

# Health Literacy and Children: Recommendations for Action

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## ABBREVIATIONS

AAP—American Academy of Pediatrics

LEP—limited English proficiency

The views and recommendations presented in this article are those of the authors and participants, not the organizations with which they are affiliated or the funders of the conference or research.

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Health literacy is a cross-cutting priority for transforming quality of health care in the United States. The informative work of the articles published in this supplement to *Pediatrics* creates an imperative for pediatricians to optimize communication with parents and children and to develop necessary tools and strategies. In the commentary that follows, we address what we believe are needed actions in the arenas of policy, practice, education, and research to address the health literacy–related issues, problems, and opportunities with reference to children and children’s health.

## POLICY

### Responsibilities of Public and Private Agencies and Organizations

Public and private agencies and organizations that affect child health policy and health care delivery, public health, and education (eg, the Maternal and Child Health Bureau, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the US Food and Drug Administration, the American Academy of Pediatrics [AAP], and the Academic Pediatric Association), whose visibility, credibility, and resources can drive change, improvement, and funding, should be at the forefront of efforts to highlight the importance of health literacy, adopt, model, teach, and incentivize clear health communication strategies, and support evaluation and research to advance the field.

Health literacy should be explicitly incorporated into the medical home model, including both implementation activities and evaluation. Instruments such as the Medical Home Index, Consumer Assessment of Healthcare Providers and Systems (CAHPS), and Hospital CAHPS should include health literacy–specific items, especially related to teach-back and the extent to which care environments foster communication, invite questions, and simplify navigation. Data from such surveys can be used to guide policy, evaluate program interventions, and improve quality.

### Support for Plain-Language Principles and Materials in Health Communication

Federal agencies and other leading health organizations should ensure that written materials for patients or caregivers use plain-language principles by reducing their complexity and cognitive burden and developing standards for reader-friendly print materials beyond consideration of reading level. For example, family information and educational materials developed through federal Healthy Tomorrows or AAP Community Access to Child Health (CATCH) grants should be required to adhere to such standards. Supportive training and

technical assistance should be available for applicants and grantees to build capacity among more pediatric practitioners. All AAP patient and family publications should use plain language or have a plain-language version.<sup>1</sup> The AAP should make every effort to draw attention to these materials, educating members about the importance of health literacy and effectiveness of materials with more accessible language. AAP policy statements that address patient/family communication should include plain-language subject-related content.

### **Improvements in Health Care Systems**

Although health literacy interventions may improve overall outcomes, they may not eliminate health disparities. In fact, health literacy–related interventions may improve outcomes for people with both low and high literacy, but differential or very specific interventions may be needed for those with low health literacy. Certain severe health conditions or high-risk family circumstances may also result in varying impact of interventions for different populations or require targeted enhanced communication strategies to improve outcomes for those who are most at risk. Supplemental resources such as patient educators, patient advocates, care coordinators, or home health visitors can be used to help those with or at risk for low health literacy. Children with special health care needs and their families are candidates for enhanced health literacy–related strategies, especially those designed to promote self-management of chronic conditions. Community-based interventions (eg, in churches, schools, or child care centers) that use health-literacy strategies to improve chronic illness care and patient safety should be explored.

### **Development of Public Health Information**

Explicit attention should be given to health literacy and numeracy when public health materials and interventions are developed. Messaging should be guided by health literacy principles, including use of plain language in communication about topics such as newborn screening, vaccination, nutrition, emergency preparedness, and support services such as the State Child Health Insurance Program (SCHIP), Medicaid, and the Supplemental Nutrition Program for Women, Infants, and Children (WIC).

### **Inclusion of Health Literacy Measures in National Studies and Surveys**

Health-literacy measures should be included in ongoing national studies and surveys to identify associations between health literacy and population health indicators (eg, breastfeeding, immunization status, behavioral risk factors, and mental health). In particular, parental/caregiver health literacy should be included in the US Department of Health and Human Services National Children's Study, as should measures for pediatric health literacy that take into account developmental status.

### **Integration of Health Literacy in Quality-Improvement Activities**

Health literacy is integral to addressing the 6 aims of high-quality health care: safety, effectiveness, efficiency, timeliness, patient centeredness, and equitable treatment. Health literacy metrics should be part of all pediatric quality-improvement and patient-safety efforts. Those who design quality-improvement activities should explore the impact of health literacy initiatives on adherence, child health outcomes, efficiency, and cost-effectiveness; apply clear communication principles in

pay-for-performance models; examine whether and how health systems should assess health literacy in their patient and family population; identify what systems are in place to address low literacy; determine how patient assessments of care can be used to measure and improve quality; and encourage patients, families, and adult-literacy students to contribute to improvement efforts.

### **Reduction of Medication Errors Through Principles of Health Literacy**

Health literacy plays a critical role in medication safety, and patients and caretakers with low health literacy are at disproportionate risk of difficulty with deciphering medication instructions. Pediatricians should work with policy makers, regulatory authorities, safety experts, drug manufacturers, and pharmacists to reduce the risk for medication errors by designing, evaluating, and standardizing drug labels, measuring devices, and written and verbal communication for prescription and over-the-counter medications.

### **Support of Literacy and Health Literacy Through Clinical and Educational Programs**

Just as helping children grow up with good general literacy skills improves their health literacy and chance of effectively understanding and managing their own health and care, improving adults' general literacy fosters health literacy skills and pediatric caregiver capacity. Lifelong literacy should be supported via primary, secondary, and tertiary prevention: fostering emergent literacy during critical developmental periods through exposure to research-based programs such as Reach Out and Read, early Head Start, and universal preschool; creating schools in which students read at their grade level, those with reading and learning disabilities are identified early, and resources are

offered; incorporating health literacy–related skills into standard kindergarten through 12th grade curricula; and funding effective adult literacy and English-as-a-second-language (ESL) programs for those with limited English proficiency (LEP). Researchers, educators, and policy makers must identify which health literacy skills can be taught through the educational system and look for evidence-based strategies to implement effective curricula. Efforts should address the developmental continuum through pre-school curricula that reinforce health promotion activities among toddlers and their caregivers, and standardize kindergarten through 12th grade curricula to teach health literacy competencies across all educational disciplines (eg, science, mathematics, reading, social studies, health, and physical education). Adult-education modules that teach health literacy skills should be used in general educational development (GED) and English-as-a-second-language curricula. Health literacy activities can be integrated into after-school, camp, home-visiting and community-based parenting programs.

## PRACTICE

Addressing health literacy should be part of any framework for effectively improving delivery of quality child health services. Pediatricians and other child health providers must shift from the traditional paradigm of health care encounters as knowledge transfer from provider to patient/caregiver to one of building children's and parents' self-efficacy, motivating health-promoting behaviors, and evolving toward a paradigm of partnerships between patients/families and the health care team for decision-making, goal-setting, and self-management. Transition to adult self-care, especially for children with special health care needs, includes developing the capacity to advocate on behalf of oneself or one's child—seeking health infor-

mation and care, eliciting teach-back, asking clarifying questions, and navigating the health system. Pediatricians should shift from their traditional focus on conveying content that is “nice to know” toward ensuring understanding of what is “needed to know and do.”<sup>11</sup> They should recognize the critical role they can play in guiding or altering the trajectory of children's transitions to self-care. Improved understanding of parent/child-provider communication should guide identification and implementation of optimal practice strategies. Health providers should identify how they can enhance health literacy skills learned through educational programs with interventions at the practice and health system levels.

Universal approaches to addressing health literacy should be implemented, because even those with excellent literacy skills who are usually proficient in health literacy can sometimes find the medical environment difficult to navigate and report episodic problems in understanding health-related information, especially under conditions of illness, pain, medication effects, worry, or sleep deprivation. Strategies for additional or enhanced interventions for those with limited literacy must also be identified. While research is underway, existing practice-related interventions should be implemented: use of plain-language communication principles, teach-back, reader-friendly print materials, and creating a “shame-free” care environment (eg, giving parents the words to use and questions to ask through programs like Ask Me 3).<sup>12</sup> The Ask Me 3 program promotes 3 essential questions to improve communication between patients and providers: (1) What is my [child's] main problem? (2) What do I need to do [for my child]? and (3) Why is it important for me to do this [for my child]?

Because low health literacy is associated with adverse health behaviors

among parents and adolescents, strategies to affect behavior change (eg, motivational interviewing) should incorporate clear health-communication principles. Nurses, health navigators, health educators, care coordinators, case managers, child advocates, community health workers, and other multidisciplinary health care team members should deliver and reinforce key messages and assist families with goal-setting and adherence.

Children have multiple caretakers (eg, separated parents, grandparents and extended family, child care providers, school personnel, coaches) in arrangements that entail multiple potential “handoffs” of health and medical information throughout their day. Confusion and errors during these times, especially when a child is ill, might be reduced by use of plain-language handouts, 24-hour telephone or Web-based access to health information, communication tools such as videos, recordings, or electronic/mobile telephone prompts and reminders, and personal health records that can be accessed by any provider or caretaker. Assessment of how health care team members' time is used in dealing with problems created by poor communication in current delivery settings can gauge the potential impact of clear communication techniques on practice efficiency and improvement of effective care processes, and inform the business case for health literacy. The identification of effective communication interventions may offset the need for added time to improve the understanding of patients and families.

Risk management should call for the application of health literacy interventions and tools to optimize patient/parent understanding, especially for informed consent, shared decision-making, and episodic and chronic care. Incentives such as premium reductions may be offered to physicians who

document the use of clear communication techniques in their practice.

## MEDICAL EDUCATION

Health literacy's fundamental role in quality health care has implications for training pediatric clinicians who must be able to use health-communication techniques such as plain-language and reader-friendly print materials principles. In particular, teach-back, which is associated with improved outcomes among adults with diabetes,<sup>3</sup> should be incorporated into educational and training assessments of pediatric health professionals' communication competence. Determining whether parents and patients can explain key information by using their own words is an evidence-based technique through which health providers can ensure understanding or identify the need for additional education or support. Additional studies are needed to identify the best practices for teach-back and other communication strategies. Faculty and other mentors must learn to model appropriate ways to request a teach-back, inquire into caregivers' reading comfort, and make referrals to adult literacy programs. Maintenance of certification activities should also incorporate health literacy.

## RESEARCH

Research in health literacy and pediatrics should be focused on identifying improved measures of child and parent health literacy; analyzing the relationship between health literacy and prevention and treatment of child health problems; and assessing the efficacy and effectiveness of health literacy-related interventions in patient care, health system, educational, and community settings. It should draw on the expertise of pediatric primary and specialty providers, health services and informatics researchers, health-communications scholars, developmental and behavioral pediatricians and de-

velopmental psychologists, professional educators, pharmacists, community organizations, and parents and caregivers of all literacy levels.

Research opportunities exist in:

- Health literacy assessment
  - identification and validation of literacy-assessment tools for children and caregivers, including those with LEP
  - determination of the effectiveness and the role of rapid health literacy screening tools for individuals and populations to evaluate the impact of interventions on improving quality of care
  - understanding developmental aspects of health literacy and transitions to self-care: understanding the progression of health literacy skills from childhood through young adulthood and parenthood and the role of health literacy in transitioning to adult care and functional independence
  - assessment of the parent-child dyad with respect to health literacy over time: the transition from total parent care through modeling, teaching, supervision, and oversight to total care by the child/adolescent/young adult and how that varies according to health activity and population and provider characteristics
- Assessment of how the variability in access and quality of children's health care is affected by caregivers' health literacy
- Determination of how best to foster child health literacy independent of parent literacy
- Examination of the impact of patient and caregiver literacy and numeracy skills on disease-specific knowledge, self-efficacy, self-management behav-

iors, and clinical outcomes for pediatric patients

- Exploration of health literacy's relationship to health disparities: the relationship between socioeconomic disparities and health literacy, and between LEP and literacy skills, and how health literacy may mediate the effect of social disparities on health outcomes
- Evaluation of interventions to improve child health outcomes and eliminate health disparities
  - study of interventions that are customized to low health literacy, LEP, and culturally diverse populations
  - examination of the effect of reader-friendly print materials and tools such as pictograms, technology, and alternate health care-delivery models on child health outcomes
  - evaluation of improved medication labeling and instructions to reduce medication-administration errors by patients and caregivers
- Practice and health care system interventions
  - understanding the role of health literacy in designing and assessing quality metrics
  - study of the use of patient assessments of care to measure and improve quality of communication between providers and patients and families with low literacy
  - exploration of the quality of current provider-patient/caregiver communication and its impact on pediatric care and safety
  - evaluation of methods for training health care professionals in clear health-communication techniques
  - assessment of the impact of better health-communication skills on improving patient/family knowledge,

behaviors, satisfaction, safety, and clinical outcomes

- examination of electronic tools and how they accommodate those with low literacy or enhance health communication for all populations

## SUMMARY

Pediatricians should advocate for increased knowledge about pediatric-related literacy and health literacy; the role of health literacy as a social determinant of child health and mediator of child health disparities; and effective health literacy–related interventions to improve the quality of individual and population-based child health care and outcomes.

To advance this agenda, the AAP should build on the work of its Health Literacy

Project Advisory Committee and the national conference in November 2008 through formal initiatives that address health literacy in pediatric practice, policy, education, and research. Child health policy makers should address health literacy and its relationship to other health indicators, thereby establishing visible, measurable opportunities to elevate national awareness of the importance of health literacy and to develop interventions related to health literacy and its interaction with child health, disparities, and cultural and linguistic competence.

By better understanding how to measure health literacy in children and their caregivers, we can hope to better understand the developmental trajectory of health literacy as a child grows; by better understanding the

role of health literacy in transitions to self-care, we can develop more effective policy- and practice-based interventions to support the caregiver-child dyad at every stage. By better understanding the relationship between health literacy and disparities, we can hope to develop policy- and practice-based interventions that will particularly support caregivers with low health literacy and thereby address those disparities. Thus, the different health literacy imperatives of researching measurements, development, and disparities, while building and testing practice-based interventions, offer a set of linked opportunities to use health literacy to explore and improve pediatric care, reduce disparities, and improve outcomes by improving care and communication.

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