insulin, physical activity, and nutrition on their blood sugar levels."

Older children in middle or high school, in the formal operational stage, are generally able to self-manage their diabetes, but they may need some help when having more severe issues. Typically, children in the formal operational stage can recognize signs of hypoglycemia (Jackson et al., 2015). Parents and caregivers often encourage these children to take responsibility for decision making around their diabetes management in order to prepare them for transitioning to adulthood.

This framework can help parents, caregivers, and health care providers foster the development of a child's health literacy skills in chronic disease management.

Health Literacy Development in the Educational Context

The National Health Education Standards (NHES) can be helpful for parents, caregivers, and health care providers to refer to when looking to foster health literacy skill development. The NHES lay out expectations for what students know and should be able to do at various stages: early elementary, late elementary, middle school, and high school. The standards come in several categories, which have specific performance indicators for each grade level (CDC, 2019):

- 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 and Assent

In order to give consent and assent, a child needs to have health literacy skills to be able to understand the treatments or interventions that they would be consenting to. They need to understand the implications of not adhering to treatment, or not engaging with an intervention. Informed consent refers to an individual's agreement to participate in a medical treatment or in research (FDA, 2011; U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). Generally, one must be 18 years or older to legally provide consent, although in some states, minors can provide consent without parental permission for medical therapies related to sexual and mental health (Katz et al., 2016).

Children who are mature enough to be part of a decision-making process but who are not yet considered legally competent to consent can provide assent and agree to participate in medical therapies, said Yin (FDA, 2011; U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). The age at which children can begin to provide assent is “a bit controversial,” she added, but typically ranges from 7 to 14 years of age. According to the American Academy of Pediatrics (AAP, 2011) guidelines, pediatric assent includes four elements:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of their condition
2. Telling the patient what they can expect with tests and treatment(s)
3. Making a clinical assessment of the patient's understanding of the situation and the factors influencing how they respond (including whether there is inappropriate pressure to accept testing or therapy)
4. Soliciting expression of the patient's willingness to accept the proposed care (Katz et al., 2016)

Yin noted that when children are minors, parents must provide permission for their children to participate, and this is often referred to as “consent”; however, “technically, it is *permission*, because a person can only provide consent for something that involves their own body.”

It is important to consider how to support health literacy skill development beginning in early childhood, and many frameworks are available to help address how to support health literacy development throughout the life span. More work is needed to think about how to support the development of child literacy skills through the health care system, and how efforts can be integrated across fields and sectors that involve children and health, including medicine, education, and media. More work is also needed to consider how to support the development of health literacy skills in parents and in family members, and how to help them pass on health literacy skills to children. A coordinated approach to these efforts is needed, and more research is needed to understand how to do this most effectively.

DISCUSSION

Smith opened the discussion for general questions and comments from the workshop participants oriented toward future research and policy (see Box 2-1).

Elaine Auld from the Society for Public Health Education (SOPHE) added that researchers need to carefully consider that cognitive development in children can be affected by many external factors, including but not limited to adverse childhood events, race, gender, and socioeconomic status. Each of these elements can greatly affect a child's ability to give informed consent or make decisions about their health, she said.

Auld added that two relevant articles had been published the morning of the workshop that attendees might find interesting:

BOX 2-1**Questions and Considerations for Future Research on Developing Health Literacy Skills in Children and Youth**

- Given that there are validated, standardized tools to measure health literacy, how should e-health literacy be measured? (AnnLouise Assaf from Pfizer Inc.)
- What is known about health literacy skill development among children under age 10? (Earnestine Willis from the Medical College of Wisconsin)
- Who monitors or enforces the usage of National Health Education Standards across school districts and/or curricula? (Cindy Brach from the Agency for Healthcare Research and Quality)
- Should the way clinicians obtain assent from children or permission from parents be reconsidered, given that the standards regarding both predate current research on health literacy in children? (Christopher Trudeau from the University of Arkansas for Medical Sciences)
- What is known about how to perform a clinical assessment of a patient's understanding of a situation and the factors influencing how they respond in an effective way? (Christopher Trudeau from the University of Arkansas for Medical Sciences)
- What would be the best age and what would be the best way to start having conversations about how to access medications or how to approach health insurance? (Sneha Dave from the Health Advocacy Summit)
- Given that suicide is the second-leading cause of death for people between ages 10 and 24 (Curtin and Heron, 2019), adolescent mental health literacy should be a focus of future research. (Jeena Thomas from the National Institute of Mental Health in the Division of Translational Research)
- There is great variation among different cultures and subcultures with regard to providing health literacy support or developing skills in children, and medical providers should take cultural context into account. (Winston Wong from Kaiser Permanente)
- What interventions might be best to teach adolescents how to find and assess the accuracy of health information? (Lawrence Smith from Northwell Health)
- Is there research evaluating the embedding of health promotion messaging into media, for example, television for children? (Nicole Holland from the Tufts University School of Dental Medicine)
- What factors are involved when it comes to individuals choosing trusted sources for health information? (Catina O'Leary from Health Literacy Media)

NOTE: These points were made by the individual workshop speakers and participants identified above. They are not intended to reflect a consensus among workshop participants.

- SOPHE released an online supplement on digital health, health education, and behavior, which contains several articles on how people interpret and access information on the Internet.¹
- *Health Education and Behavior* released “Constancy (the New Media “C”) and Future Generations,” which was authored by Dina Borzekowski, to whom Yin had referred during her talk.²

Yin noted that the descriptions of frameworks for cognitive development in children were “quite generalized,” and that social determinants of health are important to consider and acknowledge in the context of research and practice.

Hannah Lane from the Duke University School of Medicine noted that technology is being adapted to developmental timelines for children, so children are able to interact with technology at younger and younger ages.

We do need to focus on equipping kids with skills related to health literacy and navigating information sources, but I also think we need to work across sectors to ensure the onus is not exclusively on children interacting with media, but those who deliver that media—it’s a multisector problem that health literacy skills are a part of.

Yin agreed that children are exposed to technology at what seems like younger and younger ages. We can use some of these cognitive development frameworks to guide our thinking, she said, but we need to constantly adapt and shift our thoughts around what kids can or should do, and consider how to protect kids from material that is not age appropriate. Technology represents an opportunity, too, she added. Kids are active participants in using different technologies, so figuring out how to best use technology to encourage health-promoting behaviors is definitely on the “to-do” list.

Closing the discussion, Alice Horowitz from the University of Maryland School of Public Health added that it was important to remember that parents are ultimately still making decisions for children, even if the children are taught health literacy skills and have some knowledge and understanding of their own health situation. For example, she said,

In Head Start, all children have to brush their teeth with fluoride toothpaste every day. At home, they may not brush with fluoride toothpaste because one parent may not be able to afford it or they may not have

¹ To view the SOPHE supplement “Advancing the Science and Translation of Digital Health Information and Communication Technology,” see https://journals.sagepub.com/toc/hebc/46/2_suppl (accessed March 5, 2020).

² To view the *Health Education and Behavior* article, see <https://journals.sagepub.com/doi/pdf/10.1177/1090198119863775> (accessed March 5, 2020).

the same information about fluoride toothpaste. In older age groups, some young adults are finding that they never received vaccinations they had been eligible for because of their parents' lack of knowledge or misinformation. I think we need to direct a lot of effort toward raising health literacy among parents.

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3

Places: Where Youth Confront Health Literacy Challenges and Develop Skills

The first panel of the workshop was moderated by Marin Allen, who served as deputy associate director of communications and public liaison and director of public information in the Office of the Director at the National Institutes of Health (NIH) until 2017, and as scholar-in-residence at the Annenberg Public Policy Center of the University of Pennsylvania between 2017 and 2018. Allen introduced the panelists: Lloyd Kolbe, emeritus professor of applied health science at the Indiana University School of Public Health-Bloomington; Laura Noonan, founding organizer and current director of the Center for Advancing Pediatric Excellence at the Levine Children’s Hospital/Atrium Health; and Jennifer Manganello, professor at the University at Albany School of Public Health.

The panel was charged with discussing the places where youth experience health literacy challenges and where they develop skills.

HEALTH LITERACY IN SCHOOLS

Lloyd Kolbe, Indiana University School of Public Health-Bloomington

School Health Education

The U.S. prekindergarten (pre-K) through grade 12 school system includes 140,000 public and private schools in 13,000 school districts that employ 6 million teachers and staff, who serve 57 million students (NCES, 2011, 2012, 2017b, 2019). Of those students, 27 percent live in a mother-

only household, 20 percent live in poverty, and 13 percent receive special education services for disabilities (NCES, 2017a).

Evidence from the past two decades suggests that school health programs can improve both public health outcomes and education outcomes (CDC, 2019c; IOM, 1997, 2015; Kolbe, 2019; McDaid, 2016; NASEM, 2019a,c). In 2015, the Centers for Disease Control and Prevention (CDC) and the Association for Supervision and Curriculum Development developed the Whole School, Whole Community, Whole Child (WSCC) Framework (ASCD, 2014; CDC, 2020c), which includes 10 components:

1. Health education
2. Physical education and physical activity
3. Nutrition environment and services
4. Social and emotional school climate
5. Physical environment
6. Health services
7. Counseling, psychological, and social services
8. Employee wellness
9. Community involvement
10. Family engagement

School health education is a process for teaching health, either through *categorical* health education about a specific topic, or through *comprehensive* health education. Some important categorical school health education topics include the six categories of risk behaviors, monitored since the early 1990s by CDC's Youth Risk Behavior Surveillance System. These behaviors are established during childhood and adolescence, are difficult to change once established, and are associated with most of the morbidity and mortality in the United States (Kann et al., 2018). They include behaviors that contribute to unintentional injuries and violence and include the use of alcohol and other drugs, sexual behaviors that result in unintended pregnancy or sexually transmitted infection, tobacco use, unhealthy dietary behaviors, and inadequate physical activity.

Some important new categorical topics include healthy behavioral, emotional, and mental development; participating in one's own health care; online and media health literacy; genomics; the human microbiome; sleep; vaccinations; antibiotic resistance; emerging and reemerging infectious diseases; environmental health; climate change; social determinants of health; and bioethics. NIH has developed a series of curriculum supplements to address some of these new categorical topics during the past two decades (NIH, n.d.). NIH is developing K–12 science, technology, engineering, and mathematics (STEM) education to improve scientific training and public health literacy (NIH, 2016), and the National Institute of

Environmental Health Sciences is developing environmental health literacy and education (Finn and O’Fallon, 2017; NIEHS, 2019). Additionally, the National Academies of Sciences, Engineering, and Medicine have addressed school climate change education (NRC, 2012, 2016) and have developed a national agenda for fostering healthy mental, emotional, and behavioral development in children and youth—specifically addressing strategies for education settings (NASEM, 2019b).

In contrast to categorical health education, comprehensive school health education includes a planned, sequential curriculum taught from pre-K to grade 12 by teachers specifically trained to help students progressively acquire the knowledge, attitudes, and skills they need to make health-related decisions throughout their lifetimes across multiple categorical health topic areas. The ultimate goals are to help students acquire health literacy skills, adopt healthy behaviors, and promote the health of others (CDC, 2019f; Kolbe, 2019). About 10 years ago, five national organizations developed the National Health Education Standards (NHES) to improve school health education (CDC, 2019d; Joint Committee on National Health Education Standards, 1995, 2007; Tappe et al., 2009). These standards describe what students should know and be able to do by grades 2, 5, 8, and 12 to promote personal, family, and community health (see p. 12 of this proceedings).

Student Health Literacy

The Institute of Medicine (IOM) report *Health Literacy: A Prescription to End Confusion* describes health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions” (IOM, 2004, p. 2). The report states that the “most effective means to improve health literacy is to ensure that education about health is a part of the curriculum at all levels of education” (IOM, 2004, p. 149). While health education is a process, student health literacy is a critical health and education outcome. Goal 3 of the *National Action Plan to Improve Health Literacy* from the U.S. Department of Health and Human Services (HHS) is to “incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in child care and education through the university level” (HHS, 2010, p. 32).

To improve health literacy in the United States, Kolbe said, “we need to better develop the theory and measurement of student health literacy.” He continued, “We cannot expect students to know everything about health, but will need to carefully delineate what is most vital for young people to know and be able to do.” He added that this will depend on the definition of health literacy; student developmental levels; the number and scope of categorical topics; critical health knowledge, attitudes, beliefs; cognitive, emotional,

physical, and social skills; and whether students must engage in a healthy behavior in order to be considered health literate about that behavior.

Teaching Health

In 2002, Congress enacted the No Child Left Behind Act, which focused schools on testing and improving student proficiency in 10 core academic subjects:¹

1. English
2. Reading/Language Arts
3. Math
4. Science
5. Foreign Language
6. Civics and Government
7. Economics
8. Arts
9. History
10. Geography

In 2015, Congress passed the Every Student Succeeds Act, which maintained but modified the focus on student testing, and added “health” among 17 other subject areas (including music and environmental education) that would be considered part of a well-rounded education.² Today’s schools must ensure that students are proficient in tested subjects, but health is not one of them. Still, many states, school districts, and schools have policies that encourage school health education. A few surveillance systems monitor the extent to which schools address various school health program components, including school health education. These systems also monitor the extent to which schools specifically address the NHES, though they do not measure the extent to which students achieve the NHES. Illustratively, the National Association of State Boards of Education maintains a database of all existing state statutory and regulatory language for each of the 10 components of CDC’s WSCC Framework (NASBE, n.d.). In 2017, 25 states reported that they had policies for schools to address the NHES. Among the many health education topics that state policies addressed, 40 states had policies to support nutrition education, and 37 had policies to support social and emotional learning in health education (Chriqui et al., 2019).

¹ 107th U.S. Congress, 2002, Public Law 107-110, No Child Left Behind Act, January 8, 2002.

² 114th U.S. Congress, 2015, Public Law 114-95, Every Student Succeeds Act, December 10, 2015.

Among the nation's 13,000 school districts, the *CDC School Health Policies and Practices Study* found that in 2016, 63 percent reported that they were following the NHES. Among the many health education topics that district policies addressed, 85 percent of districts required that high schools teach nutrition, and 82 percent required that high schools teach emotional and mental health (CDC, 2017).

CDC's *School Health Profiles* monitors school health education and the NHES among the nation's public secondary schools, grades 6 through 12. In 2018, the percentage of secondary schools in each state that reported they required students to take two or more health education courses varied by state, from 11 percent of schools in the state with the lowest percentage of this requirement to 89 percent of schools in the state with the highest percentage. The percentage of schools that taught students to access valid information, products, and services to enhance health ranged from 69 to 96 percent of schools in various states. Meanwhile, 76 to 98 percent of schools in various states taught students to use interpersonal skills to avoid risk behaviors (CDC, 2019g).

As a result, some might question whether school health education has been a focus for the fields of public health and medicine, said Kolbe, or for the education field, which also faces challenges in addressing this. Numerous categorical topic area programs often compete for scarce time and resources. Most who teach health in secondary schools are principally trained to teach physical education. There is little support for integrated academic school health education professional preparation, research, and service programs. It is not apparent that a comprehensive plan exists to improve school health education and health literacy (ASCD, 2015; IOM, 1997, 2015; Kolbe, 2015, 2019).

However, the Healthy People 2030 National Health Objectives³ might include an objective to increase the percentage of secondary schools that require students to take at least two health education courses in grades 6 through 12. Additionally, more than 100 national organizations are currently working to improve school health programs (Kolbe, 2015); for example, the Health Resources and Services Administration (HRSA) convenes a National Coordinating Committee on School Health and Safety. CDC maintains school health surveillance systems, supports state and national nongovernmental organizational efforts to improve school health programs, maintains school health and health literacy websites, and has published characteristics of effective school health education curricula and a Health Educa-

³ Healthy People is a "national effort that sets goals and objectives to improve the health and well-being of people in the United States. Healthy People 2030 is the fifth edition of Healthy People. It aims at new challenges and builds on lessons learned from its first 4 decades" (see healthypeople.gov for more information) (accessed June 2, 2020).

tion Curriculum Analysis Tool (CDC, 2015, 2019a,b,c,d,e,f,g, 2020a,b,c). CDC also supports school health education teacher training and parent engagement. The Society for Public Health Education (SOPHE) recently published 11 challenges and related recommendations to improve school health education and provides national leadership for the accreditation of university health education teacher training programs and for the certification of secondary school health education teachers (Birch and Auld, 2019; Birch et al., 2019; Mann and Lohrmann, 2019; Videto and Dake, 2019).

The IOM's consensus study report *Schools and Health: Our Nation's Investment* recommends that all students receive sequential health education every year from elementary through junior high school (IOM, 1997). It also recommends that secondary school students receive at minimum a one-semester health education course as a requirement for school graduation and that school health education be based on the NHES, emphasize the six priority behavioral categories, and be taught by qualified health education teachers. It also recommends that colleges of education should prepare all elementary school teachers to teach health education. In addition, *Health Literacy: A Prescription to End Confusion* recommends that the U.S. Department of Education (ED) and HHS should convene task forces to identify actions that relevant agencies should take to improve health literacy in schools (IOM, 2004). It also recommends that HRSA, CDC, and ED collaboratively fund demonstration projects in each state, and that the National Science Foundation, the U.S. Department of Energy, and the National Institute of Child Health and Human Development fund research to improve health literacy (IOM, 2004).

Actions that might be considered include developing a national agenda for school health education to improve health literacy, including the following:

- A conceptual framework
- Means to measure processes and outcomes
- Means to implement school health education to scale
- Ongoing research and evaluation

HEALTH CARE ORGANIZATIONS

Laura Noonan, Atrium Health

In 2009, Atrium Health commissioned a system-wide health literacy task force, led by Noonan. During the next decade, the large health care organization began to strategically incorporate health literacy practices at every level. In 2010, the task force and organizational leadership implemented an initiative called TeachWell, focusing on two “high-leverage” changes: Teach Back and Ask Me 3 (Brach, 2017). Ten thousand nurses

and all of the employees at 25 ambulatory faculty practices affiliated with Atrium Health (then Carolinas HealthCare System) were trained. Between 2013 and 2014, a health literacy steering committee with representation across the organization was formed, “achieving excellence in health literacy” was identified as a priority on the Atrium Health Strategic Road Map, and Atrium Health adopted the framework published in the National Academy of Medicine *Perspectives* paper on the subject, which states that a “health literate health care organization:

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services” (Brach et al., 2012, p. 3).

Since 2015, Atrium Health has added health literacy as a nursing competency, launched health literacy trainings for physicians, established a patient and family health education governance council, presented on its work at the Institute for Healthcare Advancement conference, been featured in “The Journey to Become a Health Literate Organization: A Snapshot of Health System Improvement” (Brach, 2017), hosted its own health literacy summit, optimized its health literacy review process, implemented a “plain talk” initiative with the Carolinas Hospitalist Group, and began working on a patient education electronic medical record platform (Brach, 2017).

There are 11 executive functions in the frontal lobes that enable individuals to care for their own health that emerge from age 3 up to age 26, which means that health care organizations like Atrium Health require a patient-centered, child-centered, and adolescent-centered approach to their work in order to successfully care for patients. There are many factors

that can affect the path from a child's literacy development to their health outcomes, including not only child knowledge and behaviors but also several external influences, which may include adverse childhood events; cultural factors; parent literacy, knowledge, and health literacy; transportation access; and health care systems (see Figure 3-1).

While knowledge and behavior are the most frequently measured outcomes, and researchers know that parental low-literacy levels are often associated with poor health knowledge and behaviors and that adolescent low-literacy levels are associated with adverse “risk-taking” behaviors, it is still difficult to draw conclusions about the cause-and-effect relationship between literacy and child health outcomes.

Coproduction: Addressing the Patient Burden and Building Patient Capacity

Atrium Health aims to improve health literacy in youth through the use of coproduction, quality improvement, and patient portals. Coproduction was first described in the 1970s in the social sciences as a concept whereby end users should help developers design services, and in some cases, deliver services. Coproduction, as it applies to health care and health care organizations, is patients, families, clinicians, and researchers collaborating as

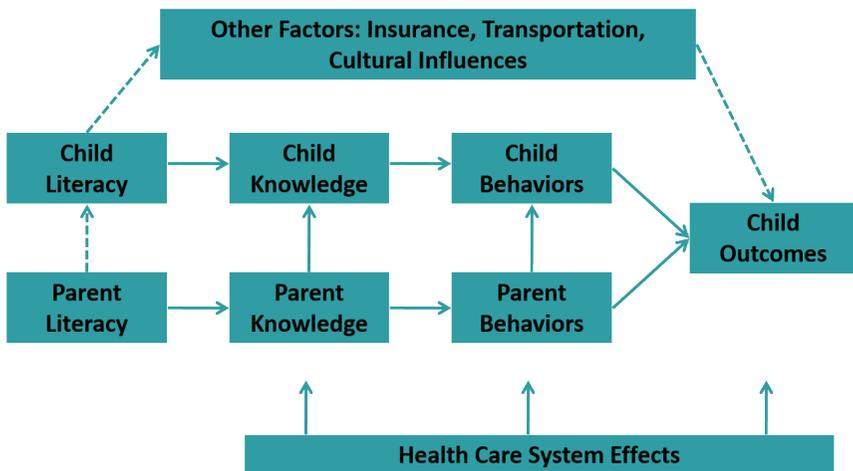


FIGURE 3-1 The working relationship between child literacy and child health outcomes.

SOURCES: As presented by Laura Noonan at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019 (adapted from Darren DeWalt).

equal and reciprocal contributors to produce information (e.g., clinical data, patient-reported outcomes), knowledge (informal insights and formal research), and know-how (expertise) to improve health care and health outcomes. In coproduction, patients, parents, and providers work together to create the best system of care. The core items of coproduction are as follows:

- Working as equals
- Believing every person adds value
- Producing as a team
 - Data
 - Insight
 - Skill
- Improving care and health for all

Although coproduction requires equality and reciprocity, the two main groups (health care providers and patients and families) start off on unequal ground. Whereas health care providers are able to incorporate the processes of coproduction into their practice, participants, including patients and their families, face other challenges. Families must manage the process of coproduction while caring for their child, managing the family, and working outside the home, and patients themselves must navigate coproduction while in treatment. Because of this, coproduction still requires new thinking to work in an effective manner, equally.

Coproduction does help balance the scale of burden versus capacity for self-management. It can increase the youth skills that are involved in self-managing care and decrease the burden of navigating the health care system. One example of this is the Pediatric Nephrology Center for Excellence at Atrium Health. Their mission is to promote patient and family-centered care for youth impacted with kidney disease by leveraging patient and clinician engagement, clinical research, improvement science, and best practices to transform the overall patient experience and quality of life.

The nephrology coproduction group works on education, quality improvement, innovation, and research by using focus groups, individual groups, round-robin table time, and organizing materials. The focus groups are unique: They are held at different times of day in different locations, and facilitators provide child care, food, and transportation. Patients and their caregivers help health care providers develop materials as well as processes for the ways that care is delivered in the clinic. For instance, the focus group is quite vocal about eliminating no-shows and about late policies that do not change behavior and punish patients. Individual groups work on creating materials. For example, when developing nutrition materials, participants asked researchers to clarify healthier options and choices to make when going to a fast-food restaurant, highlighting that a list of

forbidden items is not particularly helpful. Coproduction participants are able to develop materials and have their peers evaluate how useful they are. Round-robin table time is an opportunity to discuss ideas and implementation. Participants challenge health care providers to think about care delivery differently—for example, “Why am I made to come to the office a full hour before my CT scan? Why can’t we do that differently?” Participants also help health care providers identify information and materials that are considered “must-know” for patients and those that are interesting but not required for successful disease management.

Youth patients are also taught quality improvement methodology in coproduction, which can strengthen health literacy skills, including finding the root cause; looking through the eyes of the end user (patient); testing changes with small, rapid cycles; and using data to drive the work. Atrium Health’s coproduction work has youth patients developing numeracy and literacy skills while creating a system that decreases the burden.

Learning Health Systems and Quality Improvement

Youth are involved in many ways in learning health systems. For example, Improve Care Now is a learning health system focused on improving care for youth with inflammatory bowel disease. The majority of the work that goes on there comes from the teen work group. Their work has pushed the remission rate from 38 to 82 percent in the nation without using any new treatments, but by working together with families, and specifically young patients, to improve the processes of care in the health systems, thereby decreasing burden and increasing capacity. The Pediatric Rheumatology Care & Outcomes Improvement Network, Improving Renal Outcomes Collaborative, Epilepsy Learning Healthcare System, and ST3P-UP Transition Program: Sickle Cell Quality Improvement Collaborative are all working to improve health literacy skills among their constituents.

ST3P-UP Transition Program’s teams consist of pediatric providers, adult providers, the local sickle cell organization or community-based organization, and youth with sickle cell disease. The teams can operate only if they have all of those members, becoming integrated quality improvement teams that improve the transition from child to adult health care.

ST3P-UP Transition Program also uses a readiness assessment, which asks questions about health management, getting prescriptions filled, and scheduling appointments. If a gap is identified in patient skills, the patient will be referred to the local sickle cell organization or community-based organization, and the team as a whole will work to improve health outcomes, specifically the health literacy skills of the youth patients.

Quality improvement in action includes learning sessions and action periods, which include youth members who sit on teams, speak on panels,

share their experiences with disease, work on processes to make it easier for patients, and use data to understand the process.

Patient Portals

Patient portals have great potential in teaching youth how to manage their health and develop health literacy skills. They can increase use capacity by making records, videos, and educational materials accessible in one location, and youth are typically more digitally savvy than other age groups, as the Internet is an extensive part of daily life for most of them in the United States.

There are also special challenges for the teen age group. Different organizations use patient portals differently—in some cases, neither youth patients (between ages 14 and 17) nor their parents have access to their portal due to privacy laws around sexual and mental health. In other cases, written permission from both parent and physician is required for youths to access their own patient portals. Other barriers are not age specific and include limited cell phone and Internet access, or difficulty navigating the portals themselves.

Questions and potential topics for future research as identified by Noonan can be found in Box 3-1.

BOX 3-1

Areas for Future Research as Identified by Laura Noonan

- Does being involved in opportunities like coproduction increase health literacy? Can that be measured?
- Is there anything available through transition-readiness assessment measurements that could be used as a proxy measure for health literacy skills?
- More exploration of risks, benefits, and ramifications of privacy and other policies regarding patient portal use by 14–17-year-olds.

SOURCE: Adapted from a presentation by Laura Noonan at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

HEALTH LITERACY AND YOUTH ONLINE

Jennifer Manganello, University at Albany School of Public Health

Why the Online Environment Is Important for Youth

Youth are a connected population. According to the Pew Research Center, 45 percent of teens say that they are online “almost constantly” (Anderson et al., 2018a; Lenhart et al., 2010). In 2010, the Pew Research Center released a study noting that about one-third of teens reported searching for health information online (Lenhart et al., 2010). Meanwhile, smartphone ownership continually increased, with more than 90 percent of teens reporting having a smartphone (Rideout and Robb, 2019), meaning that most teens have access to the Internet.

Youth under age 13 are legally not allowed to have social media accounts, though many do. Ninety-seven percent of youth between ages 13 and 17 use social media (Anderson et al., 2018b), primarily YouTube, Instagram, and Snapchat. Facebook is less popular among teens, though their parents and grandparents use the social media website. There have been mixed findings for health effects, with some studies demonstrating an impact on health behaviors like alcohol and e-cigarette use, but other studies demonstrating that social media can also be used for successful health interventions (Kranzler and Bleakley, 2019). Teens themselves also have mixed reviews about social media: They can be a way to connect to their peers and find support, but they can also be a source of bullying or peer pressure (Anderson et al., 2018a). The concept of media use has also expanded for youth. It is more likely that teens will identify different types of media as devices or apps (like Xbox or TikTok) than types like television, radio, movies, video games, and so forth, which makes measuring media use difficult.

How the Online Environment Relates to Health Literacy

The online environment requires skills to navigate it, but it can also be used to build skills and educate users about health. E-health literacy can be viewed as a subset of health literacy in that it focuses specifically on digital resources. There are other related types of literacies that affect what youth are able to do online, including media literacy, information literacy, and science literacy. Of note, Karnoe and colleagues (2018) published an eHealth Literacy Assessment Toolkit, which combines health literacy, computer and digital literacy, and information literacy, and has seven unique scales. The skills in question are taught mainly through classes in school: science, health education, computer literacy, family and consumer science,

and more. Other learning opportunities may come from parents, libraries, after-school programs, summer camps, health care facilities, and online resources. The NHES Standards 2 and 8 in particular highlight how media and technology can play a major role in this crucial skill development (see p. 12 in Chapter 2 for a full list of the NHES).

One of the main uses of the online environment is to seek health information. The online environment can be a great resource for youths, but something as simple as “stomach pain” in a search engine will provide more than 250 million results. Youth need the skills to sort through this information, and even teens with seemingly higher levels of health literacy can struggle, especially with sorting information. The online environment can also be a source for unintentional exposure to negative health messages or health misinformation. Fortunately, there are some health websites specifically designed for youth, including KidsHealth.org, which has different sections for children, teens, parents, and educators. When it comes to using the Internet for health-related topics, information seeking is the most common use (Park and Kwon, 2018).

Common topics include sports injuries; influenza; chronic diseases, specifically asthma; sexual health; fitness; and mental health. Increasingly with age, youth use and rely on online sources for health information. They also report using online support groups and communities, for example, for youth with specific chronic health conditions, or for lesbian, gay, bisexual, transgender, and queer or questioning youth. Youth do have concerns about privacy and the accuracy of online information; these could be addressed with health literacy interventions.

Youth also prefer websites that are updated and easy to use, highlighting health literacy as an intersection of skills that youth have and the environment they are navigating. Health organizations that post information online should keep this in mind: They can build youth health literacy by making their information easier to find and understand. Also, some companies now have online courses available for purchase. These are often used by parents who homeschool their children, and some feature health literacy–related content. For example, a digital literacy curriculum is available for free; it is not necessarily specific to health literacy.

How the Online Environment Can Be Used for Interventions

There are three major types of e-health interventions and studies. The first type focuses on e-health interventions, meaning it uses some kind of technology to teach teens about health for the purpose of changing knowledge or behaviors, such as smoking prevention or reducing indoor tanning (Hillhouse et al., 2017; Khalil et al., 2019). These types of interventions should not be categorized as “health literacy interventions” because they

are not necessarily teaching skills, but they may incorporate some components of health literacy principles. The second type includes e-health literacy interventions. These are designed to build e-health literacy skills, which are the skills specifically related to searching for information online. Those skills can be developed through online or in-person programs and might be taught, for example, in a health education class or an after-school program. They are meant to improve e-health literacy so that teens are better able to navigate the health environment online. The third type includes online health literacy interventions. These interventions aim to develop general health literacy skills, which may include e-health literacy skills, but they are done in the online environment.

Get Health'e' Program

Manganello developed an online program called Get Health'e', which is designed to teach health literacy skills.⁴ The first module focuses on e-health literacy and takes less than 1 hour. It includes plain-language text and short videos and is in color. The module contains six lessons:

1. What is e-health literacy?
2. Online health information
3. Patient portals
4. Social media
5. Health apps
6. Wearable devices

A pilot test evaluation had a sample size of 145, with an age range of 18 to 24 years old. The sample was mostly female, and most were students. Fifty-seven percent of the participants attended a 4-year college or university, 18 percent attended a community college, and 11 percent attended another type of school. Each module had five knowledge-based multiple-choice questions at the end. Repeated analysis-of-variance measures were used to compare changes between pre- and post-quiz scores to find a medium effect size. The students who participated did have an increase in knowledge after completing the lessons. Focus group and survey results revealed that participants overwhelmingly agreed that the program would be appropriate for teens younger than 18 and thought it would better serve that age group, before members of that group have to begin navigating the health system on their own.

Major issues and questions about youth and using the online environment include the following:

⁴ For more information, see <http://www.gethealththe.org> (accessed August 15, 2020).

- Do youth have the skills needed to use the online environment to improve their health?
- Are youth able to critically evaluate information and messages they see?
- The digital divide: Most have access to the online environment, but some access may be inconsistent or limited (i.e., data limits), and what about skills or outcomes of use?
- How various youth access the Internet may differ significantly.
- Parents and families have different rules about interacting with the online environment.
- Libraries and schools often have filters, restricting certain content.

There is also a lot of potential within the online environment:

- Provides greater access to health information
- Allows youth to connect with and learn from others
- Provides an easy way to host programs, videos, and courses to teach health literacy skills to youth
- Youth are already accustomed to doing everything online
- Can consider how to use online resources to better connect youth to health services
- Can use a youth-engaged approach to designing information and programs

Ideas for future research and practice as identified by Manganello can be found in Box 3-2.

BOX 3-2

Areas for Future Research as Identified by Jennifer Manganello

- Conduct research to better understand the links between the online environment and health literacy (issues and potential).
- Consider new measurement tools.
- Support funding for the development of programs to build skills.
- Encourage multidisciplinary collaboration: public health, communication, education, information studies, and computer science.
- Partner with online learning companies, schools, and community organizations.

SOURCE: Adapted from a presentation by Jennifer Manganello at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

DISCUSSION

Terry Davis from Louisiana State University Health Shreveport asked Noonan about the process to engage participants in coproduction, noting that in her own experience, those who want to participate in such projects are often already highly engaged, or have higher levels of health literacy and access to health care services.

Noonan agreed that it was a huge challenge for her team as well. The nephrology groups she had discussed earlier were “very intentional” about finding the right mix of patients and continuing to search until they had the breadth of diversity required to ensure the project was meaningful. She noted, “We found it especially challenging to reach individuals with limited English proficiency, along with other communities that are more suspicious of the health system.”

Terri Ann Parnell from Health Literacy Partners added that in a similar project, she had found that it was effective to have patients who were “early adopters” of such programs serve as recruiters for other patients.

Bonni Hodges from State University of New York Cortland and SOPHE noted that health literacy skill development needs to start early in schools. She asked the panel, “What is the pedagogy of health literacy? How do we teach preprofessional folks how to teach health literacy skills?”

Kolbe replied that the question highlights the complexity of combining teaching health literacy skills with any other educational discipline; for example, physical education. He pointed out that SOPHE has led efforts to credential secondary school health education teachers, but that the potential utility of such credentialing could be limited by unrelated factors. A school administrator with an ever-shrinking budget might not have a choice but to hire someone primarily trained in physical education and also certified to teach health education as opposed to a SOPHE-credentialed health education teacher.

Manganello added that school health education is particularly complex for students with individualized education programs (IEPs), in that there are usually not specialized health education classes for them. Importantly, Manganello noted, students with special needs or disabilities who have IEPs should have access to comprehensive health education.

Earnestine Willis from the Medical College of Wisconsin asked how the panelists sustain or evolve models so that they remain relevant as their communities change.

Manganello said that she uses her model as a framework, considering it more as a representation of the socioecological model, applied to a certain population around the topic of health literacy, and she adjusts it depending on the project or how she needs to use it.

Olayinka Shiyabola from the University of Wisconsin–Madison School of Pharmacy asked Manganello how youth find health information at all, considering that there are access issues to getting online, and that minority and underserved populations, who are more likely to have limited health literacy, are even more likely to have access issues. Manganello replied that there are some phenomenal resources about health that are online, but they are not available in one place. One plan she has is to consolidate information where gaps exist, and better disseminate it so that youth know where it is and how to access it.

Elaine Auld from SOPHE asked if the panelists thought health literacy could ever be a metric for quality school health education and public accountability in the way many STEM subjects are, knowing that there is a lot of research needed in terms of how it is measured.

Kolbe replied that unless health researchers can work with their colleagues in education (who would be asked to implement such health education programs and use health literacy assessments) in a sustained, multidisciplinary capacity, it would be very difficult to achieve this without looking at additional educational outcomes.

Sneha Dave from the Health Advocacy Summit asked Noonan if social workers were a part of any coproduction plans, noting that social workers can provide holistic care, including promoting health literacy.

Noonan replied that it varies across the country and is based on the health care system's resources. She added that there are social workers on all of the teams at Atrium Health, adding that Atrium Health is fortunate to have that in their quality improvement process right now. However, she said, they are not working in primary care, nor in the pediatric general population of private practices, where they could also be a huge benefit to the care team and to patients.

Dave asked Noonan about the process by which medical students are taught about IEPs and 504 plans.⁵ Noonan replied that it is a question of when to incorporate those details into a pediatric residency curriculum, or a medical school curriculum, adding that she learned about both in medical school but did not realize their importance until well after she obtained her degree. She also added that in North Carolina, schools cannot suggest that a child should have a 504 plan because to do so is considered discriminatory.

Maresha Walker from Children's National Hospital asked what pediatric health systems might be able to do to fill the gap around comprehensive health education. Kolbe noted that Washington, DC, has done a terrific

⁵ For more information about the differences between an IEP and a 504 plan, see <https://www.washington.edu/accesscomputing/what-difference-between-iep-and-504-plan> (accessed May 5, 2020).

job at implementing broad-based school programs, and that one of the reasons CDC developed the WSCC framework was because health services and health education are integrated and need to complement each other. He added that the American Academy of Pediatrics has been supportive of that integration, addressing it in its guidelines, *School Health Policy and Practice*.⁶

Noonan added that Atrium Health provides virtual clinics for schools, which has resulted in dropping absentee rates at the school by about 30 percent. Children's hospitals can help lead the way, she said, as long as they collaborate with school systems and other community-based organizations to change outcomes. Partnership is also a way to build trust among patients, with multiple organizations and sectors working to serve their needs.

Elizabeth Cook from Child Trends asked if school-based health centers are particularly good models for improving health literacy.

Kolbe answered that the evolution of school-based health centers has been rapid and serves as a major way to improve health.

The evolving data on school-based health centers, continued Kolbe, suggest that they have a positive effect, particularly on students with chronic health conditions, by improving or increasing their attendance when they otherwise might be unable to either attend or adequately pay attention because of their health condition. School-based health centers provide an important way to address inequalities that stem from disparities among students both with and without chronic health conditions.

Marina Arvanitis from Northwestern University and Lurie Children's Hospital of Chicago asked panelists if there was a field adjacent to health literacy that they would encourage their colleagues to explore. Manganello replied that she has been delving more into the educational technology field, along with information studies and computer science. Librarians and information literacy faculty at the University at Albany have worked with her on the Get Health'e' project, providing different perspectives to achieve the same goal. Those different perspectives are really critical to her work, she said.

Sarah Benes from Merrimack College and SHAPE America asked what kind of research needs to be done to move the needle on health education in schools.

Kolbe replied that two types of research are critical. One is measuring health literacy, which is broad, integrated, and complex. The second type of research is trying to understand how the fields of public health and medicine can collaborate with the education field, conducting joint research that is jointly funded.

⁶ For more information, see <https://ebooks.aappublications.org/content/school-health-policy-and-practice-7th-edition> (accessed August 15, 2020).

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4

People: Research and Lessons from Addressing Specific Populations' Health Literacy Needs

The second panel of the workshop was moderated by Marina Arvanitis, assistant professor of medicine at the Northwestern University Feinberg School of Medicine. Arvanitis introduced the panelists: Deena Chisolm, professor of pediatrics and public health at The Ohio State University, director of the Center for Innovation in Pediatric Practice, and vice president for health services research in the Abigail Wexner Research Institute at Nationwide Children's Hospital; Gail Nunlee-Bland, professor of pediatrics in medicine at the Howard University College of Medicine and chief of endocrinology and director of the Diabetes Treatment Center at Howard University Hospital; and Steven Hoffman, assistant professor at the Brigham Young University School of Social Work.

The panel was charged with exploring research and lessons learned from addressing specific populations' health literacy needs.

HEALTH LITERACY FOR YOUTH WITH SPECIAL HEALTH CARE NEEDS

Deena Chisolm, The Ohio State University

“Adolescents with special health care needs” (SHCN) refers to a broad concept that includes any teen who has more interaction with the health care system than their average peer. For example, this includes but is not limited to adolescents with allergies and asthma, cystic fibrosis, sickle cell disease, cerebral palsy, or muscular dystrophy. It is a broad population, but all adolescents in this population share a need to understand how to

successfully interact with the health care system, especially as they transition into the adult health care system.

Statewide survey data reveal that 23 percent of Ohio adolescents have SHCN (Chisolm et al., 2013). Adolescents with SHCN are more likely to be from low-income and socioeconomically disadvantaged families (Chisolm et al., 2013). The combination of economic distress and health needs means that they are also more likely to have unmet medical, dental, and prescription medication needs. Adolescents with SHCN require more attention to ensure that they each receive the services they need, and that caregivers and clinicians can help them develop the skills they need to navigate the health care system.

Teen Literacy in Transition Studies: A Health Literacy Lens

Adolescents experience specific health care challenges in that they are starting to take over decision making and their own personal health care management. Unsurprisingly, this can be especially difficult for adolescents with SHCN. During transitions, families must prepare for changes in providers, disease management responsibility, insurance coverage, and more (Rosen et al., 2003). Additionally, less than 18 percent of parents receive desired, comprehensive counseling on how to prepare for transitioning their adolescent children to the independent management of their health care (Strickland et al., 2015).

Recent data show that young adults with SHCN and between the ages 18 and 25 are two to three times more likely than their adolescent counterparts to report being uninsured, having no usual source of care, having unmet prescription needs, and reporting fair or poor health (see Figure 4-1). This hurdle to receiving health care in young adulthood can be attributed to a variety of factors, for example, health insurance access or health literacy skills. While the Patient Protection and Affordable Care Act¹ (ACA) expansion of dependent-child coverage to age 26 increased some transitioning adolescents' access to health insurance, it only applied to the 53 percent of Americans under 65 who have employer health insurance (Commonwealth Fund, 2019).

Health literacy is also a major component of transition readiness. The Teen Literacy in Transition family of studies, which was funded by the National Institute of Child Health and Human Development and the National Institute on Minority Health and Health Disparities (NIMHD), explored this relationship. The NIMHD study had three main aims (Chisolm, 2018):

¹ 111th Congress, 2010, Public Law 111-148, Patient Protection and Affordable Care Act, March 23, 2010.

PEOPLE

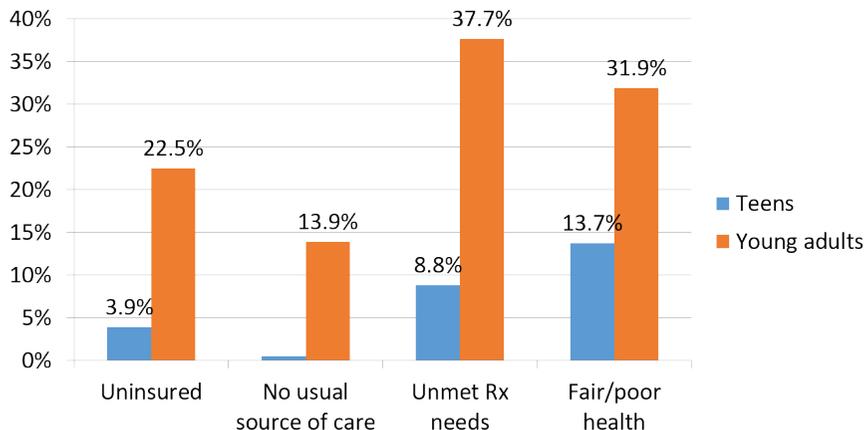


FIGURE 4-1 Health care transition measures among teens and young adults in a cross-sectional study.

SOURCE: Adapted from a presentation by Deena Chisolm at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

1. To assess the relationship between adolescent health literacy, parent health literacy, and effective planning for health care transition from adolescence to adulthood.
2. To assess the relationship between adolescent health literacy, parent health literacy, and adolescent health indicators, including health-related quality of life and health care utilization.
3. To identify mediators and moderators of racial disparity in health literacy in a large, diverse Medicaid-managed-care population of adolescents with special health care needs.

Relationships tested will include primary language spoken at home, rural/urban residence, and parental education. The study included Medicaid-managed-care enrollees in Columbus, Ohio, and southeastern Ohio, served by an accountable care organization (ACO) that was associated with Nationwide Children's Hospital Partners for Kids. Investigators used claims data to identify youth between the ages of 15 and 17 who were diagnosed with 1 of 20 conditions found in more than 90 percent of children with SHCN, and who had been enrolled in Medicaid for at least 12 months, so investigators could have some background data.

Investigators sent letters inviting each family to participate in the study; those expressing interest completed a secondary eligibility screening, which included the following:

- Using the Questionnaire for Identifying Children with Chronic Conditions–Revised (QUICCC–R)² to confirm that they had a chronic condition
- Ensuring that the participants had English proficiency because investigators were unable to accommodate other languages at the time
- Ensuring that participants had no significant developmental delay
- Establishing what, if any, level of functional limitation participants had

Investigators surveyed primary health care parents and the health care team, assessing word recognition, health literacy skills, self-reported literacy, e-health literacy, transition readiness, and health care utilization from a number of core measures:

- Rapid Evaluation of Adult Literacy in Medicine (REALM)
- Newest Vital Sign (NVS)
- Brief Health Literacy Screener
- eHealth Literacy Scale (eHEALS) Electronic Health
- Transition Core Indicator
- Transition Readiness Assessment Questionnaire
- Health care utilization (Medicaid Claims Data)

The sample size was 591 adolescents between ages 15 and 17, with an average age of 16.8 years. Regarding sex, race, and level of functional limitation,

- 48 percent were biologically male and 52 percent were biologically female;
- 58 percent identified as white, 31 percent identified as Black, and 12 percent identified as “other;” and
- 27 percent reported no level of functional limitation, 45 percent reported some level of functional limitation, and 29 percent reported a severe level of functional limitation.³

Though the ACO was based in an urban area, it also covered southeastern Ohio, a rural region otherwise known as Appalachian Ohio.

² For more information about QUICCC–R, see https://www.tn.gov/content/dam/tn/health/documents/QUiCCC_R.pdf (accessed April 20, 2020).

³ Numbers may not add up to 100 percent due to rounding.

General Health Literacy Assessment

The lack of health literacy skills among adolescents with chronic illness is a serious issue. When self-reporting through the Brief Health Literacy Screener, about two-thirds of study participants said that they had adequate health literacy skills, but when participants were assessed with REALM, a word recognition tool, the number dropped to 53 percent. Last, when asked to apply literacy and numeracy skills simultaneously through the NVS, just under 40 percent of participants had adequate health literacy skills, Chisolm explained.

e-Health Literacy Assessment

Using the eHEALS e-health tool, investigators also compared participants' confidence using e-health information with their previously assessed health literacy skills level. When it came to at least four of the eHEALS questions, having adequate or less than adequate (LTA) health literacy had no meaningful impact on the participants' confidence in their e-health literacy skills (see Figure 4-2). For example, regardless of having adequate or LTA health literacy, 46 percent of study participants agreed that they felt confident using information from the Internet to make health decisions.

Parent Health Literacy

It may be argued that youth health literacy levels are irrelevant because parents or caregivers are present during health care encounters, and clinicians can rely on them to translate or interpret material that is above the health literacy level of the youth. Chisolm and colleagues have shown that, unfortunately, this assumption is incorrect, as 23 percent of their study participants had parents who demonstrated LTA health literacy (Chisolm et al., 2015). Depending on the health literacy assessment, between 47 and 55 percent of parent–teen dyads had concordant adequate health literacy, while between 6 and 11 percent of parent–teen dyads from the study had concordant LTA health literacy (Chisolm et al., 2015). Additionally, between 22 and 36 percent of dyads had a parent with adequate health literacy and a teen with LTA health literacy (Chisolm et al., 2015). Accordingly, it should not be assumed that parents would be able to interpret important health information for their teens.

Racial Disparities in Health Literacy

One of the hypotheses of investigators has been that health literacy skills are not consistent across populations, specifically those differing with

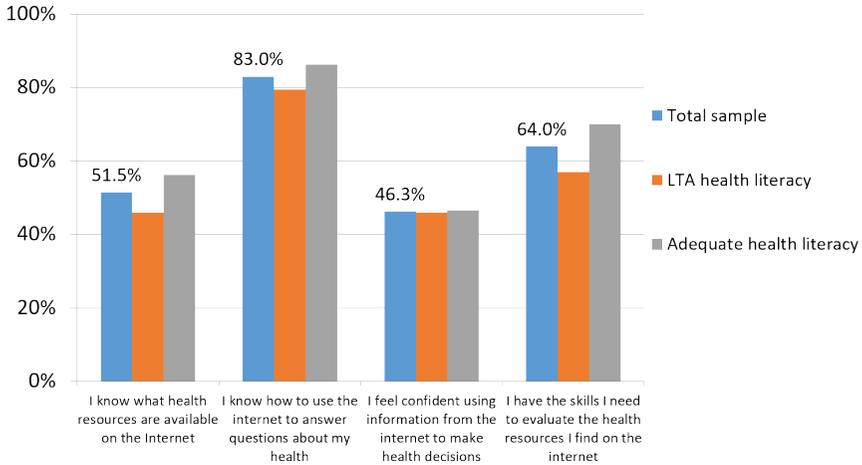


FIGURE 4-2 Self-reported confidence in e-health literacy skills compared with previous assessment of general health literacy skills among teens and young adults in a cross-sectional study.

NOTE: LTA = less than adequate.

SOURCE: Adapted from a presentation by Deena Chisolm at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

respect to race. In assessed health literacy using both REALM and the NVS, there was a significant gap between Black participants and non-Hispanic white (NHW) participants. In the REALM assessment, 42 percent of Black participants and 54 percent of NHW participants had adequate health literacy, while NVS assessments showed that 26 percent of Black participants and 48 percent of NHW participants had adequate health literacy.⁴ However, the self-reported health literacy assessment revealed that there was little to no difference in the study participants' views of their own health literacy skills (see Figure 4-3). Concordance between self-reported and assessed health literacy was much higher among NHW youth than for Black youth in the study. This concordance is another element to consider for those treating youth with SHCN in a health care setting.

Transition Communication

Investigators also examined the relationship between health literacy levels and whether the study participants were having transition discus-

⁴ There were no other racial or ethnic groups large enough to compare in this study.

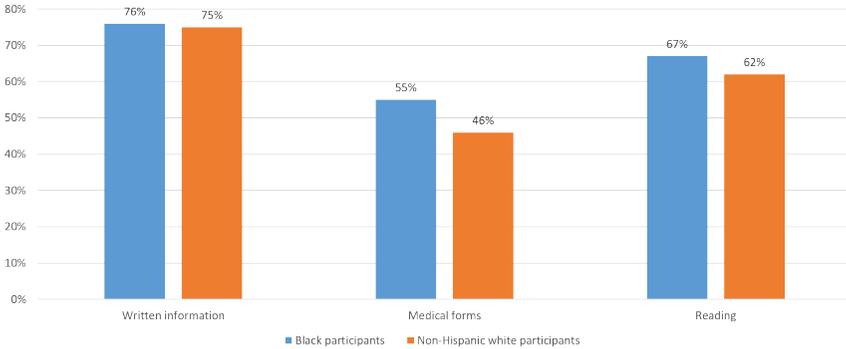


FIGURE 4-3 Self-reported assessment of health literacy skills among study participants by race.

SOURCE: Adapted from a presentation by Deena Chisolm at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

sions with their health care providers. Adjusted odds ratios indicated that there was no relationship between participant health literacy levels and having comprehensive transition communication, nor with having discussions about specifically transitioning to an adult health care provider, said Chisolm.

Clinicians were more likely to discuss adult health care needs and insurance with youth with lower health literacy skills than with youth with adequate health literacy skills but were more likely to encourage personal responsibility for health needs among youth with higher literacy levels. One possible explanation for this is that clinicians may have noticed an additional need for communication on needs-based questions with youth with LTA health literacy, and had more belief in the skill sets of youth with adequate health literacy for promoting self-management.

Key takeaways identified by Chisolm for helping teens successfully transition to the adult health care system are noted in Box 4-1.

BOX 4-1**Key Takeaways Identified by Deena Chisolm**

- Teens with chronic illness are increasingly expected to actively engage in their own health management.
- For some teens, health literacy limitations make that engagement difficult.
- Parents are not always the solution to communicating with teens about their health management.
- Health literacy is an important consideration for transition planning and education.

SOURCE: Adapted from a presentation by Deena Chisolm at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

**COMMUNICATING WITH A HIGH-RISK YOUNG
ADULT POPULATION: W.E.I.G.H.T. STUDY**

Gail Nunlee-Bland, Howard University College of Medicine

Background in Earlier Diabetes Research

Between 1996 and 2009, AARP and the National Institutes of Health (NIH) conducted a study that concluded that individuals who gain weight and have a body mass index (BMI) greater than or equal to 25 at age 18 will have a twofold increase in mortality risk compared with individuals who have a BMI greater than or equal to 25 at age 50 (Adams et al., 2014).

Between 1996 and 1999, NIH conducted another study to investigate the efficacy of different interventions for individuals at high risk for developing diabetes (DPP Research, 2002). The study's control group had no intervention, the second group was given a drug that was known to prevent or delay the onset of diabetes (metformin), and the third group was given a lifestyle intervention that included a case manager, supervised exercise sessions, culturally and linguistically appropriate educational materials, and more (DPP Research, 2002). The incidence of diabetes in the control group was 11 percent; the incidence in the group taking metformin was 7.8 percent; and the incidence in the group with lifestyle interventions was 4.8 percent (Knowler et al., 2002), demonstrating that the lifestyle intervention was by far the most effective at preventing or delaying the onset of diabetes. The average age of these study participants was 51 years.

W.E.I.G.H.T. Study

To adapt the W.E.I.G.H.T. (Working to Engage Insulin-Resistant Group Health Using Technology) study for young adult participants, Nunlee-Bland and colleagues started with a behavior-change counseling system known as Avoiding Diabetes thru Action Plan Targeting: T2D Prevention (ADAPT). The ADAPT system included behavior-change principles and persuasive psychology similar to the NIH lifestyle intervention study, but it also included a technology component: website-based, tailored reminders; frequent feedback about progress via e-mail and text; and other factors (Mann and Lin, 2012). The W.E.I.G.H.T. study aimed to “compare the effectiveness of a lifestyle change intervention delivered either using state-of-the-art communications or networking technologies or using lifestyle group visits” (Nunlee-Bland, 2020). The design was a nonmasked, randomized interventional parallel assignment trial, and participants were required to be African American, between 18 and 24 years old, with an impaired fasting blood glucose between 100 and 125, with a family history of type 2 diabetes mellitus, and with a BMI greater than or equal to 25. Participants were ineligible for the study if they were pregnant, unwilling to participate, had no web-enabled cell phone, had previously been diagnosed with diabetes, or had been previously diagnosed with a significant chronic illness.

Among other factors, investigators scored the following for the participants: Patient Activation Measure (PAM)-10 (see Box 4-2), Patient Health Questionnaire 9 (PHQ 9), Physical Activity–Godin Leisure Time, motivation for weight loss, the NVS, International Physical Activity Questionnaire, height, weight, BMI, and fasting blood glucose. The primary outcome for

BOX 4-2

Patient Activation Measure (PAM-10)

The Patient Activation Measure (PAM-10), developed by Judith Hibbard at the University of Oregon, assesses how activated a patient is in managing their own health, with four stages:

1. No active/important role in their health
2. Lacks confidence and knowledge to take action
3. Beginning to take action
4. Maintains behavior over time

SOURCES: Adapted from a presentation by Gail Nunlee-Bland at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019; Hibbard et al., 2004.

the W.E.I.G.H.T. study was improved patient activation; Nunlee-Bland and colleagues hoped that the final 172 participants would leave the study feeling more in control of their own health. Secondary outcomes included lowered BMI and hemoglobin A1c. The participants were divided into two groups: The Lifestyle Group Visits participants followed the Diabetes Prevention Protocol interventions. The participants worked in a workbook, tracked a log of their steps and calories, and used a CalorieKing book to look up calorie counts for foods they were eating. Participants in this group logged everything in a journal and met with a lifestyle coach for about 1 hour each week for 12 weeks.

The second group was the “tech group.” They were not required to come in person for weekly visits—every study component was available online. Participants received weekly compliance text reminders to encourage participants to take 10,000 steps daily and to make healthy choices about foods. The tech group participants also downloaded the MyFitnessPal and FitBit apps so they could record their caloric intake and track movement. Investigators provided the participants with personal health records from the Howard University Hospital Diabetes Treatment Center, which were integrated into and linked with their individual MyFitnessPal accounts.

Using the curriculum from the Group Lifestyle Balance Program developed at the University of Pittsburgh, Nunlee-Bland and colleagues developed their curriculum with pragmatics in mind. Participants were supplied with measuring spoons and cups for portion sizes, body scales, and, for the tech group, FitBits to correspond with their mobile apps.

After 12 weeks, 104 participants finished the study. The baseline characteristics between the tech and nontech groups—weight loss, PAM-10 scores, motivation for weight loss—were not notably different. However, during a 12-month follow-up (which included 64 participants), investigators found that the tech group had a significantly lower PHQ 9 score and better sleep habits, and that they were also more physically active.

Over time, the tech group became much more activated in their own health management, though there were no differences between BMIs or A1c changes over time. There are a few possible reasons for these results. As many as 75 percent of people between ages 18 to 29 get the majority of their health information using a smartphone (Smith and Pew Research Center, 2015) compared with 62 percent of the general population, suggesting that smartphones can be a crucial tool for sharing health information with young adults. Additionally, after 1 hour, people retain less than half of the information presented to them. After 6 days, they forget 75 percent of that information. The tech group was required to take quizzes and have minimum pass scores regarding health, whereas the control (nontech) group did not, possibly affecting retention of information. Overall, technology including smartphones and apps may be useful for reaching late adolescent and young adult populations to engage them in their health care.

HEALTH LITERACY IN YOUNG ADULTS AGING OUT OF FOSTER CARE⁵

Steven Hoffman, Brigham Young University School of Social Work

Youth in Foster Care

Approximately 437,465 youths are in U.S. foster care, with about 25 percent residing in relatives' homes; 45 percent residing in nonrelatives' homes; and 12 percent residing in residential or group homes (Child Welfare Information Gateway, 2017). About 55 percent of youth are “in the system” for more than 1 year. Youth who are adopted or reunified with family are no longer considered to be “in the system” (Child Welfare Information Gateway, 2017). A disproportionate number of youths in the foster care system are racial or ethnic minorities.

Youths in the system have an increased likelihood of chronic health conditions, substance use, and behavioral or mental health disorders, and they often struggle with health across the board (Council on Foster Care et al., 2012; Jones, 2014; Vestal, 2014). It is important to note that youths in the foster system should not be considered “bad,” as they are occasionally generalized. They have often had challenging childhoods compared with youths not in the foster care system. Youths in the system are also more likely to be homeless—between 31 and 46 percent have been found to experience homelessness at least once before age 26.

While working at Boys Town, a large residential treatment center in Nebraska, Hoffman assessed the health literacy of patients while they were in care, and then investigated educational outcomes after they left. Although the patients were not necessarily doing “terribly well” while in treatment, any educational gains they might have made had completely disappeared after they left treatment. Often, those patients were reading three to five levels below their grade level, and many of them would not graduate high school. In a residential treatment program like Boys Town, those patients might get “bumped up” by having intensive planning and training, but when they return to their community with the same people or situations they left, which may not be positive, they have a “big drop” in educational skills. Because health literacy is correlated strongly with educational outcomes, this is a problem.

⁵ A note about the limitations of the conclusions drawn from data presented during Steven Hoffman's presentation: The information for this presentation comes from two exploratory studies with small sample sizes focused on individuals facing unique circumstances. Information gathered does help to formulate an initial understanding of these populations but should not be considered conclusive or generalizable. Additional studies looking at youth formerly in foster care and Preparation for Adult Living program curricula across states are needed before firm recommendations can be made.

Former Foster Youth and Health Literacy

Youth who have grown up in the foster system face significant challenges that may put them at a higher risk of having limited health literacy (Shah et al., 2010; Trout et al., 2014) (see Box 4-3). They experience high rates of mobility—between five and seven foster home placements over the course of a few years. This can make it very difficult to maintain health records, in addition to the problem of lacking caregivers who might be aware of family medical history.

It is required that youth new to the foster care system be seen by a doctor and psychologist within their first few months. However, after the initial checkup, any health care they receive is often crisis care—a response to issues as they arise—as opposed to regular preventive care. When youths age out of foster care, they lose some state support services, one of the biggest of which is housing. The ACA was helpful in maintaining some access to health insurance, and there are certainly a lot of services that remain available to recently aged-out young adults, but those young adults may not be aware of them. They also often do not have any adult to turn to—they may have a case manager, but they also may never have met that case manager. In general, young adults transitioning out of the foster system may be inadequately prepared for the transition to adult living, and they have high rates of experiencing homelessness and unemployment.

Young Adult Medicaid Study

There are some services, like Preparation for Adult Living (PAL) programs, that have been instituted across several states to help youth prepare to manage their own health and lives. In Texas, a state-sponsored provider

BOX 4-3

Compounding Problems Associated with Health Literacy Among Young Adults Formerly in Foster Care

- High rates of mobility
- Low educational attainment
- Fragmented care and incomplete or inaccurate health histories
- Lack of preventive care (more often “crisis care”)

SOURCES: Adapted from a presentation by Steven Hoffman at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019; Trout et al., 2014.

of post-foster care services for youth provided a PAL facility and program in collaboration with a team of researchers at The University of Texas at San Antonio. The PAL case managers helped young adults who had recently aged out of the foster care system, mainly with employment and housing concerns.

Researchers recruited study participants from those in the PAL program, using e-mail, text messages, and talking with participants when they came into the PAL facility for checkups. Researchers used surveys, assessments, and small focus groups with a sample of 57 young adults between the ages of 18 and 26 who had aged out of foster care. About half of the sample identified as women, 56 percent of participants identified as Hispanic and/or Latinx, and 14 percent of participants identified as Black. Researchers used the NVS tool, although the focus groups conversation mainly steered toward critical health literacy. Based on the NVS tool, about 28 percent of the sample had adequate health literacy.

Compared with other populations where educational attainment is considerably higher, Hoffman and his colleagues knew that educational attainment would be a challenge for this population of foster youth, and because health literacy is strongly correlated with education, health literacy skills development was also expected to be a challenge. Existing research informed the researchers that fewer than 2 percent of the sample would go on to obtain a bachelor's degree, and the majority of them would never graduate high school. With high rates of homelessness and unemployment among the foster youth population, the case managers reported to the researchers that they focused primarily on meeting baseline checkpoints (housing, employment, health care), necessarily delaying a major focus on education and thus delaying a large building block of health literacy skills development.

Of note, every single focus group in the study had participants that were not aware that they were covered with former foster youth Medicaid health insurance until age 26. Some system-level issues that were difficult to navigate included the following:

- Automatically being removed from Medicaid coverage, requiring the individual to find out that they were no longer covered, call their case manager, and confirm that they are a former foster youth and do not have a job that covers health insurance
- Being provided with thick books listing local providers who accepted their insurance—except the books were usually outdated, and most of the providers no longer accepted their Medicaid plan
- Having to use a significantly outdated online patient portal system, requiring case managers to spend 3–4 hours on the phone with individuals to help them find a Medicaid customer service repre-

sentative who was knowledgeable about the specific former foster youth group

While the PAL program used by Hoffman's collaborating partners in San Antonio taught important life skills and subjects like banking, nutrition education, and sex education, it did not teach about health insurance, or navigating the health care system. An informal survey of states providing PAL programs revealed that the curricula are focused largely on nutrition education and sex education. There is inconsistency across and within states: Many states contract their programs out, and others operate independently, county by county. States that do have a statewide curriculum have little emphasis on critical health literacy so, practically, the existence of a PAL program does not provide any tangible health literacy skills development among youth aging out of foster care. The PAL programs could be significantly improved by providing critical health literacy training. Steven Hoffman's proposed recommendations for future research and practice can be found in Box 4-4.

BOX 4-4

Key Practical and Research Highlights Identified by Steven Hoffman

- Incentivized aging-out programs are great. Content and presentation need significant work to appeal to target audience.
- Effective Preparation for Adult Living programs are needed in every state.
- Former foster care Medicaid should be patient-centered and user-friendly.
- Possible solutions could include projects that pair doctors with youth as they age out of foster care.

SOURCE: Adapted from a presentation by Steven Hoffman at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

DISCUSSION

Arvanitis opened the discussion by asking all of the panelists what their research in special populations may be able to teach the workshop about promoting health literacy among all youth.

Chisolm replied that the right approach is likely modular, with some core foundational skill sets that every young person needs and that are age appropriate but, beyond that, there is no “one-size-fits-all” approach. Nunlee-Bland agreed, adding that the patient needs to be the center of their own health. The concepts of patient centeredness and activation are a major part of her own research focus. Hoffman added that the parent–child relationship should also be considered given that a number of studies support the importance and relationship of parents’ health literacy to their child’s health literacy and health outcomes.

Chisolm agreed and added that the parent–child relationship is more complex than sometimes acknowledged. For example, there are parents with high levels of health literacy and who are engaged with their children who do not allow their children to transition to self-managing their care, leading to teens and young adults with low self-efficacy and low self-advocacy because they have not been empowered by their parents. On the other end of this spectrum, there are parents juggling care for multiple children, their own multiple health issues, and even holding multiple jobs, who may rely on their child to manage their own health at a younger age because they are unable to manage it for them. It is important to recognize that the relationship between parent and child is different for each family, and all of those components need to be accounted for when building a model to promote health literacy among all youth.

Trina Anglin, formerly from the Health Resources and Services Administration, noted that since 2011, if states have PAL programs, they are required by the Administration for Children and Families to participate in the National Youth in Transition Database, reporting on six areas, all of which are related to health literacy:

1. Financial self-sufficiency
2. Experience with homelessness
3. Educational attainment
4. Positive connections with adults
5. High-risk behaviors (as measured by involvement with the criminal–legal system, among other factors)
6. Access to health insurance

These data can be accessed at the National Youth in Transition Database within a series of briefs. Unfortunately, Anglin noted, they stop at 2017.

Hoffman added that these data were informative, though the questions were more focused on whether the young adult had health insurance, not whether they could manage it, and there should be more qualitative data collected.

Earnestine Willis from the Medical College of Wisconsin asked whether states required preparation for PAL programs. For example, in prisons, transition programs must begin 6 months prior to discharge. Willis also asked whether Hoffman had any other proposed system changes. Hoffman was unsure about every state's requirements but confirmed that Texas started PAL programs about 1 year prior to discharge from the foster system, with monthly meetings. He noted that considering the cognitive developmental frameworks discussed earlier in the day, starting transition readiness programs "the year before youth turn 18 is probably a little late."

Hoffman added that if he could choose one recommendation, it would be how PAL programs are delivered, adding, "Most states are doing something, and we can change or mandate content, but delivery is often a challenge."

The NVS, REALM, and Other Assessment Tools

Hannah Lane from the Duke University School of Medicine noted that each panelist used the NVS in their work. The NVS has been validated for use in children and adolescents, though only from a few studies. Lane noted, "I think a larger conversation needs to be had among health literacy researchers and those collecting data on health literacy with children about whether or not the NVS is appropriate, or if it is sufficient, and if we need to develop modifications for using it to assess children."

Nunlee-Bland noted that she was particularly interested in using the NVS because her research was mainly focused on nutrition and health, specifically looking to see if study participants were able to read a food label and understand caloric intake. The NVS was a useful tool for assessing that among her college-aged population.

Chisolm said that the NVS is limited, so her team used the NVS with REALM. One of the reasons they used the NVS in addition to REALM was because participants capped out of the REALM assessment; they also had significant challenges using it. Chisolm explained, "Some of the younger people and even some parents just found the NVS too difficult. They were willing to walk away from the whole study if they were required to answer those questions." The information was helpful for the investigators but the respondent burden was high, and there is a lot more work to do to improve measurement and assessment.

Terry Davis from Louisiana State University Health Shreveport explained that she developed REALM and its derivatives, and that none

of the assessments measure health literacy. She noted, “REALM measures literacy, which is a marker for health literacy.” She believes that the best assessment for health literacy is teach-back.

Arvanitis noted that there are a number of recent systematic reviews of existing child-focused health literacy measures (e.g., Okan et al., 2018), and one criticism was that the measures were not developmentally appropriate. Manganello added that she does not look at tools like the NVS or REALM as measures of health literacy, but more to compare groups, as markers to assess change over time, or to see differences among groups. She acknowledged that it can be difficult trying to submit a grant proposal for intervention research, because funders want investigators to use a validated tool, but it can be difficult to access funding to validate newer tools.

Annlouise Assaf from Pfizer Medical and Safety added that one of the best uses for the NVS was in a health care provider’s office. Because it is a short assessment, it would give the health care provider an idea of what level of understanding a patient may have for the content the provider is presenting. And rather than burden the patient to increase their health literacy level, the burden is placed on providers and pharmaceutical companies to ensure that their materials are optimized and tailored in a way such that the patient would understand them fully.

Davis noted that her research showed that using the NVS could interfere with doctor–patient relationships because patients were ashamed or embarrassed about their literacy skills. She asked, “What does it mean to a doctor that your EHR [electronic health record] says you read at a middle-school level? Does the clinician have the skills to communicate effectively with the patient in an appropriate manner?” She is a firm believer in using assessments like the NVS for research but is more cautious about their clinical utility.

Arvanitis noted that her colleagues are considering using the Brief Health Literacy Screener as part of clinical care. She agreed that there are many limitations in that they might flag patients with low levels of health literacy, but it depends on the intentions of the assessor. She agreed that it would be difficult to roll out something as potentially challenging and frustrating as the NVS in a clinical environment.

Christopher Trudeau from the University of Arkansas for Medical Sciences asked how the NVS or a similar type of assessment conducted in a clinical setting might affect the way resources are allocated in health systems.

Nunlee-Bland said that the NVS is useful for ascertaining a patient’s baseline literacy level and using that information to help increase their skills. She and her colleagues tailored healthy lifestyle information for their participants and used the NVS to assess whether those materials improved their knowledge.

Chisolm noted that she is not conducting health literacy screenings in a clinical setting. She believes health literacy is more effective as a population-

level measure than as a practice or clinical-level measure. In the clinical setting, she said, “universal precautions should rule the day,” and teach-back and plain language should be the standard for care delivery. However, it is important to use tools like the NVS to understand a population and know what their limitations are, because populations with 30 percent or 90 percent low health literacy levels would require different approaches in terms of interventions.

Laura Noonan from Atrium Health noted that using validated tools in clinical settings can be confusing for families, especially when this affects treatment. For example, the Juvenile Arthritic Disease Activity Score is a validated tool used to identify juvenile idiopathic arthritis, but the questions only ask about the past week of the child’s health, as opposed to the past several weeks or months. These were validated in research for research purposes, she said, but does that mean they are useful in a clinical context?

Sarah Benes from Merrimack College and SHAPE America said that an important component in moving forward is how to bridge the gap between developing evidence-based measures and implementing them quickly enough that they positively affect health outcomes.

Chisolm added that researchers and implementers need to start thinking about the “acquisition of knowledge” component as opposed to the “knowledge” component or measure, because some skills can quickly become outdated, but the ability to develop and grow skills will always be important.

e-Health and Technology

Manganello asked how the panelists see technology or the online environment specifically being able to help the unique populations they work with, if at all.

Chisolm noted that she conducted a number of focus groups when her team was developing their e-health literacy video set. They had considered developing apps, but their focus group participants did not want them. Ultimately, their team hired two 16-year-olds to evaluate the videos they designed, which proved to be very helpful. Chisolm added that health systems and organizations need to be flexible enough to keep up with youth because whatever technology is best used one year among youth to share health information will be considered *passé* the next.

Hoffman noted that one of his two takeaways from the former foster youth study he conducted in San Antonio was that everyone should have a phone. He also thought that e-health literacy might be able to mitigate some of the lack of trust with the system, so that youths aging out of foster care can successfully navigate the online world, especially when they are unable to turn to family, parents, or a good social support network.

Activation and Transition Readiness

Arvanitis asked the panelists how they saw activation or transition readiness relating to health literacy among youth. In adults, she said, there is some evidence that they are independently affecting health outcomes, but is it the same case with youth? What research needs to be done?

Nunlee-Bland said that in her work with a young adult population, the patient activation measure correlated with adult literature in terms of improvement and in terms of health outcomes. Participants became more motivated in losing weight or maintaining weight loss, in knowing how to speak with their doctor, and in knowing when and how to take their medications.

Hoffman noted that the connection between actual health literacy and health outcomes is fuzzy and only gets fuzzier the younger the population is.

Chisolm explained that from her research, transition readiness and health outcomes appear to be independent. They do have some relationship, she said, but it is not very strong. In her research, reviewing health care utilization and outcomes going forward, there does not appear to be a significant relationship with transition readiness. As a researcher, the Transition Readiness Assessment Questionnaire (TRAQ) could be frustrating because it is not always clear if the lack of significant relationship means that they were measuring the wrong thing or measuring in the wrong way, or even asking the wrong questions. “I think there is still a lot of opportunity,” she said. “I think TRAQ is a great tool, and there is still opportunity to refine it to be more predictive of actual health care utilization and outcomes over time.”

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5

Partnerships and Community: Working with Youth and Their Communities to Address Their Health Literacy Needs

The next panel of the workshop was moderated by Elaine Auld, chief executive officer at the Society for Public Health Education (SOPHE). Auld introduced the three panelists: Hannah Lane, medical instructor, Duke University School of Medicine Department of Population Health Sciences; Rory Parnell, principal, August Martin High School, New York City Department of Education; and Sneha Dave, a student at Indiana University studying chronic illness, advocacy, and journalism and founder of the Health Advocacy Summit (HAS) and its program, Crohn's and Colitis Young Adults Network.

The panel was charged with exploring the importance of partnerships and intersectoral work to develop health literacy skills among youth.

DEVELOPING YOUTH PARTICIPATORY RESEARCH

Hannah Lane, Duke University School of Medicine

Youth participatory research is a research process that draws equally on the expertise and resources of researchers and youth community members. Youth and adults recognize each other's unique strengths, combine their collective knowledge, and take action to improve the conditions of young people's lives and communities through research. Youth participatory research is driven by five key principles:

1. Youth opinions are solicited, respected, and applied.
2. Youth identify their own issues, problems, and possible solutions.

3. Youth initiate project ideas and carry out goal setting, planning, and action.
4. Youth drive the process and are involved in all states of decision making.
5. Youth teach and empower other youth.

Civically engaged youth are less likely to participate in health-damaging behaviors. Including youth voices results in more appropriate youth-focused health prevention and intervention programs. This is especially true for communities that face stark health inequities, may have skepticism toward outside programs, or may have deep mistrust of health care professionals. Youth engagement in participatory research also builds skills in strategizing, critical thinking, leadership, communication, and a sense of community responsibility.

The following are some benefits of youth participatory research:

- Participation as researchers helps build health literacy skills.
- Partnering with young people helps researchers stay relevant.
- Young people can help researchers design age-appropriate measures.
- When young people drive the data, adults listen.

The Kids SIPsmartER Study (KSS) is illustrative of these benefits. Conducted in the Central Appalachian region of Virginia, the study focused on sugar-sweetened beverage (SSB) consumption. Children and adolescents in this highly rural, highly medically underserved region consume three to four times the amount of SSBs compared with the average American, but few intervention efforts had been attempted. The study aimed to engage children in a participatory research process to build local capacity for SSB-focused programs and adapt an existing health literacy-based curriculum for adults; the sample included nine children in grades 6 through 8 in a small Central Appalachian Virginia community. The theoretical framework for the curriculum was guided in part by the adult intervention, which focused on the theory of planned behavior, health literacy, and media literacy. Researchers added public health literacy, a concept developed in 2009 by Darcy Freedman, which encourages understanding information to make public health decisions that benefit an entire community, understanding health disparities, and understanding that kids can play a role in eliminating those disparities. An adult community advisory board helped researchers recruit a group of kids, whom they called Youth Ambassadors. The Youth Ambassadors attended a summer camp to help researchers adapt the curriculum, helped with the feasibility testing of the curriculum as well as some of the intervention delivery, and planned and executed a community advocacy event. Last, the Youth Ambassadors attended a few

meetings of the adult community advisory board to provide testimonials on their experiences.

During the week-long summer camp, researchers delivered the six KSS lessons, pausing after each one to solicit feedback from the Youth Ambassadors. The researchers used structured forms and discussions to help the middle school-aged participants provide input, asking what they liked and did not like, what they learned, and more pointed questions about what they might improve. The researchers also asked the Youth Ambassadors to review the measures the researchers had planned and highlight any items that they did not understand or that they thought might be confusing to their peers. The researchers conducted focus groups and surveys with the Youth Ambassadors at the beginning and end of the camp to see if the learning objectives targeted in the curriculum were satisfied, and facilitated some brainstorming among the Youth Ambassadors about how they wanted to continue to build capacity in their community.

During the feasibility study, conducted at a middle school in the region, the Youth Ambassadors helped researchers with some of the intervention delivery, including automated phone calls, writing and recording a public service announcement (which was included as a media literacy lesson), and helping with other general intervention delivery elements.

In preparation for the community advocacy event, the Youth Ambassadors designed a flier. They selected the most relevant information they wanted to include and distributed the flyers at a local grocery store with sugar-free hot chocolate samples. They also tracked who they spoke with and their responses.

The researchers found that right after the summer camp, the Youth Ambassadors recognized the health effects of high rates of SSB on their community, and they had many ideas about communicating that message through environmental changes to improve their community's health.

Although the Youth Ambassadors were initially less sure about their role in improving their community's health, their confidence increased with each conversation and brainstorming discussion, as did their understanding that this public health threat to their community was not inevitable. They developed a critical public health literacy skill: They believed that public health issues were not inevitable and that they had agency and power to help address them.

At the end of the KSS study and year, follow-up interviews revealed that the Youth Ambassadors continued to learn more about the excessive intake of SSB in their community. They continued to pay attention, they continued to associate SSB consumption with adverse health and environmental outcomes, and they understood the costs beyond health. The Youth Ambassadors were also confident that they could make a difference and reduce the problem long term, and many of them felt they had already made

a difference. They were proud of their contributions in helping deliver the interventions to their school, and they also felt they had made a difference at home with their families. They felt they had learned the skills they needed and gained the confidence to continue to advocate for reducing SSB in their community. Not only does participation in research build the skills targeted by the intervention the youth are meant to help develop, it can also lead to additional exposure to the importance of healthy behaviors and the costs of unhealthy behaviors for individuals and communities. It can also build capacity for skills like problem solving, communication, and leadership. Finally, it can encourage kids to become advocates for others to understand the adverse health outcomes others might experience even if they do not experience these outcomes themselves.

Another benefit of participatory research is that partnering with young people helps researchers stay relevant. It ensures that materials reflect reality in a fast-changing world, and that they are interesting, and combat misinformation as a trusted resource. Having youth involved in the development process also generates hype within the community, so researchers were more easily able to recruit youths for the second phase of the study.

Youth research participants help researchers design age-appropriate measures, ensuring that tools are relevant, understandable, and measure what is intended. They can also provide creative ideas to improve readability and make data collection more fun. Some common examples among young people include Photo Voice, apps, reflection journals, mapping, and community surveys. Also, when data collectors are peers, youth are more likely to respond with enthusiasm.

Having youth participants collect data and provide interpretation of the data increases the relevance, ensures information is shared with appropriate parties (the community advisory board, the middle school board), and can improve relationships, respect, and trust between youth and adults. Youth driving data can also increase the belief that programs should be expanded and institutionalized or well funded. For example, in KSS, the community advisory board was enthusiastic about the SSB efforts but skeptical about scaling. They were convinced to fully support the expansion of the project only after several of the Youth Ambassadors came to the advisory board meeting to share their experiences and explain how it had built their skills and affected their health behaviors.

Youth participatory research is crucial but not without its challenges. It is time and resource intensive, especially to scale. Researchers must provide incentives, transportation, food, and prizes, all of which would be difficult to do on a larger scale. Youth will also age, and their interests and motivations may shift over time. Also, when conducting youth participatory research, the sample may not be representative of youth with the highest need. In that vein, it is important to authentically engage youth, and not

BOX 5-1
**Best Practices for Youth Participatory Research Identified by
Hannah Lane**

- Understand the readiness of the community organizations that will be involved.
- Make sure research team members are well trained in youth participatory research principles and that you have a plan in place to deal with turnover of adult staff.
- Be realistic about your time frame based on your budget, age group, location, and priorities, and be transparent if things are not going as planned.
- Offer youth multiple ways to participate and be clear on specific tasks.
- Monitor the implementation process, make adjustments if necessary, and share your successes!

SOURCES: Adapted from a presentation by Hannah Lane at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019; LPC Consulting Associates, Inc., 2012.

tokenize them to further a project. Lane’s best practices can be found in Box 5-1.

**WORKING WITH PARENTS, STUDENTS, AND
COMMUNITY ORGANIZATIONS TO IMPLEMENT
HEALTH LITERACY IN A SCHOOL**

*Rory Parnell, August Martin High School,
New York State Department of Education*

Parnell was presented with the opportunity to become principal of August Martin High School (AMHS) in 2015. At the time, the school was formally labeled as “out of time,” and slated to close its doors. It was considered persistently dangerous and persistently struggling. It was also recognized as the least chosen high school in New York City. It was a less than ideal principalship for Parnell, but she could not reconcile the idea that children would need to travel even farther to get to school, or the idea that closing the school was the solution.

Students at AMHS are referred to as scholars. Two-thirds of AMHS scholars are Black, and most of them live in displaced housing. Many of them began grade 9 with a reading level between grades 4 and 6. AMHS scholars have working parents, three or more siblings in their household,

and travel between 45 minutes and 2 hours using multiple modes of public transport to get to school. When AMHS graduates go to college, they are likely to be the first in their family to attend. What never makes it into the demographic profile of AMHS scholars is their “unquantifiable resiliency that is innate in each of their spirits,” said Parnell.

Before Parnell became principal of AMHS, 98 percent of AMHS parents did not engage in school activities, and less than two-thirds of scholars attended school on average. Additionally, in a school of 550 scholars, 174 had long-term absences, meaning they had 10 or more consecutive days of absences, or they had never attended at all. The year Parnell started, the June graduation rate was about 24 percent, scholars had no access to mental health services within the school building, and there was one school nurse who was available 3 days per week.

The social, emotional, physical, and academic challenges that AMHS scholars faced needed to be met with a triangulation of support (see Figure 5-1). Closing the achievement gap academically required closing the

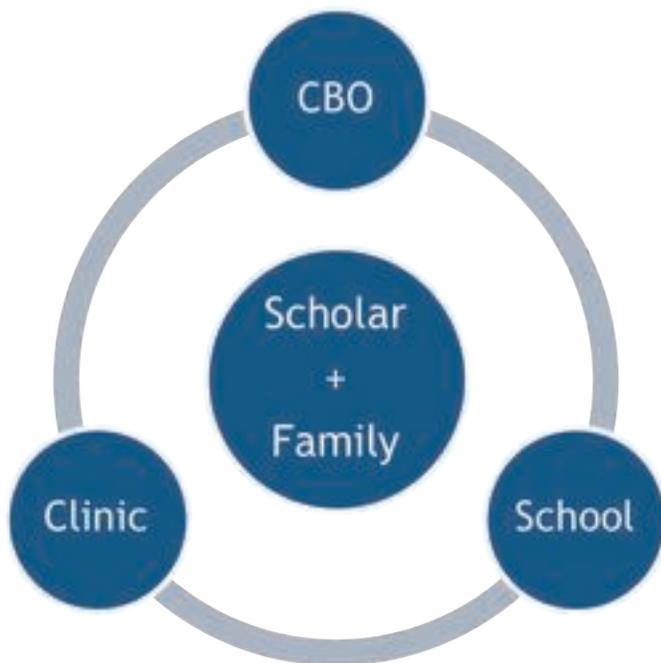


FIGURE 5-1 Health literacy partnership to close the access gap.

NOTE: CBO = community-based organization.

SOURCE: As presented by Rory Parnell at the workshop on Developing Health Literacy Skills in Children and Youth on November 19, 2019.

access gap to health literacy: The language of academics would depend on the language of health in order for AMHS to achieve its mission to inspire lifelong learners, and not just by sustaining life for youth but by enabling a high quality of life for them. To this end, AMHS utilized two main partnerships: a community-based organization (CBO) and a medical health clinic. Parnell replaced between 10 and 15 CBOs that were already affiliated with the school and had focused their services on extracurricular engagement with one CBO, whose sole focus was on the social and emotional welfare of youths, the Child Center of New York (CCNY). CCNY was also rooted in Jamaica, Queens, and was familiar with the needs of the youth in the community.

In an effort to support the school's turnaround, the Cohen Children's Medical Center (CCMC) collaborated with the school construction authority to open a medical clinic on the campus. Together, AMHS worked with CCNY and CCMC to create the support the scholars and their families needed.

CCNY offered vision screening and free eyewear, as well as family and individual counseling. They also provided support groups during lunch, including groups focusing on gay-straight alliances, mindfulness, yoga, leadership, and conflict resolution. They provided immigration services and clinics for AMHS families, along with relationship abuse prevention, attendance outreach and interventions, and home visits with the school to help scholars reengage. They also provided nutritional snacks, breakfasts, lunches, and dinners for scholars. CCNY also offered a restorative justice advisory whereby scholars participated in reflective processes to create action plans for their behavior as opposed to suspending them.

CCMC provided physical and behavioral health services right on campus. This allowed students to have materials and regular services accessible to them, including physicals for school or sport registration or job applications, immunizations, urgent visits for illnesses and injuries, laboratory screenings, reproductive health care, chronic illness care, weight management and nutritional counseling, HIV and sexually transmitted infection screenings, pregnancy screenings, diabetes care and management, health education counseling, and specialist referrals. The mental health services provided included clinical assessments and evaluation; individual, group, and family therapy; reproductive health counseling; crisis intervention; classroom education; and trauma-informed care.

CCNY and CCMC aligned their values with the values the school embedded in its learning community:

- High expectations academically, socially, and emotionally
- Scholar-centered (voice, choice, and leadership) values
- Unity: uniform, community gatherings

- Academics: college and career, music and art
- Restorative justice: scholar ownership
- Hands-on leadership
- Extended learning
- Trust

All teachers, school partners, and administrative faculty now know the names of every single child in the school. Two scholars also sit on the Food Scholar Advisory Council, where they can decide whether the meals that scholars are receiving throughout the district and city are nutritional enough to meet their needs for a good quality of life. AMHS supports families by offering workshops on nutrition, stress management, and “who their child is,” exploring challenges to academics. AMHS also offers family counseling so that parents, families, and community members can come throughout the year to build trust and relationships.

To create a true health literacy partnership, the AMHS community had to come together with reciprocal commitments from CCNY and CCMC. The changes have been remarkable. The first community school forum saw seven families show up; 4 years later, 347 families attended. The graduation rate increased from 24 percent to 84 percent.

Health literacy may not be a familiar concept for everyone who teaches, but it is still important to incorporate it into education. Well-developed health literacy skills open the door for overall improved health and well-being for children as they grow into adults: It is a skill set that can inspire lifelong advocacy.

FINDING COMMUNITY AND DEVELOPING SELF-ADVOCACY SKILLS

Sneha Dave, Indiana University, Healthy Advocacy Summit

Dave was diagnosed with ulcerative colitis at age 6. In middle school, the disease became so severe that she had colectomy surgery, along with multiple follow-up surgeries in a period lasting through the middle of high school. As Dave transitioned to adulthood, she realized there was not enough support for young adults living with invisible conditions, whether it was emotional, social, vocational, educational, or institutional support. She knew that young adults with chronic conditions have a period of incredible instability as they transition to independence. They have more autonomy, sometimes resulting in breaks in medical follow-up and non-adherence to treatment. Transition and transfer into adulthood are periods of immense change, and she knew this demographic had often been forgotten or left out.

In mid-2017, Dave decided to hold an event in Indianapolis to bring together young adults to discuss important topics, such as navigating the school system, and what transition looks like from high school to college and how to register with disability student services. The first event was held in October 2017, and the event grew into HAS. It received inquiries from all over the United States, reinforcing Dave's belief that there is a vast unmet need to connect and share resources among young adults with chronic health issues. Though originally based exclusively in Indiana, HAS now has chapters in several states, with plans to expand further throughout 2020 and beyond.

HAS is a first-of-its-kind organization that focuses on peer connection, advocacy, and access to educational information and resources as fundamental pathways to empowerment. The summits are a way to connect with peers, as well as a way to learn concrete tools and resources to use during transition through the school system and into the workplace.

The summits focus on adolescents and young adults between ages 13 and 30. In many ways, living with a chronic condition can render someone "ageless." For example, many young adults lost years-long periods of their childhood or adolescence with their condition, and they might be completing their undergraduate degree when they are 28 years old, or they might still be in school, taking periodic breaks. Thus, addressing transition topics should extend beyond their early 20s.

HAS is led entirely by young adults with chronic and rare diseases. The summits are exclusive to young adults, which provides a safe space for attendees to share their challenges. Some have compared this experience with serving on a patient advisory council, and reported that at the summits they have been able to share a lot more and be more honest about what they need.

In 2018, HAS expanded to North Carolina and Texas, and in 2019, added California. Once a summit is developed in a state, the goal is that it will sustain indefinitely, so HAS volunteers and staff work to foster a community and shared connection. Their advocacy is focused on a variety of topics, and the topics change each year. They have previously included health care policy and legislative initiatives. HAS provides ways for attendees to not only engage in personal advocacy but also advocate for their community and for their peers. For example, at the 2019 Indiana summit, a representative from Patients for Affordable Drugs spoke about drug pricing and how attendees can get involved in advocating for a better system that works for patients.

HAS also hosts speakers who focus on vocational rehabilitation and counseling. The HAS team has observed that their summit attendees tend to seek out disability student services when they already have an issue, and it can take up to 6 months to actually get accommodations. Attendees are

also sometimes unaware of their rights to accommodations, or that they are covered under the Rehabilitation Act of 1973, and the Americans with Disabilities Act. HAS events also address issues like workplace disclosure, including how individuals with chronic illnesses in the workplace have approached a conversation with their employer to discuss their illness. These presentations and discussions extend to the potential additional burden of disclosing an invisible illness to an employer, particularly if it is cyclical. These are complex topics about which attendees really appreciate being able to hear from their peers. Summit discussions also include Supplemental Security Income, and possible options for those who are unable to work, along with addressing mental health issues like anxiety and depression, both of which are common among young adults with chronic illnesses. This is another reason why those who do not have a chronic health condition are not allowed in the summits: Attendees are able to open up about emotional barriers and isolation they might face when they are young and have a chronic illness.

Summit discussions range from health insurance and managing care across states to pain management and communication strategies. Communication strategies are particularly helpful for the younger adults just transitioning to self-management. They start to think about how to prepare for a doctor's appointment, what types of questions to ask, and more. Additional topics include recreational therapy and maintaining reasonable levels of activity post-diagnosis.

The HAS community is also passionate about health policy literacy and transparency to ensure that patients in the next generation have a voice in the health care system and for policy issues that most affect them. HAS runs the Crohn's and Colitis Young Adults Network, which facilitates an international fellowship program for young adults living with inflammatory bowel diseases. In the coming years, they also have plans to roll out increased online programming, health equity initiatives, and a different overarching organization to encompass all of their programming for young adults.

DISCUSSION

Catina O'Leary from Health Literacy Media asked Dave how HAS navigates a situation in which someone's lived experience does not match medical accuracy. She asked, "How would you advise older adults with privilege and power on navigating that? How can we do better based on what you have learned?"

Dave noted that while HAS sessions are all peer led, some more technical topics are led by social workers, as attendees seem to trust social workers much more than doctors or other health care professionals. Other

peer-led discussions, such as navigating the education system and workplace, are better done by those with lived experience. They have a balance of both but strive to keep it peer led. She added that she has not encountered a discussion in which someone's personal experience was inaccurate, but that she and others are present to ensure concepts are communicated properly and that clarifying questions can be answered appropriately. She recommended following up with "how" questions, to explore further without making the speaker feel intimidated.

Nicole Holland from the Tufts University School of Dental Medicine asked Parnell about follow-up for scholars post-graduation. Parnell replied that no AMHS scholars were attending college when she began her role as principal, and now, nearly 40 percent are attending post-secondary education. She noted that when she started, she and her team were so busy triaging the situation that when the scholars left, the school team had no capacity to follow up. Now, AMHS has a tracking mechanism to follow them through post-secondary graduation, and they link the scholar to a success mentor for their post-secondary education.

Holland also asked Lane to elaborate on any of the frustrations or challenges she experienced conducting youth participatory research. Lane replied that authentically engaging community members in every step of a study process is really challenging. Projects can be hard to get off the ground because they take so much relationship building, but they can also be difficult to carry out, she added. It is the most important way to make changes that actually can be sustainable in a community, but it is also incredibly difficult to make sure your partnership and academic community relationship are authentic every step of the way. This challenge is only exacerbated with kids—for example, they are unable to provide their own transportation.

Chisolm asked Dave about how attendees on Medicaid might be able to learn about their own transition process, and if there is a contingent of summit attendees who are on Medicaid.

Dave replied that the summits do not only have attendees who are just turning 18, so they do not solely address the initial conversation around Medicaid transition. She added that they often have a social worker attend in order to break down every component of health insurance for attendees, which is usually helpful for all of them, and confirmed that HAS has more Medicaid-eligible attendees in Indiana compared with other summit sites. She added that health insurance is an area of greater focus for HAS because more and more attendees are worried about it.

Olayinka Shiyabola from the University of Wisconsin–Madison School of Pharmacy asked Parnell if AMHS faculty were able to track or evaluate health outcomes in terms of behavior change, and asked about the challenges they experienced and lessons learned.

Parnell said that it is easier to track academic data than behavioral data, but the school is working on it so they have more data on specific programs and their influences on scholar behaviors. She also added that the biggest challenge was to build trust between the community outside the school and the community inside the school. “We overcommunicate,” she said. “I am at the table with the CBO and medical health clinic weekly, even daily.”

H. Shonna Yin from New York University asked Lane about the extent to which she would engage youths in the process now that initial program development for the SSB study is done.

Lane answered that it is also really difficult because kids may move on to high school and change interests, but she does think youths can be engaged in helping with scaling the project as well. On the flip side, she said, it could be done on a smaller scale, because the participation itself could be the intervention: “You are simultaneously building a smaller group of champions who are involved to make sure that your research is going to be sustainable and institutionalized in the school or community, and that you are also potentially developing those kids into deliverers of the intervention.”

Auld asked if Lane had used PhotoVoice, a type of qualitative method in which community participants use photography and stories about their photographs to identify and represent issues of importance to them. Lane said that they did not, but she knows the method is useful and resonates with kids.

Sarah Shinkman from the Hemophilia Federation of America asked Dave if there were strategies or tools she found useful in training other young people to continue to train their own communities on why health literacy is important. Dave replied that she found teaching attendees about different topics to begin with was helpful. For example, a lot of attendees had never considered vocational rehabilitation as something that was applicable to them, and they were able to develop knowledge to talk about it with others. In this vein, attendees have been coming for years, and are now able to recruit others to attend the summits. They are able to share experiences about technical details, for example, “This is what you should do if you have a dietary restriction in college and are required to eat in dining halls.”

Earnestine Willis from the Medical College of Wisconsin asked Lane about how she dealt with the institutional review board (IRB) component of her research. Lane replied that there was a lot of back and forth on the IRB to ensure that the instructive structure was present and not coercive. The biggest issue they had was getting parental permission. The researchers had a very long permission form, mainly because they were providing food and transportation and working in small groups, so they relied heavily on

parents to make sure kids got to places on time. This is an issue with data collection in general, she added.

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6

Reflections on the Workshop

PREPARED REMARKS

The final panel focused on reflecting on individual takeaways from the workshop. Terri Ann Parnell moderated the discussion, which opened with three presenters offering prepared remarks (see Boxes 6-1, 6-2, and 6-3). The presenters were Trina Anglin, former chief of the Adolescent Health Branch, Maternal and Child Health Bureau, Health Resources and Services Administration; Vanessa Simonds, associate professor of community health, Montana State University; and Earnestine Willis, Kellner Professor of Pediatrics, Medical College of Wisconsin.

DISCUSSION

Parnell asked Willis what common thread is necessary throughout all of the sectors to truly enhance health literacy among youth. Willis replied that the health professionals do not know the health education standards in schools well enough to reinforce them, and pediatricians do not always work closely with early childhood education and school systems to advocate for brain and cognitive development. She added that she would teach her pediatric residents about how to help parents make decisions about quality early childhood education environments—to help with bridging across sectors for families that otherwise may not occur.

Anglin agreed, adding that although there is wonderful evidence of early childhood education program effectiveness, it has not been translated

BOX 6-1
Remarks by Trina Anglin

As an adolescent medicine physician, I think about health literacy skills from both a clinical and a youth development perspective. My federal position in HRSA's [Health Resources and Services Administration's] Maternal and Child Health Bureau had a dual focus: school health, especially school health services, and comprehensive adolescent health from the perspective of public health, especially health care services. My comments reflect this background.

I want to tell you about an experience I had early in my career that confirmed for me the importance of school health education classes for developing students' health literacy skills. In the mid-1970s, I worked at a large county hospital as part of my advanced fellowship training in ambulatory pediatrics. The young man who delivered my family's newspaper was then 13; we lost touch with him when his newspaper route was changed. Several years later, while a senior in high school, he contacted me at the hospital, worried that his girlfriend was pregnant. When they arrived for their visit, he explained that they had been using the rhythm method, but he had been excused from health education classes because he was an honor student. He found out from his friends, too late, that he and his girlfriend had been using the rhythm method incorrectly, so that every sexual experience had taken place during a time of peak fertility. He ruefully declared that his school should have required health education for all students, including honor students—no one should be excused. Clearly, this life-changing experience could have been prevented by having accurate information, a foundation for developing health literacy skills. I started my career with a high regard for quality health education for all students.

I want to express my deep appreciation for all the excellent and thought-provoking presentations. I know that each speaker exerted tremendous effort to develop a thorough and scholarly presentation. I do have several comments and suggestions.

My first comment reinforces the importance of reaching out to young adults, youth who have left high school and are between the ages of 18 and 26. Compared to adolescents, young adults have higher rates of adverse health behaviors and difficulty with behavioral health issues. They bear the consequences as measured by higher morbidity and mortality rates. I am especially concerned about the many young adults who are not attending college. They face greater socioeconomic and behavioral challenges compared to students attending 4-year colleges, and there is no easy way to reach them as a population to strengthen

their health literacy skills. More than 30 years ago, the William T. Grant Foundation called this diverse group of young adults the “forgotten half,” and they indeed largely remain forgotten.^{a,b} It is essential for us to learn how to help young adults develop health literacy skills as a strategy for decreasing their involvement in risky behaviors and increasing their access to health care services. As a community of health educators and health care professionals, we need to develop sets of strategies for reaching the many subgroups of the young adult population.^c

My second comment concerns our charge to think about collaboration. I would like to focus on how communities can strengthen the development of young people’s health literacy skills. As emphasized by Dr. Kolbe, it is extraordinarily important that states and local school districts assure high-quality, comprehensive health education for, and deliver it to, their students.^d These efforts can be augmented and complemented by including other community stakeholders in these efforts.

First—and this comment is more of a vision than a construct or an action with an empirically studied methodology—is that health care professionals, including pediatricians, family medicine physicians, and nurse practitioners, can reinforce and affirm health education messages provided within classroom settings. We know that every clinical visit, if it is conducted well, should include a health education message targeted to the reason for the visit. If the young person is there for a health care checkup, more formally called a visit for clinical preventive services, the young person and even his or her parents should receive what pediatricians call anticipatory guidance. These health messages are framed according to the patient’s development; they are based on the young patient’s age, address their risk status, and consider the patient’s life situation. *Bright Futures: Guidelines for the Health Supervision of Infants, Children and Adolescents*, now in its fourth edition and published by the Academy of Pediatrics with support by the Maternal and Child Health Bureau, contains extensive descriptions of health messages for almost any scenario. We know that many pediatricians are interested in school health and would welcome working collaboratively with their local school districts’ health educators to develop such a collaborative effort.

^a William T. Grant Foundation Commission on Work, 1988.

^b Rosenbaum et al., 2015.

^c IOM, 2015.

^d For more information, see <https://www.cdc.gov/healthyyouth/data/profiles/index.htm>, <https://www.cdc.gov/healthyyouth/data/shpps/index.htm>, and <https://nces.ed.gov/nationsreportcard/about> (all accessed May 5, 2020).

BOX 6-2
Remarks by Vanessa Simonds

The first point that really resonated with me is the role that young people play in their families, thinking about the role of parents' literacy, how that impacts their children, how child literacy impacts their health, and how that can be a very complex interaction. We need to think about the role that culture plays in families and how that is impacting youth health literacy skills and outcomes.

Among the Crow Indian people, where my family comes from, children are viewed as sacred and pure, and through the research that I do, we have found ways to promote health literacy among youth and, in turn, have youth share that information with their parents. However, we first had to have conversations with the community to make sure it would be appropriate in Crow culture. My community advisory board talked about it, too, but we had to make sure that I talked to the larger community. I spoke with elders about whether children can play a role in sharing information with their parents. There are cultural strengths regarding the child's role in the family that we can build on when we want to think about health literacy among youth.

Second, I want to highlight partnering with schools. I really enjoyed Parnell's presentation today because schools are places where we can develop those [healthy] behaviors, and redirect those negative behaviors we start when we are young, and that's a place where we can reach youth to provide health education. I appreciate the calls to develop recommendations for health education.

However, again, culture and context need to be attended to. Research in science education shows that minority youth, and American Indians particularly, can be alienated by the way that science is presented to them, particularly when it is not in a culturally responsive manner. And health education has a similar problem that may need attention.

I am a community-based participatory researcher, and I appreciate the multiple presentations today that included participatory approaches. That is one way to address cultural incongruence and misunderstanding, to address the mistrust that was discussed today, and to build health literacy skills among youth. We have seen in our work that having youth be on participatory projects builds their health literacy skills.

However, I also appreciate the challenges of working with youth. I use Hart's participation ladder in my research, and it can be difficult. We get information [about the community] from our advisory board, which is made up of adults who have an agenda. I have approached the youth, and it was difficult to present information about the study in a way that engaged them as authentic partners. I appreciate the challenges around engaging youth discussed today, as well as identifying who the community is, who the community partners are, and maintaining respectful and reciprocal relationships.

In closing, education systems, medical systems, and health care providers that don't integrate cultural understandings and interests will fail to engage youth. That disconnect could further alienate them from receiving health information and/or accessing health services.

BOX 6-3
Remarks by Earnestine Willis

This morning, we started with a presentation of foundational information about child development and the current understanding of basic skills that we know children should have as they move along the different stages of their development. Dr. Yin did a great job of helping the audience understand the complexity of child development as a continuous learning process. We recognize that children's developmental changes depend on others' resources. They also have vulnerability, and their epidemiology is not that of adults.

The discussion today brought up several important components of this topic:

- Places where health literacy skills can develop
- Populations and people with special health care needs, and lessons learned from research and practice among them
- Partners and the roles they play, and partnerships that we need to have which add broad complexity to this area

However, one element that I want to make sure we pay attention to is the policy piece that has to thread across all of those components. We must recognize that we have to advocate for those policy changes that prevent barriers to effectively implementing health literacy skills development for children and youth populations.

As the planning committee developed this workshop, I looked at some of the systemic reviews out there on health literacy, and some of my colleagues in pediatrics, and some of them have done tremendous work around the four skills—reading skills, oral expressive language skills, numeracy skills, and system navigation skills. All of those are very important, but there is still a lot more work to do.

In the 2017 systematic review of health literacy definitions and models, they reviewed 21 different models of health literacy, and found that 16 of them were designed and developed from a conceptual perspective providing a broad theoretical base for health literacy. The other five models were operational health literacy dimensions for the development of measurement tools. While 3 models represented a clinical—medical perspective, the other 18 took on a public health perspective. Each model was developed from a multisystem perspective; that is, health and education and community systems. They covered domains including health care, disease prevention, and health promotion, but because most of them were theoretical, it is difficult to determine the extent to which the models may be generalized.

The more important component in that review was that very few of the models looked at children less than 10 years of age, and those years are the essential building-block years, where core literacy dimensions are developed in childhood. Those key dimensions are clusters of related abilities, skills, commitments, and knowledge that enable one to approach health information competently and effectively, which results in health-promoting decisions and actions. Not only does this mean the acquisition of knowledge, it includes knowing when many necessary

continued

BOX 6-3 Continued

literacy attributes and their antecedents are developed. There are also consequences for families and communities and society that we need to be aware of and continue to study while ensuring that we mitigate unintended consequences.

Children are very resilient. We, as professionals, have to make sure we conduct programs and research that have some relevance and allow children and youth to become empowered in health-related decision making.

Many of the presentations today reflected that we are dealing with multi-dimensional and complex systems and processes that children and youth have to navigate, including the digital world and social media.

So how do we create research opportunities within this complex world that help us to be more effective in enhancing the health literacy of children and youth such that we get the empowered health-literate adult? This has the potential to result in a healthier adult society that lives on, so we can truly realize health equity.

Since I work in the world of community-based participatory research and in the community, some of my concern is always focused on sustaining the health literacy programs. How do I ensure that the community owns the programs after I—the health professional—move on to another topic of interest, whether I am dealing with oral health or dealing with vaccines? I think we do not always spend enough time finding ways to leave individuals and populations empowered by the research we conduct.

What often happens in studies that involve community organizing with youth is that the programs often resolve or are not sustained. The adults are the program's champions, and the youth move on in their development. There are studies and publications throughout the literature that talk about how we teach our graduate students how to do community organizing: Whenever youth conduct participatory research, as they age out, whether the subject is violence prevention or health literacy or any other subject, how do you ensure that the next cohort of children and youth are engaged and willing to pick it up and carry it on based on findings such that the research is iterative?

I have that same challenge with my residents. We conduct community initiatives, like adopting a school, and examine how to sustain those efforts with quality and effectiveness, or best practices for the population who will benefit from it.

Today has been rewarding. I think it challenges us all as health professionals to figure out where we should adjust our contributions to enhance health literacy among children and youth. I conclude with, start early, early, early!

into policy across the country. “Programs and policy can relate back and forth between each other. To me, that is a common thread.”

Willis noted that because she works in both the medical and early childhood education (ECE) communities, she knows that the ECE community does a thorough assessment of social determinants of health for each family, but they do not share that information with pediatricians. She added, “Families shouldn’t have to repeat that information.”

Jennifer Manganello from the University at Albany School of Public Health noted that policy issues regarding the online environment are enormous. She also added that in her focus groups, young adults often said that they were not taught how to understand health information, with the occasional exception prefaced by “one of my parents is a medical professional.” “Maybe we should do a better job of working with parents to let them know they should be working on developing these skills with their kids,” she said.

Cindy Brach from the Agency for Healthcare Research and Quality noted that crucial developmental moments in children’s lives are often overlooked in a child health context, especially if they are healthy. But those early moments are the perfect time for interventions to develop health literacy skills. She wondered how institutions can serve both parents and adolescents and navigate tension as adolescents assume more self-management responsibilities but are not yet fully independent.

Willis noted that, as a physician, she encourages a collective approach to serving patients.

Winston Wong from Kaiser Permanente wondered if any speakers could talk about how health literacy could have played a more proactive role in anticipating the phenomenon of e-cigarette use among adolescents.

Willis replied that youth were active in tobacco control campaigns. When she served as the chair for the Tobacco Control Board in Wisconsin, they had a modest initiative to have 100 municipalities adopt a nonsmoking policy, and it caught on rapidly because young people were active participants in the initiative. She added that more research should be married with interventions.

Closing out the discussion, H. Shonna Yin from New York University noted that parents often play the role of the trusted and knowing other actor who will help the child build health literacy skills. In that sense, health care providers can play an important role in guiding parents on how to engage their children in their illness, be it minor or chronic. She added that more thought should go toward developing frameworks that can specifically help health care providers know how to engage children every step of the way, starting in early childhood.

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Appendix A

Workshop Agenda

WORKSHOP OBJECTIVES

- To explicate the necessity of developing health literacy skills in children and youth
- To examine the research on developmentally appropriate health literacy milestones and transitions and measuring health literacy in children and youth
- To explore how children and youth learn about health and opportunities to develop health literacy skills through places, people, and partnerships

TUESDAY, NOVEMBER 19, 2019

- 8:15–8:45 a.m. **Registration open**
- 8:45–9:00 a.m. **Welcome and workshop overview**
Lawrence G. Smith, Roundtable on Health Literacy
- 9:00–10:00 a.m. **Session 1: Setting the stage**
- 9:00–9:30 a.m. **Health literacy in youth: Milestones and development**
H. Shonna Yin, New York University Grossman
School of Medicine

- 9:30–10:00 a.m. **Moderated discussion**
Moderator: Lawrence G. Smith
- 10:00–10:10 a.m. **Break**
- 10:10 a.m.–
12:00 p.m. **Session 2: Places**
- 10:10–10:15 a.m. **Where youth confront health literacy challenges and develop skills**
Moderator: Marin Allen, National Institutes of Health (retired)
- 10:15–10:35 a.m. **Health literacy in schools**
Lloyd Kolbe, Indiana University School of Public Health-Bloomington
- 10:35–10:55 a.m. **Health care organizations**
Laura Noonan, Atrium Health, Levine Children’s Hospital
- 10:55–11:15 a.m. **Health literacy and youth online**
Jennifer Manganello, University at Albany School of Public Health
- 11:15 a.m.–
12:00 p.m. **Discussion**
- 12:00–1:00 p.m. **Break**
- 1:00–2:50 p.m. **Session 3: People**
- 1:00–1:05 p.m. **Research and lessons from addressing specific populations’ health literacy needs**
Moderator: Marina Arvanitis, Northwestern University Feinberg School of Medicine
- 1:05–1:25 p.m. **Health literacy for youth with special health care needs**
Deena B. Chisolm, The Ohio State University College of Medicine

- 1:25–1:45 p.m. **Communicating with a high-risk young adult population: W.E.I.G.H.T. Study**
Gail Nunlee-Bland, Howard University College of Medicine
- 1:45–2:05 p.m. **Health literacy in young adults aging out of foster care**
Steven Hoffman, Brigham Young University School of Social Work
- 2:05–2:50 p.m. **Discussion**
- 2:50–3:00 p.m. **Break**
- 3:00–4:45 p.m. **Session 4: Partnerships and community**
- 3:00–3:05 p.m. **Working with youth and their communities to address their health literacy needs**
Moderator: Elaine Auld, Society for Public Health Education
- 3:05–3:25 p.m. **Developing youth participatory research**
Hannah Lane, Duke University School of Medicine
- 3:25–3:45 p.m. **Working with parents, students, and community organizations to implement health literacy in a school**
Rory Parnell, August Martin High School
- 3:45–4:05 p.m. **Finding community and developing self-advocacy skills**
Sneha Dave, Health Advocacy Summit
- 4:05–4:45 p.m. **Discussion**
- 4:45–5:45 p.m. **Session 5: Reflections on the day**
- 4:45–4:50 p.m. **Highlights of the workshop focused on research, collaboration, and policy opportunities**
Moderator: Terri Ann Parnell, Health Literacy Partners
- 4:50–5:15 p.m. **Prepared remarks**
Trina Anglin, Health Resources and Services Administration’s Maternal and Child Health Bureau (retired)

Vanessa Simonds, Montana State University
Department of Health and Human Development

Earnestine Willis, Medical College of Wisconsin
Department of Pediatrics

5:15–5:45 p.m. **Discussion**

5:45 p.m. **Adjourn**

Appendix B

Biographical Sketches of Workshop Moderators, Speakers, and Panelists

Marin P. Allen, Ph.D., has nearly three decades of experience in public and strategic communication in health and science at the National Institutes of Health (NIH). She served as the deputy associate director of communications, a public liaison, and the director of public information in the Office of the Director at NIH from 2004 to 2017, after which she retired from federal service. Her previous appointment at NIH had been as the communication director and a public liaison officer for the National Institute on Deafness and Other Communication Disorders. Prior to serving at NIH, Dr. Allen was a tenured, full professor and the chair of the Department of Television, Film, and Photography at Gallaudet University and served on a dual appointment as the interim director of public relations for the university. She began her career as a faculty member in communication at the University of Maryland, College Park. Dr. Allen served on the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy, led the NIH working group on health literacy, and has written and presented on a variety of health literacy, cultural respect, and disability topics. She has earned two Emmy awards for productions that aired on PBS and The Discovery Channel. Most recently, Dr. Allen was a scholar-in-residence at the Annenberg Public Policy Center of the University of Pennsylvania for the 2017–2018 term, where she developed and offered a seminar course in visualizing health and science. She is at work on a book on that topic, several articles, and a chapter on K–12 health literacy.

Trina Menden Anglin, M.D., Ph.D., recently retired from her federal position as the chief of the Adolescent Health Branch in the Health Resources

and Services Administration's Maternal and Child Health Bureau. During her 23-year federal career, Dr. Anglin conceptualized and framed guiding policies for 14 national discretionary grant programs addressing adolescent health and school health, and served as the project officer for many of them. Her portfolio emphasized capacity building for health care and public health professionals as well as improving the quality of health services delivery in multiple venues, including office-based settings, school-based health centers, and comprehensive school mental health systems. She also oversaw the National Coordinating Committee on School Health and Safety, which convened about 75 national organizations and professional associations with several federal departments and agencies to promote the health, safety, and academic success of children and youth. She co-chaired two Healthy People topic area workgroups for both Healthy People 2020 and 2030: adolescent health and early and middle childhood. Each topic area contains objectives pertinent to school health.

Subspecialty board certified in adolescent medicine, Dr. Anglin is an alumna of the Robert Wood Johnson Foundation's Clinical Scholars Program and holds a doctorate in sociology. Prior to joining the federal government, Dr. Anglin held pediatric faculty positions in two medical schools. She is a past president of the Society for Adolescent Health and Medicine and a senior fellow of the Council for Excellence in Government. She has received several national awards for her efforts to advance school health.

Marina Arvanitis, M.D., M.P.H., is a primary care internist, a pediatrician, and a health services researcher focusing on health literacy, patient-reported outcomes, and health care quality. She is particularly interested in understanding the life-course development of health literacy, its effects on individual and family health, and opportunities for its promotion. After completing a combined internal medicine–pediatrics residency, Dr. Arvanitis went on to a National Research Service Award Primary Care Research Fellowship at the University of North Carolina at Chapel Hill (UNC). Her fellowship work included completing a master's degree in health care and prevention at the UNC Gillings Global School of Public Health, and engaging in research in health literacy, health care quality, and evidence-based medicine, including at the RTI-UNC Evidence-based Practice Center. In 2016, Dr. Arvanitis began a faculty position at the Northwestern University Feinberg School of Medicine, where she is a researcher in the new Center for Applied Health Research on Aging. Within the center, Dr. Arvanitis is working with her mentor and health literacy researcher, Dr. Michael S. Wolf, to build a Life Course Health Transition Program. Dr. Arvanitis continues to provide primary care to children and adults through her practices at Northwestern Medicine and Lurie Children's Hospital of Chicago. She is also engaged in developmental and health literacy initiatives through-

out Northwestern and its affiliated institutions, including the Institute for Innovations in Developmental Sciences, and the Lurie Children's Health Literacy Task Force.

Elaine Auld, M.P.H., MCHES, has served as the chief executive officer of the Society for Public Health Education (SOPHE) since 1995. She oversees the organization's portfolio in professional preparation, professional development, research, advocacy, and public policy. She has steered four psychometric studies of the health education profession that undergird the health education professional preparation and practice of the health education workforce in all settings (K–12 school health, health care, public health, nongovernmental organizations, work sites, and international practice). She serves as the Coalition of National Health Education Organizations and American Public Health Association (APHA) Public Health Education and Health Promotion Section's advocacy chair and inaugurated SOPHE's Advocacy Summit, which has trained thousands of health education advocates in the past 20+ years. More recently, she has provided input to SOPHE's leadership on the future of school health education and health literacy, and she has published in professional journals and advocated for changes in professional preparation at the community college, baccalaureate, and master's level, toward stronger alliances between school and public health education. Ms. Auld holds her M.P.H. from the University of Michigan School of Public Health with a concentration in behavioral science and health education, is a charter Certified Health Education Specialist and Master Certified Health Education Specialist® (#0056), and has been honored with awards from SOPHE, APHA, Eta Sigma Gamma, Health Education Directory, and the National REACH Coalition.

Deena Chisolm, M.D., is the director of the Center for Innovation in Pediatric Practice and the vice president for health services research in the Abigail Wexner Research Institute at Nationwide Children's Hospital. She is also a professor of pediatrics and public health at The Ohio State University. Her research focuses on improving health and health care for children and families, and she has produced more than 75 peer-reviewed publications on pediatric health services, outcomes, and disparities. Her current projects explore how health literacy, health policy, and social factors, including housing, influence the health of at-risk adolescents transitioning to adulthood. Her research is funded by agencies including the National Institute on Minority Health and Health Disparities and the National Institute on Drug Abuse. Dr. Chisolm currently serves as the chair of the Ohio Commission on Minority Health, a board member for the Health Policy Institute of Ohio, and a member of the Centers for Medicare & Medicaid Services Advisory Panel on Outreach and Education. She earned her B.S. in biological science

education from Miami University and her M.S. in preventive medicine and a doctorate in public health from The Ohio State University.

Sneha Dave is a senior at Indiana University majoring in chronic illness advocacy and journalism. She created the Health Advocacy Summit, a nonprofit that facilitates advocacy events and year-long programming for young adults with chronic and rare diseases. She also created the Crohn's and Colitis Young Adults Network to connect young adults worldwide suffering from inflammatory bowel diseases. She writes for media platforms, such as the *U.S. News & World Report*, and has been published by outlets including the Center for Health Journalism. Ms. Dave has a research fellowship from the Harvard T.H. Chan School of Public Health, and she has received two fellowships from the Association of Health Care Journalists. Ms. Dave speaks publicly about advocacy for young patients, including on national television on Capitol Hill and at Stanford Medicine X as well as at the Harvard T.H. Chan School of Public Health. She also created and now chairs the first disability caucus in Indiana, and developed a voting guide to engage people with disabilities in the democratic process. Ms. Dave has served on various advisory boards and is currently on the board of directors for RespectAbility.

Steven Hoffman, Ph.D., is an assistant professor in the Brigham Young University (BYU) School of Social Work. He received degrees in social work from BYU–Idaho, Walla Walla University, and Arizona State University. Prior to joining the faculty at BYU he worked as an Institute of Education Sciences postdoctoral research fellow at the University of Nebraska–Lincoln, and as an assistant professor at The University of Texas at San Antonio. Dr. Hoffman's research looks at health disparities among underserved youth. He has studied health literacy, suicidal ideation, religiosity, mental well-being, and health-related quality of life among youth from various parts of Mexico, Guatemala, and throughout the United States. His current projects focus on health literacy among young adults formerly in foster care, and health literacy and emotional well-being among youth from rural areas of Central Mexico. Prior to beginning his academic career Dr. Hoffman held various positions as a social worker and community volunteer. He worked with youth as a psychosocial rehabilitation specialist, facilitated parenting groups for high-conflict divorced fathers, and functioned as a forensic social work consultant for a law firm.

Lloyd Kolbe, Ph.D., is an emeritus professor of applied health science at the Indiana University School of Public Health–Bloomington. He conducts public health policy research and development to improve child and adolescent health and education in the United States and in other nations. Dr.

Kolbe has held senior positions across private-sector, government, and academic institutions; has worked within the Reagan, G.H.W. Bush, Clinton, and G.W. Bush administrations; and has written more than 160 scientific publications about the health and education of young people, school health programs, and public health policies.

Among other appointments, he has served as the chief of evaluation for the Office of Disease Prevention and Health Promotion; the associate director of The University of Texas Center for Health Promotion and Prevention Research; a member of the U.S. Public Health Service Senior Biomedical Research Service; the chairman of the World Health Organization Expert Committee on School Health; the associate dean for global and community health at Indiana University; a member of the U.S. Environmental Protection Agency's Children's Health Protection Advisory Committee; and the chair of the Board of Scientific Counselors for the Centers for Disease Control and Prevention's (CDC's) National Center for Birth Defects and Developmental Disabilities, and for CDC's National Center for Chronic Disease Prevention and Health Promotion. Dr. Kolbe has worked to improve adolescent and school health programs in 28 nations, and served for 18 years as the founding director of CDC's Division of Adolescent and School Health.

Hannah Lane, Ph.D., M.P.H., is a medical instructor in the Department of Population Health Sciences at the Duke University School of Medicine. Her research uses multilevel intervention strategies to improve healthy eating and physical activity opportunities within organizations (e.g., schools) that serve socially disadvantaged children and adolescents. As a graduate student and postdoctoral fellow, she and her team developed and tested two health literacy and media literacy-focused interventions in both rural and urban schools. These interventions combined participatory action research approaches with advocacy training, with the dual goal of improving individual diet and physical activity behaviors as well as training students to be ambassadors for improving schools' health-promoting environments. As an early-career researcher with an implementation science-focused National Institutes of Health career development award, she continues to promote youth-driven integration of health literacy interventions in settings where children and adolescents frequently make decisions about their health, as well as developing more pragmatic, age-appropriate, and mixed-methods strategies to measure child and adolescent health literacy. Dr. Lane holds an M.P.H. from The George Washington University Milken Institute School of Public Health and a Ph.D. in behavioral and community science from Virginia Tech, and she completed a postdoctoral research fellowship at the University of Maryland School of Medicine.

Jennifer Manganello, Ph.D., M.P.H., is a professor at the University at Albany School of Public Health. She is a health communication scholar whose research focuses on health literacy as well as the effects of media on attitudes, behaviors, and policies that put young people (children, adolescents, and young adults) at risk for negative health outcomes. Other areas of interest include identifying best practices for the dissemination of health information to the public, as well as research on groups impacted by health disparities. Professor Manganello also examines the use of digital technology for health information and health interventions, also known as e-health. She has published work in journals such as the *Journal of Health Communication*, *Pediatrics*, *Public Health Management and Practice*, the *Journal of Children and Media*, and *Public Health Nutrition*. She earned her Ph.D. from the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health and was a postdoctoral research fellow at the Annenberg Public Policy Center of the University of Pennsylvania, before becoming a professor at the University at Albany.

Laura K. Noonan, M.D., joined the Department of Pediatrics at Carolinas Medical Center (CMC) in 1994. She is a founding organizer and the current director of the Center for Advancing Pediatric Excellence at Levine Children's Hospital at CMC. For more than 20 years, her focus has been on health care quality improvement (QI) while teaching courses at the local, regional, and national levels. She is currently involved in QI teaching or coaching roles for a variety of state and national collaboratives. Dr. Noonan also has extensive experience teaching and advising about health literacy. She was the collaborative director for Carolinas HealthCare System's (now Atrium Health's) QI-based health literacy initiative for 24 facilities across the second-largest nonprofit health care system in the United States. She is currently co-chair of the system's Health Literacy Steering Committee and has been an advisor for subsequent phases of the original initiative. She frequently lectures on this topic locally and nationally, including at the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy, the Institute for Healthcare Improvement's National Forum, the American Academy of Pediatrics' National Convention, and Boston University's Health Literacy Annual Research Conference. From 2015 to 2016, she was included in an Agency for Healthcare Research and Quality grant as part of a Technical Expert Panel for Organizational Health Literacy. She continually works on a national level to integrate health literacy into broader health care discussions.

Gail Nunlee-Bland, M.D., is the chief of endocrinology and the director of the Diabetes Treatment Center at Howard University Hospital. She is a professor of pediatrics and medicine. Dr. Nunlee-Bland has received several

grants to explore the use of technology to improve diabetes outcomes and patient engagement in underserved minority communities in Washington, DC. Most recently, she was the principal investigator on the DC-Baltimore Research Center on Child Health Disparities grant titled the W.E.I.G.H.T. (Working to Engage Insulin-Resistant Group Health Using Technology) Study funded by the National Institute on Minority Health and Health Disparities. The overall objective of the study is to educate adolescents and young adults on how to prevent diabetes by using state-of-the-art communications and networking technologies. Dr. Nunlee-Bland is the recipient of the 2010 American Association of Clinical Endocrinologists' Outstanding Endocrine Service to Minority Communities Award. Dr. Nunlee-Bland is passionate about improving access to quality diabetes care. This passion has translated into the American Diabetes Association Recognized Diabetes Education program. Dr. Nunlee-Bland is a graduate of the Howard University College of Medicine.

Rory Parnell has spent more than 20 years working as an inner-city educator for the New York City Department of Education. She has served inner scholars as a high school English teacher, an assistant principal, and an instructional coach for the Office of Renewal Schools, and she is currently in her fifth year as the principal of August Martin High School. Ms. Parnell has spent the past 4 years creating systems of culture and instructional improvement through a turnaround effort at August Martin, a previously state-designated "Out of Time" school. Ms. Parnell and her team have increased the school's graduation rate by 60 percent in 4 years, and August Martin is currently a school in "good standing." Ms. Parnell dedicates her career to the courageous, resilient, and soulful scholars that she has the honor to serve every day as she stands by her claim, "My scholars save me, way more than I will ever save them."

Terri Ann Parnell, DNP, M.A., RN, FAAN, is a nurse, a nationally recognized health literacy expert, and an award-winning author. She is the principal and the founder of Health Literacy Partners, a corporation that specializes in providing a tapestry of solutions to promote health equity by enhancing person-centered care, effective communication, and the patient experience. Her recent experience includes providing health literacy education and consultation to several New York State Delivery System Reform Incentive Payment Performing Provider Systems. Previously, Dr. Parnell was the vice president for health literacy and patient education for the Northwell Health System, where she was responsible for the health literacy strategic plan and integrating concepts of health literacy, language access services, and cultural awareness into core activities across the system. Dr. Parnell is a graduate of the St. Vincent's Hospital School of Nursing in

New York City. She earned a B.S. in nursing from Adelphi University, a master's degree in health care administration from Hofstra University, and a Doctor of Nursing Practice degree from Case Western Reserve University. Dr. Parnell is a member of the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy and has served as a committee member on the American Nurses Association Care Coordination Quality Measures Panel. She is a fellow in the American Academy of Nursing and The New York Academy of Medicine and has been selected for the 2016–2017 New York Academy of Medicine Fellow Ambassadors Program. In 2016, Dr. Parnell joined the TVR Communications Advisory Board as its chief nursing officer. Her second book, *Health Literacy in Nursing: Providing Person-Centered Care*, received an *American Journal of Nursing* 2015 Book of the Year Award in the category of Nursing Management and Leadership.

Vanessa Simonds, Sc.D., completed her graduate studies at the Harvard T.H. Chan School of Public Health, earning an M.S. from the Department of Epidemiology and a Sc.D. from the Department of Society, Human Development, and Health. In 2011, Dr. Simonds finished a postdoctoral fellowship with the Robert Wood Johnson Foundation Center for Health Policy at the University of New Mexico, where she was mentored by Dr. Nina Wallerstein. After her postdoctoral training, she joined the faculty at The University of Iowa College of Public Health as an assistant professor. While at The University of Iowa, she was selected for the 2012–2014 Native Investigator Development Program funded by the National Institute on Aging. Dr. Simonds uses community-based participatory research approaches to address health and health literacy issues ranging from chronic disease to environmental health among Native Americans. She is especially committed to designing and evaluating strength-based, community-centered outreach strategies designed in partnership with Native American communities. She is currently funded through Montana State University's Center for American Indian and Rural Health Equity to work in partnership with Crow community members to develop an environmental health literacy program for Crow youth and their families.

Lawrence G. Smith, M.D., MACP, is Northwell Health's physician-in-chief, serving as the senior physician on all clinical issues. He previously served as Northwell's chief medical officer. Dr. Smith is the founding dean of the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, which received full accreditation by the Liaison Committee on Medical Education and whose first class graduated in 2015.

Dr. Smith earned a B.S. in physics from Fordham University and an M.D. from the New York University Grossman School of Medicine. His

residency in internal medicine at Strong Memorial Hospital was followed by military service as a captain in the Army Medical Corps at the Fitzsimmons Army Medical Center in Denver.

Dr. Smith has held senior leadership positions in national societies for medical education and residency training, has authored numerous peer-reviewed publications in the area of medical education, and has received many awards and honors from national and international organizations. He is a member of the Board of Visitors of Fordham College. In 2011, he was elected to Mastership in the American College of Physicians. Dr. Smith was inducted into the Gold Humanism Honor Society in 2014, invited to join the Arnold P. Gold Foundation Board of Trustees in 2017, and made chair of the Gold Foundation's Program Committee in 2018. Dr. Smith serves on the executive committee and as the treasurer for the Associated Medical Schools of New York. He serves as the chair of the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy and is a member of the New York State Board of Education Advisory Committee on Long-Term Clinical Clerkships, and he is on the University of Rochester's Board of Trustees Advisory Council. He is a former regent of the American College of Physicians, a former member-at-large of the National Board of Medical Examiners, and a former member of the board of directors of the American Board of Internal Medicine.

Dr. Smith is the first recipient of the Lawrence Scherr, MD, Professorship of Medicine at the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell. He is the recipient of the Solomon A. Berson Alumni Achievement Award in Health Science, given by the New York University Grossman School of Medicine.

Earnestine Willis, M.D., M.P.H., is a Kellner Professor in Pediatrics, the director of the Center for the Advancement of Underserved Children, and the director of Health Equity and Urban Clinical Care Partnerships at the Medical College of Wisconsin. She has almost three decades of experience in addressing health disparities by the development of successful community initiatives to include research, education, and community services. Her interests span from analyzing the impact of systems on children and adolescents to applied public policy, community-oriented programs, medical education, health assessments, and diversity in medicine and child advocacy.

Shonna (Hsiang) Yin, M.D., M.Sc., is an associate professor of pediatrics and population health at the New York University (NYU) Grossman School of Medicine. She is nationally recognized for her research accomplishments focused on health literacy as a key factor related to adverse child health outcomes and poverty-associated health disparities. Her work in developing health literacy-informed strategies addressing medication safety, chronic

disease management, and obesity prevention, conducted as a Robert Wood Johnson Foundation Physician Faculty Scholar and as the principal investigator on grants from the National Institutes of Health/National Institute of Child Health and Human Development, the Centers for Disease Control and Prevention (CDC), the U.S. Food and Drug Administration (FDA), and the Patient-Centered Outcomes Research Institute have been recognized as models for transforming the delivery of clinical care, and have informed CDC and FDA initiatives. Dr. Yin serves as an executive committee member of the American Academy of Pediatrics' Council on Quality Improvement and Patient Safety, is the co-chair of the Research Standards Committee of the International Health Literacy Association, and has served on FDA's Risk Communication Advisory Committee. She is a key member of CDC's Prevention of Overdoses and Treatment Errors in Children Taskforce initiative, and served as the co-chair of the subcommittee focused on the standardization of pediatric medication dosing instructions. Her research, focused on improving the labeling and dosing of pediatric medications using a health literacy perspective, led her to be awarded the Institute for Safe Medication Practices Cheers Award in 2017. Dr. Yin is a graduate of the Massachusetts Institute of Technology and the University of Rochester School of Medicine. She completed residency training in pediatrics and an M.S. in clinical investigation at the NYU Grossman School of Medicine.