

# **State Official's Guide to Health Literacy**

by Trudi L. Matthews and Jenny C. Sewell



The Council of State Governments

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Manufactured in the United States of America  
ISBN #0-87292-899-3 ■ Price: \$35.00

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## Foreword

Health literacy—the ability to read, understand and act on health information—is essential for successfully navigating today’s complicated health care system. Studies have shown that individuals with low health literacy are more likely to have difficulty understanding health issues and following a doctor’s instructions, and are less likely to understand how to access appropriate care.

Given these facts, low health literacy inevitably leads to increased health care expenditures. A 1998 study by the National Academy on an Aging Society estimated additional Medicaid expenditures resulting from low health literacy could be as high as \$10.3 billion annually.

With the support of Pfizer, Inc., The Council of State Governments (CSG) conducted the *National Survey on Health Literacy Initiatives*. Governors’ offices, departments of public health, Medicaid and State Children’s Health Insurance Program offices, departments of education, and offices of adult literacy were contacted to find out what their respective states are doing to address this issue.

This *State Official’s Guide to Health Literacy*—the first of CSG’s new series on critical policy issues relevant to state officials—reports the results of this survey, supporting and expanding on these results using data from academic research and private-sector initiatives. Readers will gain an understanding of the problem, what can be done to improve health literacy and how to make the current system more accessible to someone with low health literacy.

CSG would like to thank the state officials who took the time to respond to the survey and made themselves available for follow-up questions about their state’s activities. Considerable thanks also go to members of the Health Literacy Advisory Board for their guidance and support.



Dan Sprague  
Executive Director  
The Council of State Governments



## Table of Contents

List of Tables and Figures	iv
Acknowledgments	v
Private Sector Collaborative Principles	vii
Executive Summary	viii
<b>Chapter One:</b>	
What do you need to know about health literacy?	1
<b>Chapter Two:</b>	
Who can make a difference?	15
<b>Chapter Three:</b>	
What are states doing?	29
<b>Chapter Four:</b>	
What do you need to consider when addressing low health literacy?	39
<b>Appendices:</b>	
Appendix A: Sample language for state legislation, contracts and health education frameworks	51
Appendix B: Methodology	55
Appendix C: State profiles	57
Appendix D: FAQs	111
Appendix E: Glossary	113
Appendix F: Additional resources and references	115

## List of Tables and Figures

### Figure E-1

The cost of low health literacy by payee in 1998 dollars . . . . . x

### Figure I-1

The cost of low health literacy by payee in 1998 dollars . . . . . 6

### Figure I-2

Medicare beneficiary who did not know how to take medication on an empty stomach by health literacy skills . . . . . 10

### Figure 3-1

Number of times seen or heard the term “health literacy” as reported by governors' offices, departments of public health, Medicaid/SCHIP offices . . . . . 32

### Figure 3-2

Number of times seen or heard the term “health literacy” as reported by departments of education and offices of adult literacy . . . . . 32

### Figure 4-1

Percent of residents per state age 65+, 2001 . . . . . 42

### Figure 4-2

Percent of people in poverty by state, 1999–2000 average . . . . . 43

### Figure 4-3

Language spoken at home, population five years and older, by state, 2000 U.S. Census . . . . . 44

### Figure 4-4

Percent of population at Level 1 or 2 on NALS by state . . . . . 45

### Figure 4-5

High school completion rates among the population 25 years and older, by state, March 2000 . . . . . 46

## Acknowledgments

The Council of State Governments (CSG) would like to thank Pfizer, Inc. for its support in conducting and reporting the results of this survey. Pfizer has a long history of working to address the issue of health literacy and CSG hopes this guide will assist in these efforts.

CSG also wishes to thank the members of the CSG Health Literacy Advisory Board:

- **Dr. Georges Benjamin**, Secretary, Maryland Department of Health and Mental Hygiene
- **Ms. Anna Fallieras**, Senior Program Officer, Center for Health Care Strategies
- **Ms. Myra Johnson**, Literacy Specialist, Illinois Secretary of State's Office
- **Ms. Cheryl King**, Commissioner of Adult Education, Department for Adult Education and Literacy
- **Dr. Marvin Singleton**, State Senator, Missouri Senate
- **Ms. Charlene Landis**, Consultant, Pfizer, Inc.

Finally, CSG wishes to thank the following experts for their assistance in designing an effective survey tool:

- **Dr. Terry Davis**, Louisiana State University Medical Center
- **Dr. Susan Scollay**, University of Kentucky

Funding for the *State Official's Guide* series is provided in part by The Council of State Governments' 21st Century Fund. The 21st Century fund is an internal foundation operating within the Council's 501(c)(3) organization. The purpose of the fund is to strengthen the Council's policy and research capacity by supporting innovative and entrepreneurial approaches to product development. Contributors include:

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The Council of State Governments (CSG) is the only national organization serving every elected and appointed official in all three branches of each state and territorial government. Since 1933, CSG has championed excellence in state government by advocating multi-state problem solving and states' rights, recognizing and tracking national trends, identifying innovations, and providing nonpartisan groundbreaking leadership training and support. CSG performs this work through its national office, as well as regional offices based in the East, Midwest, South and West.

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**The major obstacle to achieving a more informed and active health care consumer, however, is the lack of basic health literacy in the United States.**

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### **Health Literacy**

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**The ability to read, understand and act on health information.**

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## **Executive Summary**

Health care in the United States is in crisis. The return of double-digit health care inflation, the continued difficulties many have with affordability and access to basic health care and insurance, and alarming reports of widespread medical errors and other concerns with the quality of health care are just a few of the problems that confront state policy-makers. These issues, combined with severe economic troubles at the state level, leave state leaders with few remedies for treating what ails the nation's health care system.

One approach widely promoted as a solution to problems with cost, access and quality is to encourage consumers to be more involved in health care decisions. In theory, a more informed and involved health care consumer would know where to find affordable health coverage, would be more cost-conscious, would know what questions to ask about a test or procedure and would feel empowered to prevent medical errors before they happen. An active consumer would act as a guardian of quality and affordable care in a way that state governments, insurance companies and other payers never could.

The major obstacle to achieving a more informed and active health care consumer, however, is the lack of basic health literacy in the United States.

Health literacy—the ability to read, understand and act on health information—is essential for anyone trying to navigate today's complicated health care system. To be health literate, one must possess the reading, listening, reasoning and problem-solving skills necessary to make informed choices about health and health care.

Research points overwhelmingly to the conclusion that large numbers of patients do not possess the necessary skills and knowledge to make sound health care decisions. The results of the 1992 National Adult Literacy Survey (NALS) indicate more than 46 percent of the adult population in the U.S. possess low or marginal literacy skills. Given the NALS findings and the complex and technical nature of health care, it is possible to conclude that more than half the population has difficulty understanding health care information due to inadequate health literacy. Consider also the following research findings:

- According to a study of patients at two public hospitals, 33 percent of English-speaking patients could not read basic health materials, 42 percent of patients did not know what “taking medication on an empty stomach” meant, 26 percent did not understand the information on an appointment slip, and 43 percent and 60 percent respectively could not understand the rights and responsibilities section of a Medicaid application or an informed consent document.<sup>1</sup>
- A survey of Medicare managed care enrollees in four cities found that more than a third of English-speaking and more than half of Spanish-speaking enrollees had inadequate or marginal health literacy. The study also found that reading skills decreased significantly with age.<sup>2</sup>
- Individuals with low health literacy who tested positive for HIV were four times more likely to be non-compliant with their medication.<sup>3</sup>

<sup>1</sup>Williams M., Parker R., Baker D., et al. “Inadequate functional health literacy among patients at two public hospitals.” *JAMA*, December 6, 1995: v274 n21.

<sup>2</sup>Gazmararian, J., Baker, D., Williams, M., et al. “Health Literacy Among Medicare Enrollees in a Managed Care Organization.” *JAMA*, February 10, 1999: v281 n6.

<sup>3</sup>Kalichman, S., Ramachandran, B., and Catz, S. “Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy.” *Journal of General Internal Medicine*, May 1999: v14 n5.

- Only 31 percent of patients with low literacy diagnosed with asthma understood that they needed to see their doctor even if they had not had an asthma attack, and only 45 percent knew that they must avoid the substances to which they are allergic, even when they were taking their medication as instructed.<sup>4</sup>
- A study published in the *Journal of American Medical Association* found that of the 3,442 clinical decisions made during 1,057 encounters between a physician and a patient, only 9 percent met the criteria for informed consent.<sup>5</sup>
- A 1996 survey of 400 Medicaid managed care beneficiaries in New York found that more than 30 percent did not know managed care limited them to a specific network of providers; 60 percent did not know a referral was required to see a specialist; and 80 percent did not know use of the emergency room was limited.

Inadequate health literacy costs the U.S. health care system an estimated \$30–\$73 billion annually, according to a 1998 study done by the National Academy on an Aging Society.<sup>7</sup> When broken down into expenditures by payer, this means that low health literacy costs Medicaid as much as \$10 billion annually—almost as much as Medicaid spent on prescription drugs and more than one-and-a-half times the amount it spent on physician services in 1998. (See Figure E-1 on the following page.)<sup>8</sup>

Many of the individuals who are most at risk of having low health literacy—seniors, low-income individuals and the chronically ill—are enrolled in public health care programs such as Medicaid, the State Children’s Health Insurance Program (SCHIP) and Medicare. Because participants in these programs are also likely to be heavy users of health care services, it is especially important for state policy-makers to understand the barriers posed by low health literacy and to assess its impact at the state level.

If patients do not possess a basic knowledge of health and health care and the fundamental literacy skills necessary to actively participate in their care, they cannot be the informed and empowered consumers that the U.S. health care system needs if it is to achieve greater quality, efficiency, cost-effectiveness and access.

### CSG’s Survey of Health Literacy Efforts

To assist state policy-makers in addressing this problem, The Council of State Governments (CSG) undertook a major national research project. The goals of this project were to:

- Gather data from the latest research findings on health literacy.
- Determine what states are doing to make it easier for someone with low health literacy to navigate the health care system and efforts to improve health literacy.
- Prepare a report that provided the information and tools necessary for state leaders to determine what appropriate action they might take.

<sup>4</sup>Williams, M., Baker, D., Honig, E., et al. “Inadequate Literacy Is a Barrier to Asthma Knowledge and Self-Care.” *Chest*, 1998; v114 n4.

<sup>5</sup>Braddock, C., Edwards, K., Hasenberg, N., et al. “Informed Decision Making in Outpatient Practice.” *JAMA*, December 22/29, 1999, v282 n24.

<sup>6</sup>Molnar, Christine. “The Next Steps in Fostering Consumer Participation in Medicaid and S-CHIP Managed Care.” *Journal of Ambulatory Care Management*: July 2001.

<sup>7</sup>“Low Health Literacy Skills Increase Annual Health Care Expenditures by \$73 Billion.” <<http://www.agingociety.org/healthlit.htm>>.

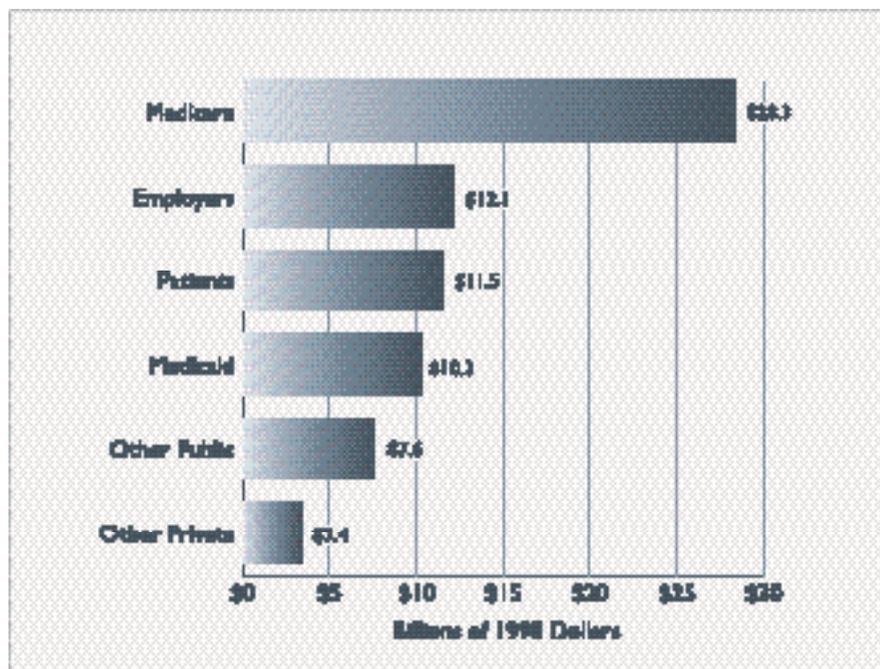
<sup>8</sup>“Chart Book 2000: A Profile of Medicaid” Health Care Financing Administration.

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**Low health literacy costs Medicaid as much as \$10 billion annually—almost as much as Medicaid spent on prescription drugs and more than one-and-a-half times the amount it spent on physician services in 1998.**

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**Figure E-1. The cost of low health literacy by payee in 1998 dollars**



Source: “Low Health Literacy Skills Increase Annual Health Care Expenditures by \$73 Billion.: <<http://www.agingsociety.org/healthlit.htm>>.”

Early in 2002, with the assistance of a distinguished group of advisors, CSG prepared and sent its *National Survey on Health Literacy Initiatives* to governors’ offices, departments of health, Medicaid and SCHIP offices, departments of education and offices of adult literacy. The purpose of the survey was to determine state officials’ awareness of health literacy as an issue and to identify the state laws, rules or programs that assist individuals with low health literacy.

**Conclusions from CSG’s research**

The most important finding of CSG’s survey is that health literacy is an emerging issue that few states have addressed specifically and directly. Thus, for public policy-makers, health literacy is an issue ripe for leadership.

While no state is addressing health literacy in a comprehensive, multi-faceted manner, individual agencies in a handful of states—including Georgia, Illinois, Massachusetts, and Virginia—have established programs, hired staff or created task forces to respond to low health literacy and its effects on health care delivery. From these states, as well as from several others, a number of notable approaches emerged from the survey responses:

- Virginia’s Center for Primary Care and Rural Health established a Health Literacy Network to promote the use of plain language and to offer resources to health care providers, agency staff and others wanting to assist specific populations access care. In 1999, the Center sponsored a health literacy conference for national, state and local health care programs.

**Health literacy is an emerging issue that is ripe for leadership.**

- The Illinois Secretary of State's Literacy Office created a Health Literacy Task Force to spearhead "Health Literacy For All," a program designed to aid parents in understanding health information.
- The state of Alaska produced "Healthy Reading Kits" for grades two through eight. The texts referenced in the kit have strong health content and the teacher's manual that accompanies the kit helps educators tie the books to Alaska's reading standards.
- California approved its *Health Framework for California's Public Schools, Kindergarten Through Grade Twelve*, a tool to aid health education curriculum development at the local level and to promote collaborations between schools, parents and the community.
- Massachusetts' medical assistance programs have been at the forefront of providing multi-lingual assistance, videos in multiple languages and training staff to convey health care information in a way that is easy to understand. Massachusetts also has an Adult Basic Education Health Curriculum Framework for adult literacy classes.
- Georgia's Department of Adult and Technical Information has hired a Health Literacy Coordinator to oversee the implementation of a series of health literacy classes throughout the state. Still in its early stages, this program has hosted classes in hospitals, senior centers, mental health facilities and community centers.
- Alabama's Medicaid agency has done extensive pilot testing of materials for enrollees. Through this work, the agency has learned that easy-to-read materials are preferred, even by those with proficient reading skills.

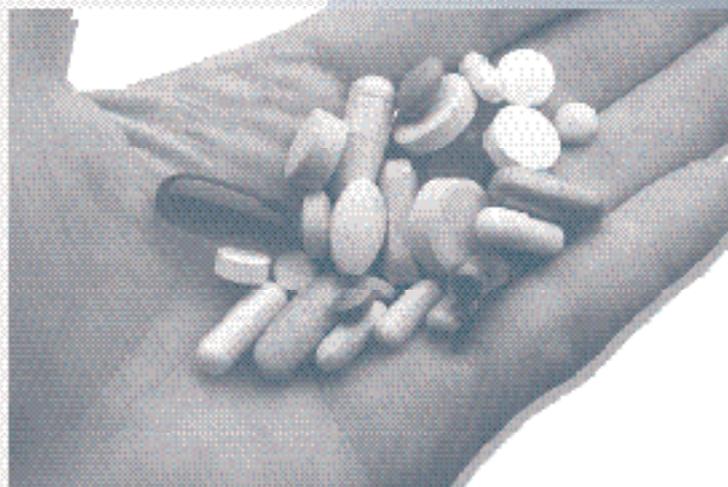
A number of states are also involved in activities that make it easier for someone with low health literacy to navigate public assistance programs—such as simplifying enrollment materials and procedures—or to increase health literacy by setting health education standards in both K–12 and adult literacy classes. Although these efforts have not been initiated or recognized to address the problem of low health literacy per se, they have been successful in removing barriers just the same.

### **CSG's State Official's Guide to Health Literacy**

The *State Official's Guide to Health Literacy* provides an overview of research findings on the issue of health literacy and a summary of CSG's survey results. Chapter One defines health literacy and offers evidence as to why it matters to states. Chapter Two discusses various stakeholders involved in addressing low health literacy and provides information on resources and information available from a variety of organizations around the country. Chapter Three summarizes the findings from CSG's survey and highlights innovative programs and promising state approaches for dealing with low health literacy. Chapter Four offers state policy-makers a number of questions and data sources for determining the degree to which low health literacy affects their respective states.



## **Chapter One**



**What do you need to know about health literacy?**



## What do you need to know about health literacy?

Before she retired, Mrs. Irwin had a successful career as a bus driver. She did not go to school and reads at a second grade reading level. She recognizes the many medications she takes by their color and shape, not by reading the label on the bottles.

*Researcher: Tell you what . . . take these two and tell me which one is which and what you take them for.*

*Mrs. Irwin: That looks like my medicine that he gives me in the morning. I take that and the little pill that—no this is lithium. Ain't it? Yeah, that's lithium. (The label says Lipitor [sic].)*

*Research: Okay, what do you take that medication for?*

*Mrs. Irwin: Don't ask me. He puts me on that and I just take it. Anything he tells me to take, I'll take it.*

*Researcher: Okay. So you trust him?*

*Mrs. Irwin: Oh, you better believe it. With my life.<sup>1</sup>*

There is no question about it: Navigating the health care system today is more complex than ever before. Almost everyone can describe an encounter with a doctor or a health plan where the use of scientific terms, acronyms and jargon resulted in confusion or misunderstanding. Managed care, complex insurance benefit plans, the necessity to read and fill out numerous forms and complicated medical treatments pose problems for even the most educated in our society. For people with low literacy, the difficulties can be overwhelming.

Consider the following scenario: Imagine the additional difficulties and anxiety inherent in each step for someone with low or marginal literacy skills.

**Step 1: Getting insurance**—You are given multiple forms to complete that ask for a lot of personal information. The text is written in a tiny font and responses are limited to a small, boxed space. The form may ask questions that are difficult to understand or that use unfamiliar terms. While a toll-free number is provided if you have questions, you must navigate through multiple computerized menus before reaching a live human being. At the bottom of the form, you are asked to sign your name, indicating you understood the form and completed it truthfully. You are told that no changes will be allowed in coverage until the next enrollment period begins. Any problems or questions resulting from the completed form may delay coverage or result in denial of coverage.

**Step 2: Understanding the system**—After enrollment, a thick packet of information arrives in the mail including: a densely written description of the covered benefits; what the deductibles, co-payments and coinsurance are for various services and in- and out-of-network providers; the steps that must be followed to ensure that health care services will be covered; and a list of participating providers. To find a doctor in the network for your health plan, you look through the directory until you find your city and state. Doctors are separated into categories such as Allergists, Internists, Family Practitioners, Pediatricians and Surgeons. You pick one near where you work.

<sup>1</sup>Schwartzberg, Joanne, and Lagay, Faith. "Health Literacy: What Patients Know When They Leave Your Office or Clinic." *Virtual Mentor*. June 2001. <<http://www.ama-assn.org/ama/pub/printcat/5154.html>>.

**Step 3: The appointment**—When you show up for your appointment, you are again given multiple forms to complete—a medical history, insurance forms and consent forms. “Does your mother have hypertension?” “Did you grandfather die of cardiovascular disease?” The consent form has been photocopied many times, making the words fuzzy. The text is small and the wording is dense. You sign the form agreeing that you have read the document and understand what it says.

**Step 4: Seeing the doctor**—The nurse sees you first, checks your vital signs and asks you why you are there to see the doctor. The doctor spends about 10–15 minutes with you, possibly ordering tests or lab work to help him arrive at an accurate diagnosis of your condition. He gives you some pamphlets and prescribes a medication to be taken “twice daily on an empty stomach” for a specified number of days. You want to ask him what times during the day you should take the drug and what the drug will do, but you are afraid he might have already answered these questions. You had tried to listen to him explain what he felt was wrong but had been distracted by watching him put equipment away, wash his hands and make notes in your file. On the way out the door, he asks if you have any questions and you shake your head.

Even individuals with excellent reading and analytical skills would find the situation described above challenging. For someone with low literacy, the difficulties would be multiplied. From choosing health insurance coverage to deciding which doctor was most appropriate to taking prescribed medication, the presentation of information was inappropriate for someone who has problems with reading and listening comprehension. Each encounter not only assumed that the patient could read, but that he or she could read well.

Shame, too, plays a role. Admitting that you don't understand can be difficult. No one wants feel “stupid.” And yet, that is often how people feel after an encounter with today's health care system. This embarrassment, coupled with a desire not to inconvenience someone as educated as a doctor, may prevent a person from asking questions. If other factors, such as a complicated medical problem, the emotional stress of being ill or characteristics associated with growing old—loss of hearing or eyesight and senility—are involved, the effect of low literacy on health care increases substantially.

### **The connection between literacy and health**

Because communication lies at the core of quality health care, the inability to read, understand and act appropriately on health care information—the very definition of health literacy—results in a fundamental disconnect between the patient and the health care system. This rift inevitably leads to a lack of trust and honesty, poorer quality care, errors and omissions and higher costs.

Individuals with low literacy skills—those who struggle to read and write, have problems analyzing and integrating information, and have difficulty performing even simple mathematical equations—are also likely to have low *health* literacy skills. It would be wrong, however, to assume that only this group is affected. The language of health care—long, scientific words with difficult spellings and pronunciations, acronyms and codes—intimidates even the most educated among us. This means that no one is immune from leaving the doctor's office feeling more confused than when they entered. Adopting communication techniques that make use of plain language and appealing images helps everyone.

Health literacy is not an “either/or” category but a continuum. It goes beyond reading level to include cultural differences, knowledge of a language, education level attained and readiness to comprehend what is being said. Any factor affecting communication affects an individual’s level of health literacy.

### Why worry about low health literacy?

Low health literacy affects health care by increasing costs, compromising quality, and limiting access.

### Costs

Low health literacy significantly increases health care expenditures. According to a 1998 study by the National Academy on an Aging Society, the cost of low health literacy in the United States could be anywhere from \$30 billion to as much as \$73 billion annually.<sup>2</sup>

A breakdown of the effects of low health literacy by payer shows that of the estimated expenditures, 39 percent is for additional Medicare expenditures and 14 percent is for increased Medicaid costs.<sup>3</sup> (Figure 1-1 on the following page provides specific dollar amounts by who bears the costs.)

What does this mean for state officials? It means that the inability of patients to understand and act appropriately on health information costs Medicaid an estimated \$10.3 billion a year, almost as much as Medicaid spent on prescription drugs and more than one-and-a-half times the amount it spent on physician services in 1998.<sup>4</sup>

Low health literacy also increases the likelihood of costly medical errors, a subject that has received considerable attention in the last several years following the publication of the Institute of Medicine’s “To Err Is Human: Building a Safer Health System.”

According to this report, medical errors are responsible for between 44,000 to 98,000 deaths annually at an estimated cost of between \$38 billion to \$50 billion.<sup>5</sup> The report lists miscommunication as one common form of error. Encouraging patients to be active, informed and involved health care consumers would work to minimize errors. Low health literacy, however, acts as a major barrier to achieving this goal. Efforts to improve health literacy among at-risk populations could enhance state efforts to decrease medical errors and the costs associated with them.

### Quality

Quality care relies implicitly on successful communication between the patient and the health care provider. Because low health literacy limits such communication, its impact on quality is inevitable.<sup>6</sup>

<sup>2</sup>“Low Health Literacy Skills Increase Annual Health Care Expenditures by \$73 Billion.” <<http://www.agingsociety.org/healthlit.htm>>.

<sup>3</sup>*ibid.*

<sup>4</sup>“Chart Book 2000: A Profile of Medicaid” Health Care Financing Administration.

<sup>5</sup>“To Err Is Human: Building a Safer Health System,” Institute of Medicine, 1999. <[http://www.nap.edu/html/to\\_err\\_is\\_human/](http://www.nap.edu/html/to_err_is_human/)>.

<sup>6</sup>*Health Literacy: The Impact and Strategies for Moving Forward.* National Health Council, Dec. 2000: 7.

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### Health Literacy

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“The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”  
(*Healthy People 2010*)

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The cost of low health literacy in the United States could be anywhere from \$30 billion to as much as \$73 billion annually.

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### What is meant by “low” and “marginal” literacy skills?

According to the 1992 National Adult Literacy Survey, 21–23 percent of the population fell into the Level 1 (low) category of literacy and 25–28 percent fell into the Level 2 (marginal) category of literacy.

Examples of the tasks individuals perform at each level are listed below. Skills vary significantly within each group, but especially in Level 1 where respondents range from those being able to complete all the tasks to those who were essentially unable to respond to the survey at all.

#### Level 1

- Read short sections of text.
- Locate a piece of information in a text if it is an exact match to the question being asked.
- Enter information from personal knowledge onto a document.
- Perform simple math if numbers are provided and type of arithmetic function is specified.

An individual at this level might be able to fill out a deposit slip and read a bus schedule or a brief news article.

#### Level 2

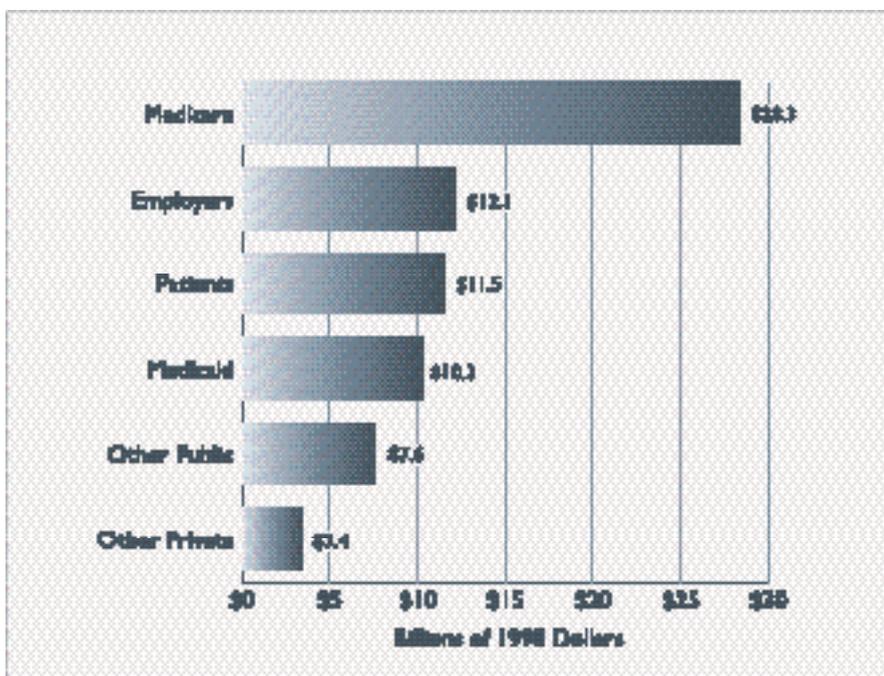
- Make low-level inferences.
- Integrate information from various parts of a document.
- Compare or contrast easily identifiable information when criteria are provided within the question.

An individual at this level might be able to figure the total of a purchase or subtract the cost of one item from another; read a map, and fill out a simple form.

#### Sources:

- “Fast Facts on Literacy,” National Institute for Literacy. <[http://www.nifl.gov/nifl/facts/facts\\_overview.html](http://www.nifl.gov/nifl/facts/facts_overview.html)>.
- Kirsch, Irwin, Yamamoto, Kentaro, Norris, Norma, et al., *Technical Report, and Data File User’s Manual For the 1992 National Adult Literacy Survey*. US Department of Education, January 2001. <[nces.ed.gov/pubs2001/2001457.pdf](http://nces.ed.gov/pubs2001/2001457.pdf)>.
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Figure 1-1. The cost of low health literacy by payee in 1998 dollars



Source: “Low Health Literacy Skills Increase Annual Health Care Expenditures by \$73 Billion,” <<http://www.aging society.org/healthlit.htm>>.

A variety of studies illustrate the effect of low health literacy on understanding health issues:

- Of those women claiming to know what a mammogram was, only one in four were able to describe it correctly. Often, it was confused with a Pap smear.<sup>7</sup>
- Individuals with low health literacy who tested positive for HIV were four times more likely to be non-compliant with their medication.<sup>8</sup>
- Only 31 percent of patients with low literacy diagnosed with asthma understood that they needed to see their doctor even if they had not had an asthma attack, and only 45 percent knew that they must avoid the substances to which they are allergic, even when they were taking their medication as instructed.<sup>9</sup>

Low health literacy also decreases quality by limiting a person’s ability to participate in medical decision-making and to provide informed consent. A study published in the

<sup>7</sup>Davis, T., Arnold, C., Berkel, H., et al. “Knowledge and Attitude on Screening Mammography Among Low-literate, Low-income Women.” *Cancer*, November 1, 1996: v78 n9.

<sup>8</sup>Kalichman, S., Ramachandran, B., and Catz, S. “Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy.” *Journal of General Internal Medicine*, May 1999: v14 n5.

<sup>9</sup>Williams, M., Baker, D., Honig, E., et al. “Inadequate Literacy Is a Barrier to Asthma Knowledge and Self-Care.” *Chest*, 1998: v114 n4.

*Journal of the American Medical Association (JAMA)* evaluated 1,057 doctor-patient visits to determine if decisions made during the interaction qualified as informed using pre-determined criteria. The study found that of the 3,442 clinical decisions made during the visits, only 9 percent met the criteria. “Among the elements of informed decision making, discussion of the nature of the intervention occurred most frequently (71 percent) and assessment of patient understanding least frequently (1.5 percent).”<sup>10</sup>

## Access

In addition to increasing costs and decreasing quality, low health literacy also limits an individual’s ability to access appropriate care. The barriers to participation in state Medicaid and State Children’s Health Insurance Programs (SCHIP) illustrate this point.

Traditionally, enrollment in Medicaid has been characterized by multiple forms (as many as 18 pages in one state according to results from CSG’s *National Survey on Health Literacy Initiatives*) that require a great deal of documentation. Complex eligibility requirements relating to income, assets, number of dependents and age are difficult to understand for anyone, but especially for someone with low health literacy. Participation in public health care programs requires a range of skills including reading comprehension, listening comprehension, prioritization, synthesizing data from multiple sources, decision-making and writing.

While states have made great strides in the past few years toward simplifying the enrollment process, procedures and rules for public health care programs remain complex and present numerous challenges. And, because of eligibility review requirements, the re-enrollment process could occur as often as every six months.

Once someone is enrolled, understanding and following the rules for use of health care services may also present a number of challenges. Managed care plans can be especially intimidating. During the last decade, market penetration of Medicaid managed care increased tremendously. In 1993, only 14 percent of the Medicaid population was enrolled in managed care. By 1998, that number had increased to 54 percent, or 16.6 million beneficiaries.<sup>11</sup>

Christine Molnar, in an article titled “The Next Steps in Fostering Consumer Participation in Medicaid and SCHIP Managed Care,” notes that “managed care—much more than fee-for-service system—creates an environment in which patients must take an active role in their own care, and, in fact, become discerning and vocal consumers.”<sup>12</sup>

Enrollees must understand: the rules regarding covered and non-covered services such as emergency room care; the need for a medical home; the need for a referral by a primary care physician for testing or specialty care; and use of in- versus out-of-network providers. Without assistance, individuals with low health literacy will not be able to assume the responsibilities necessary to successfully participate in managed care, undermining any attempts to control health care expenditures.

<sup>10</sup>Braddock, C., Edwards, K., Hasenberg, N., et al. “Informed Decision Making in Outpatient Practice.” *JAMA*. December 22/29, 1999, v282 n24.

<sup>11</sup>“1998 Medicaid Managed Care Enrollment Report: Summary Statistics as of June 30, 1998.” Health Care Financing Administration. <<http://www.hcfa.gov/medicaid/omc1998.htm>>.

<sup>12</sup>Molnar, Christine. “The Next Steps in Fostering Consumer Participation in Medicaid and S-CHIP Managed Care.” *Journal of Ambulatory Care Management*: July 2001.

Nearly half of the adult population of the United States does not possess the literacy skills necessary to function well in today's sophisticated health care environment.

A 1996 survey of 400 Medicaid managed care beneficiaries conducted by the Community Service Society of New York illustrates this point. Results showed that:

- More than 30 percent did not know their managed care program limited them to a specific network of providers.
- Sixty percent did not know a referral was required to see a specialist.
- Eighty percent did not know use of the emergency room was limited.<sup>13</sup>

If enrollees avoid seeing a doctor until they are seriously ill because they do not understand how to navigate the system, managed care—a system Molnar notes is “based on the premise that regular use of primary and preventative care can prevent illness and reduce costs”—will always fail to achieve its purpose.<sup>14</sup>

**Who is most at risk?**

While there is no national measure of health literacy, information about general literacy skills can help define individuals at risk for low health literacy—and point to possible solutions.

According to the 1992 National Adult Literacy Survey (NALS) over 90 million people in the United States have low or marginal literacy skills. Because individuals with low literacy will almost certainly have trouble understanding complicated health information, this means that nearly half of the adult population of the United States does not possess the literacy skills necessary to function well in today's sophisticated health care environment.

Using data from the NALS, as well as studies of specific patient populations, groups vulnerable for low health literacy can be identified. It is important to remember that this list is not exhaustive. Because of the technical and scientific nature of health care, simply being able to read above the tenth or twelfth grade level does not ensure that a person is health literate. However, because of the relationship between low literacy and the ability to understand health information, certain populations are likely to be affected.

**Seniors**

As people age their use of health care services increases tremendously. Seniors are more likely to suffer from multiple chronic diseases that require more frequent visits to the doctor, lengthier hospital stays, ongoing drug therapy, and long term care services.

Complicated treatments force seniors to absorb a lot of new information in a short amount of time. However, as Helen Osborne notes in “Literacy and the Older Adult,” this isn't easy for most seniors. “To maintain independence and functioning, older adults have to become good students. But being a student when you're over 60 years old can be very difficult.”<sup>15</sup>

Factors affecting the health literacy level of seniors include:

- Lower educational levels among seniors due to the fewer years of formal schooling prior to entering the workforce.

<sup>13</sup> *ibid.*

<sup>14</sup> *ibid.*

<sup>15</sup> Osborne, Helen. “Literacy and the Older Adult.” *Health Literacy Toolbox 2000*. <<http://www.prenataled.com/healthlit/hlt2k/script/index.asp>>.

- A reduction in reading, math and problem-solving abilities from lack of use.
- The stress and anxiety associated with aging and illness.
- Sensory changes such as loss of sight or hearing.
- Impaired cognitive function due to Alzheimer's or other form of dementia.<sup>16</sup>

Research confirms the difficulties seniors face. According to the Center for Health Care Strategies, Inc., more than two-thirds of U.S. adults age 60 or older have low or marginal literacy skills.<sup>17</sup> In addition, a 1997 survey of Medicare beneficiaries participating in four Prudential HealthCare plans found that more than a third of English-speaking and more than half of Spanish-speaking enrollees had inadequate or marginal health literacy. The study found that of those with low health literacy, more than half did not understand what it meant to take medicine on an empty stomach. (See Figure 1-2 on the following page.)<sup>18</sup>

While Medicare pays for a significant share of senior health care costs, states, too, have a vested interest in ensuring seniors have the ability to participate fully in their health care. In addition to state-run drug assistance programs, states are also responsible for covering a portion of the costs of treating low-income seniors who qualify for Medicaid. Although the elderly make up only 10 percent of enrollees, they are responsible for 27 percent of Medicaid expenditures.<sup>19</sup> Introducing programs that aid seniors in seeking appropriate care, taking medications correctly and offering strategies for staying healthy are important first steps states can take.

### Low-income individuals

Several studies have shown that those with low incomes are especially at risk for low health literacy. The 1992 National Adult Literacy Survey revealed that 43 percent of individuals with low literacy lived in poverty and 70 percent had either no job or only a part-time job.<sup>20</sup>

A 1995 study conducted at two public hospitals showed that of the 2,659 low-income patients interviewed, 26 percent could not read their appointment card and nearly half were unable to determine if they qualified for free care after reading information provided by the hospital. The study also found that 33 percent of English-speaking patients could not read basic health materials, 42 percent of patients did not know what “taking medication on an empty stomach” meant, and 60 percent could not understand an informed consent document.<sup>21</sup>

This has tremendous implications for state Medicaid and SCHIP programs. In response to pressure to decrease the number of people without health insurance, states

<sup>16</sup>*ibid.*

<sup>17</sup>“Who Suffers from Poor Health Literacy?” Center for Health Care Strategies, Inc. <<http://www.chcs.org/resource/hl.html>>.

<sup>18</sup>Gazmararian, J., Baker, D., Williams, M., et al. “Health Literacy Among Medicare Enrollees in a Managed Care Organization.” *JAMA*, February 10, 1999: v281 n6.

<sup>19</sup>“State Health Facts Online.” Kaiser Family Foundation. <<http://www.statehealthfacts.kff.org/>>.

<sup>20</sup>National Institute for Literacy. “Fact Sheet: Adult and Family Literacy April 2000.” <<http://www.nifl.gov/nifl/policy/familifactsheet.doc>>.

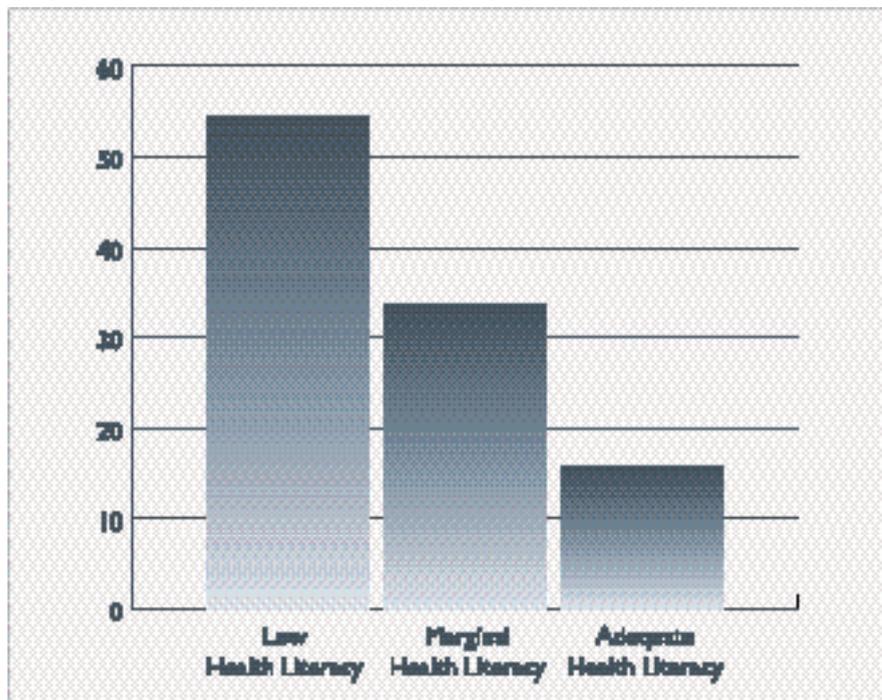
<sup>21</sup>Williams, M., Parker, R., Baker, D., et al. “Inadequate Functional Health Literacy Among Patients at Two Public Hospitals.” *JAMA*, 1995, v274 n21: 1677–1682.

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**More than two-thirds of U.S. adults age 60 or older have low or marginal literacy skills.**

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**Figure 1-2. Medicare beneficiary who did not know how to take medication on an empty stomach by health literacy skills**



Source: "Literacy and Health," National Institute for Literacy <<http://www.nifl.gov/nifl/facts/health.html>>.

have expanded eligibility and made use of savvy marketing techniques and outreach programs to get the word out to low-income families and children. Despite these efforts, however, enrollment in Medicaid and SCHIP remains far below the number of people eligible for coverage. While the roots of this problem are many, low health literacy represents a formidable obstacle that states have only recently begun to recognize and address.<sup>22</sup>

In addition, cost containment efforts that ignore the difficulties individuals with low health literacy have in accessing and understanding care lead to inefficiencies in service delivery. One-on-one assistance, for example, is consistently identified as one of the most successful strategies for assisting individuals with low health literacy enroll in and access care. Personnel costs, however, make this service an easy mark by policy-makers looking to decrease health care expenditures.

### **Chronically ill**

Low health literacy also affects those with chronic illnesses at an alarming rate: over 40 percent are functionally illiterate.<sup>23</sup> This factor has a significant impact on an individual's ability to manage his or her illness.

<sup>22</sup>See comments by Laura Summer in "Eliminating Barriers to Enrollment in the Children's Health Insurance Program," *CSG Health Policy Monitor*, Spring 2000.

<sup>23</sup>"Who Suffers From Poor Health Literacy?" Center for Health Care Strategies, Inc. <<http://www.chcs.org/resource/hl.html>>.

In fact, two 1998 studies of people with diabetes, high blood pressure and asthma found that literacy skills were the strongest link between patients and their knowledge of their disease, even when other factors such as education were taken into consideration.<sup>24</sup>

What does this mean for state policy-makers? Because of the costs associated with treating the chronically ill, ensuring that these individuals are able to read, understand and act on health information is critical. In 2000, an estimated 125 million Americans suffered from at least one chronic illness—less than half the U.S. population—and yet the chronically ill were responsible for more than 75 percent of health care spending.<sup>25</sup>

Among Medicaid beneficiaries, the portion is even higher:

- Adult beneficiaries with chronic or disabling conditions account for 96 percent of the total amount Medicaid spends on non-elderly adults.
- Child beneficiaries with chronic or disabling conditions account for 76 percent of the total amount Medicaid spends on children.<sup>26</sup>

### Non-English speakers

Patients who do not speak English, or have limited English-speaking abilities, represent another vulnerable group.

While Title VI of the Civil Rights Act, as well as provisions of Medicare and Medicaid, forbid discrimination by institutions receiving federal monies, adequate translation services are often not available.<sup>27</sup> According to *The Commonwealth Fund 2001 Health Care Quality Survey*, “among the non-English speakers who said they needed an interpreter during a health care visit, less than one-half (48 percent) said they always or usually had one.”<sup>28</sup>

In the absence of a translator, some patients are forced to rely on family members to aid in doctor-patient communication. However, this is inherently problematic for several reasons:

- The family member may omit or substitute information, or unintentionally alter the doctor’s meaning.
- It violates confidentiality and may cause difficulties in the development of a relationship between the doctor and the patient.
- Mental health evaluation and treatment may be compromised.
- Depending on familial hierarchies, the aid of a family member could disrupt relationships and threaten cultural norms.

<sup>24</sup>Greenberg, Daphne. “Health Literacy Statistics.” *Health Literacy Toolbox 2000*. <<http://www.prenataled.com/healthlit/ht2k/script/index.asp>>.

<sup>25</sup>Anderson, Gerard, and Knickman, James. “Changing the Chronic Care System to Meet People’s Needs.” *Health Affairs*. November/December 2001: 146–160.

<sup>26</sup>“The Faces of Medicaid.” Center for Health Care Strategies, Inc. <<http://www.chcs.org/publications/pdf/cfm/Identify.pdf>>.

<sup>27</sup>Smith, Sandra. “Health Literacy & the Law Quiz.” *Health Literacy Toolbox 2000*. <<http://www.prenataled.com/healthlit/ht2k/script/index.asp>>.

<sup>28</sup>Collins, K., Hughes, D., Doty, M., et al. “Diverse Communities, Common Concerns: Assessing Health Care Quality for Minority Americans.” *The Commonwealth Fund*. <[http://www.cmf.org/programs/minority/collins\\_diversecommunities\\_523.pdf](http://www.cmf.org/programs/minority/collins_diversecommunities_523.pdf)>.

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**96% of Medicaid spending on adults is for adults with chronic and disabling conditions.**



**76% of Medicaid spending on children is for children with chronic or disabling conditions.**




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**40% of individuals with chronic illnesses are functionally illiterate.**

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- Translation by family members for matters relating to gynecology, reproductive health and sexually transmitted diseases may be both uncomfortable and inappropriate.<sup>29</sup>

Responses to CSG's *National Survey on Health Literacy Initiatives* indicate that efforts have been made to provide written materials in an individual's native language. Two questions, however, must be asked when evaluating the effectiveness of this activity: is the translation culturally appropriate and is the individual literate in his or her native language.

### **Trends in health care: Why health literacy? Why now?**

While health literacy has very important consequences in today's health care environment, there are a number of trends in the American health care system that highlight the importance of health literacy, especially among beneficiaries of public health insurance programs.

**Rising health care costs:** The 2001 recession left states scrambling to balance budgets. Medicaid and SCHIP costs came under intense scrutiny, and many states were forced to consider scaling back outreach programs and optional services or limiting eligibility. Because of the increased costs associated with low health literacy, providing appropriate information or increasing skills among beneficiaries will increase efficiencies and decrease expenditures.

**Managed care:** With the increased use of managed care to control Medicaid costs came increased complexity for beneficiaries. As mentioned previously, managed care assumes that patients will play an active role in managing their health care. Without the tools and skills needed to access and navigate these complex systems, however, individuals with low health literacy will be unable to take on the responsibilities required by managed care.

**Innovations in treatment:** Advances in medicine have done much to improve quality of life and increase longevity. However, understanding new medical treatments as well as possible side effects and risks challenges even the most sophisticated health care consumer. For someone with low health literacy this information can be completely overwhelming. As genetic testing and treatment become more common, individuals with low health literacy will face an increasingly complex health care environment. These difficulties may hinder informed consent and quality care.

**An aging population:** The growth in the number of elderly in the United States will put an increased burden on the U.S. health care system. The elderly are heavier users of healthcare due to the increased incidence of chronic illness and disability compared with younger populations. Studies have shown that aging is associated with decreased health literacy. Efforts to control costs and improve the quality of care for seniors must include strategies for improving seniors' ability to understand and act on health information.

**Cultural and linguistic diversity:** Expected shifts in demographics don't stop at aging. The cultural make up of the U.S. population is changing as well. According to U.S. Census Bureau population projections, in 2050 non-Hispanic whites will make

<sup>29</sup>Smith, Sandra. "Health Literacy & the Law Quiz." *Health Literacy Toolbox 2000*. <<http://www.prenataled.com/healthlit/hlt2k/script/index.asp>>.

up only 74.9 percent of the population compared with 81.9 percent in 2002.<sup>30</sup> Differences in language and cultural beliefs will act as a barrier to successful communication between physician and patient, health plan and member if the health care industry fails to respond to these changes.

### **National Survey on Health Literacy Initiatives**

Some policy-makers and health care providers have already recognized the potential benefits associated with improved health literacy and have instituted programs to address this issue. These initiatives help policy-makers identify who plays a role in improving health literacy as well as what policy-makers need to consider if they wish to fully understand the problems within their states.

During the spring of 2002, The Council of State Governments (CSG) conducted a national survey to find out more about these activities. The *National Survey on Health Literacy Initiatives* was sent to governors' offices, departments of public health, Medicaid and SCHIP offices, departments of education, and offices of adult literacy. Information gleaned from this survey is highlighted throughout this report, especially in Chapter Three, where state strategies that have proved particularly helpful are discussed. Appendix C reports out selected responses by state.

### **Conclusion**

Low health literacy presents a significant challenge to state officials. While all populations run the risk of being affected—from those who drop out of high school to college graduates—studies indicate that participants in public programs such as Medicaid, Medicare and SCHIP are particularly vulnerable.

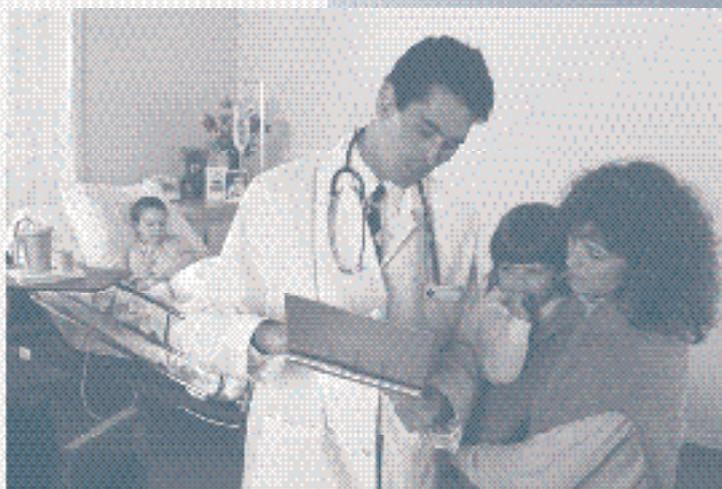
The estimated costs associated with low health literacy are substantial. But improving health literacy is about more than just saving money. Poor communication between the health care provider and the patient decreases the quality of care and, therefore, quality of life. Navigating the modern health care environment demands an individual be ready to learn not only about a health condition, but how to get health insurance, what treatment may be covered, which doctor to see, when to take prescribed medication and more. When someone has low health literacy, this just isn't possible without targeted assistance.

The following chapters will identify who plays a role in improving health literacy, what states have done or are planning to do, and what policy-makers need to consider if they wish to fully understand the problems within their states. The innovative programs highlighted throughout these chapters will help state policy-makers better understand what they can do to improve health literacy.

<sup>30</sup>"National Population Projections." U.S. Census Bureau. <<http://www.census.gov/population/www/projections/natsum-T5.html>>.



## Chapter Two



Who can make a difference?



## Who can make a difference?

Mr. Dallas serves as a deacon in his church and is highly respected within his community. He reads at a third-grade level.

*Mr. Dallas: I would go to the lady, you know, that passed me the thing [clipboard], and say, "Look, I need some help with this, I can't fill it out." I'd ask for help. [She would answer] "I don't have time right now. Can you wait a while, 'cause I don't have time; you're going to be last." You're always last when you don't know.<sup>1</sup>*

Responding to the problem of low health literacy involves many sectors. Obvious players, such as the health care industry and health care professionals, have an opportunity to implement strategies to assist individuals with low literacy to access care, understand their diagnosis and treatment options and act appropriately based on what they learn. State officials have the authority to enact policies and establish programs that assist health plans, providers and state agencies in efforts to communicate effectively with people with low health literacy. State officials also affect education and literacy through curriculum requirements, and can highlight the importance of health education and its integration in both K–12 and adult literacy classrooms.

Other players, too, make a difference. Efforts to make health care more accessible or to improve health literacy through education would not be nearly as advanced without the support of academia, voluntary health associations, advocacy groups and other relevant organizations.

### State policy-makers

State leaders can address the issue of low health literacy in a number of ways:

- Raising awareness of the issue among practitioners, researchers and the general public.
- Ensuring access to helpful, simple, easy-to-understand health information on disease, health care services, assistance programs and processes and procedures for those participating in state health care programs.
- Providing incentives to health plans and providers to make simple, clear health information available to patients and to make health literacy a priority.
- Creating programs and devoting resources and personnel to improve health literacy through education and literacy efforts.

### Constitutional offices

Governors, lieutenant governors, secretaries of state and other elected officials play an important role in setting the agenda for state policy efforts and bringing visibility to certain key issues. These officials often serve as champions and spokespersons on behalf of important issues. In addition, governors possess the ability to issue executive orders and proclamations, establish advisory boards or task forces and sign legislation.

For years, constitutional officials have coordinated reading programs in recognition of the economic consequences of low literacy. More recently, *computer* literacy has

<sup>1</sup>Schwartzberg, Joanne, and Lagay, Faith. "Health Literacy: What Patients Know When They Leave Your Office or Clinic." *Virtual Mentor*. June 2001. <<http://www.ama-assn.org/ama/pub/printcat/5154.html>>.

### Canada's National Literacy and Health Program (NLHP)

Sponsored by the Canadian Public Health Association, the purpose of Canada's National Literacy and Health Program (NLHP) is to increase awareness among health care providers of the relationship between literacy and health. Two subjects are of particular importance: using plain language in preparing health materials and encouraging clear spoken communication between patients and providers.

The program's Plain Language Service will assess the reading level of materials, make revisions to language or formatting, and test materials with the intended audience to determine their appropriateness. The NLHP also coordinates a Medication Packaging and Labeling project. The purpose of the project is to develop a set of guidelines to help incorporate plain language and smart design in the packaging and labeling of prescription drugs.

For more information about these and other projects, please go to [www.nlhp.cpha.ca/index.htm](http://www.nlhp.cpha.ca/index.htm).

become a top priority as well. Incorporating health literacy into such efforts makes sense. Health and wellness initiatives that focus on screening and educating the public—programs often spear-headed by state governments—offer important opportunities to highlight health literacy. In addition, many state officials have been champions of patient-protection efforts. Health literacy is key to creating informed and empowered health care consumers and should be part of these efforts.

### Legislatures

State legislators play an essential role in literacy and health efforts. By holding hearings, passing legislation, performing oversight and ensuring funding for programs, state legislators can raise awareness and provide essential resources to address health literacy issues.

Legislators on health and human services committees can ensure that Medicaid, Maternal Child Health programs, mental health and substance abuse programs and other health care initiatives administered by the state provide health information and assistance suitable for individuals with low health literacy.

Legislative committee members responsible for K–12 education, adult education and workforce development can also focus on the link between health and literacy. Activities include: establishing health education standards and curriculum guidelines for K–12 public education, integrating health units into adult literacy programs, and improving the overall educational achievement in the state.

### Medicaid/SCHIP offices

In the past, Medicaid was linked closely with welfare and, therefore, operated much like a welfare program. Long and complicated applications, extensive documentation of proof of income and assets, face-to-face interviews and other methods were meant to discourage fraud and abuse of the system. In practice, these methods also served to discourage truly needy applicants from enrolling in Medicaid and added to the stigma of the program.

Welfare reform in 1996 and the creation of the State Children's Health Insurance Program (SCHIP) in 1997 dramatically changed federal legislative requirements for medical assistance programs. Separating Medicaid eligibility from welfare eligibility gave states the ability to expand health coverage to more working, uninsured families with incomes above the federal poverty level. States were given the flexibility and funding to experiment with less complex procedures that encouraged families and children to access the new expansions in health care coverage through Medicaid and SCHIP. A complete paradigm shift occurred as Medicaid and SCHIP programs moved from finding ways to keep people off the rolls to encouraging more people to sign up.

Efforts to increase enrollment weren't as successful as most states had hoped. While the mentality of the agencies had altered, the complexity of the system continued to pose a significant barrier to those with low health literacy. Strategies state Medicaid/SCHIP can undertake to overcome this barrier include:

- **Outreach:** Evaluate marketing tools to make them easily accessible for those with low health literacy.
- **Enrollment:** Simplify the language, organization and formatting on enrollment forms and information to make them more user-friendly and accessible to clients

with low health literacy. Provide instructions for enrollment that include instructive cartoons or other graphics or audio-visual components that demonstrate what the client should do to enroll. Offer facilitated enrollment or one-on-one assistance.

- **Access:** Provide simple, clear information to clients about health benefits, procedures for accessing care, filing claims and possible co-payments. Train staff and health care providers in strategies for communicating with individuals with low health literacy. Provide one-on-one assistance in answering questions about services.
- **Cultural and linguistic difference:** Provide forms and materials in the languages and dialects spoken in that state. Materials should be culturally competent, incorporating the differences in beliefs and attitudes of the target population. Because individuals may be illiterate in their native language, whenever possible state agencies and clinics should make translators available.
- **Grievance procedures:** Provide clear, member-friendly information on how to file complaints or appeals in situations where the quality of care is in question or coverage is denied.
- **Financing and delivery of care:** Tie purchasing decisions and contracting with health plans and providers to efforts to deal with low health literacy. Encourage vendors to identify populations at risk for low health literacy (e.g. low-income seniors and the chronically ill in particular who frequently use health care services) and create interventions that will educate clients about disease and encourage appropriate use of health care services.

## Health departments

State health departments play a key role in addressing low health literacy. In addition to traditional activities such as monitoring public health and tracking disease, these agencies operate a number of programs and initiatives that serve individuals at-risk for low health literacy:

- Women, Infants and Children program (WIC).
- Chronic disease and health promotion programs.
- Child and adult immunization programs.
- Maternal child health programs.
- Lead poisoning and environmental health programs.
- Adolescent and teen health programs.

Providing more user-friendly materials to clients and training office staff and health care providers in working with populations at risk for low health literacy will result in more effective use of resources and better customer service.

Citizens also look to state health departments for information on preventing disease and improving overall health. States disseminate this information using a variety of sources, including health fairs, toll-free information lines, public service announcements, presentations to local community groups and partnerships with community-based organizations and local health departments. Adapting educational materials and offering opportunities to learn that appeal to those with low health literacy will benefit the community as a whole.

## National School Health Education Standards

In 1995, the Joint Committee for National School Health Standards formed to develop a framework to guide health education curriculum development. The committee—sponsored by the American Cancer Society and comprised of representatives from the Association for the Advancement of Health Education, the American Public Health Association, the American School Health Association and the Society of State Directors of Health, Physical Education and Recreation—recommended seven broad standards to promote health literacy.

- **Standard One:** Understand basic health promotion and disease prevention concepts.
- **Standard Two:** Be able to access health information as well as products and services that promote health.
- **Standard Three:** Be able to act on health information to reduce health risks.
- **Standard Four:** Critically analyze how culture, media, technology and other factors affect health.
- **Standard Five:** Use communication skills to reduce health risks.
- **Standard Six:** Set goals and make decisions to reduce health risks.
- **Standard Seven:** Argue on behalf of personal, family and community health.

Source:

- Summerfield, Liane. "National Standards for School Health Education," ERIC Clearinghouse on Teaching and Teacher Education: 1995. <[http://www.ed.gov/databases/ERIC\\_Digests/ed387483.html](http://www.ed.gov/databases/ERIC_Digests/ed387483.html)>.

## Departments of education

According to CSG's *National Survey on Health Literacy Initiatives*, most public schools require some type of health education. Across the country, states have adopted standards for K–12 health education and have provided curriculum guidance to local schools as a way to ensure that students have a basic level of health literacy. Evaluating the effectiveness of state mandates, however, is difficult. Because curriculum decisions are made at the local level, the form these classes take, the grades in which health education is taught and even the expected outcomes of the classes vary significantly.

Professional development and teacher training also improve basic health literacy among children and adolescents. Survey results indicate that many states and local school districts provide health education training to teachers and partner with organizations like the American Heart Association, the American Cancer Society and others to raise awareness of health issues among students.

A number of states also have established school health programs with grant support from the Centers for Disease Control and Prevention (CDC). These programs create partnerships between health and education officials to educate students, train staff and promote healthy behaviors, including reducing tobacco use and promoting exercise and good nutrition. Comprehensive school health programs are another method for addressing low health literacy and giving young people the knowledge and skills they will need later in life.

## Offices of adult literacy

Health information may also be incorporated into adult basic education. Many of the tools available to adult education teachers that provide basic health care information also build reading and listening comprehension skills, increase vocabulary, and call for simple math calculations. Several of these resources are highlighted in the next chapter.

Adult literacy classes also often make use of real-world forms and documents when teaching literacy skills. Partnerships with state Medicaid and SCHIP agencies and local health care organizations could result in an improved relevancy in classroom content.

## The health care industry

In addition to efforts by state governments, health care organizations and professionals can also be involved in improving health literacy. The core of health care is the relationship and communication between a patient and a health care professional. Thus, it is critical that health care professionals, providers and health plans all participate in improving the system of care for those with low health literacy. States can partner with organizations and professionals and draw on their expertise in designing health literacy initiatives.

## Physicians

Physicians are the most logical instrument for successfully communicating with a patient about disease prevention and management, treatment options, and how and when to take a prescribed medication. For most people, respect for doctors and a desire to follow their instructions is a given: a doctor's job, after all, is to maintain or restore health. Many factors, however, affect a doctor's ability (and opportunity) to communicate with his or her patients, highlighting the need for a team approach in addressing the issue of health literacy.

Although managed care is often blamed for rushing doctors from one exam room to another, two separate reports show the length of an office visit actually increased from 1989 to 1998. Both the National Ambulatory Medical Care Survey (NAMCS) and the American Medical Association's Socioeconomic Monitoring System (SMS) showed increases of between one and two minutes per visit.<sup>2</sup>

Despite this, doctors still don't feel they spend enough time interacting with patients. A recent survey of doctors conducted by the Kaiser Family Foundation shows 74 percent of physicians are dissatisfied with the amount of time spent on direct care compared with that spent on administrative duties.<sup>3</sup>

Why this contradiction between actual and perceived time? An article in the *British Medical Journal* reflecting on this phenomenon cites several reasons:

- Performance standards established by highly competitive managed-care organizations increase the pressure on physicians to receive high marks on patient satisfaction surveys. Longer office visits are related to increased satisfaction.
- The increased availability of health information obliges doctors to spend more time responding to questions about symptoms and care options, as well as correcting misinformation. This may leave less time for diagnosis and explanation of treatment.
- Patients expect more from their physicians. Mental health issues, substance abuse and preventive medicine are all part of today's office visit. There is also increased pressure to work along a continuum of care, collaborating with other professionals both inside and outside the medical arena to deal with issues affecting patient health.
- Rotation among physicians within a provider group, as well as movement between health plans, results in fewer patients regularly seeing the same doctor. The familiarity and trust established during a long-term physician-patient relationship enables the doctor to better use the time allotted to an office visit.<sup>4</sup>

In addition to time, medical terminology poses problems. In an article on medical ethics, one physician described the language of medicine as "careful and elusive, Aristotelian and poetic, it takes years to learn, lasts forever, and is known only to the privileged. It is hard to mimic without giving away one's pretension, and it is hard to shed without giving away the farm."<sup>5</sup>

Medical jargon continues to act as a barrier between the patient and his or her doctor. While many physicians are aware of this problem and do try to use less scientific words and phrases (high blood pressure instead of hypertension), more help is needed for those with low health literacy.

One of the main difficulties is that medicine *is* complicated and it is not always possible to translate difficult concepts into plain language. Doctors using confusing terms may believe they are adequately defining these words either because of the context in

<sup>2</sup>Mechanic, David, McAlpine, Donna, and Rosenthal, Marsha. "Are Patients' Office Visits with Physicians Getting Shorter?" *New England Journal of Medicine*. January 18, 2001, v 344 n 3: 198–204.

<sup>3</sup>"National Survey of Physicians Part III: Doctor's Opinions about their Profession." Kaiser Family Foundation, March 2002. <[http://www.kff.org/content/2002/200204\\_26c/](http://www.kff.org/content/2002/200204_26c/)>.

<sup>4</sup>Mechanic, David. "How Should Hamsters Run? Some observations about sufficient patient time in primary care." *British Medical Journal*. August 4, 2001, v 323: 266–268.

<sup>5</sup>La Puma, John. "When Ethics Leans on Jargon Patients Often Denied Choice." *Managed Care*. July 1999. <<http://www.managedcaremag.com/archives/9907/9907.ethics.html>>.

### Recognizing and assisting individuals with low health literacy

As stressed in Chapter One, there is no easy way to identify someone who has difficulty reading, understanding and acting on health information. While educational attainment, income status, age and knowledge of the English language may distinguish someone as high-risk, these are not fool-proof indicators.

An article recently published in the *American Journal of Health Studies* offers these suggestions:

- Do not assume a person knows how to read.
- To prevent feelings of shame, don't ask "Can you read?" Instead, ask "How do you learn best?"
- Be aware of people who make excuses not to read or who ask someone else to read for them.
- When offering written materials, hand them to the person upside down.
- Use pictures to explain concepts.
- Use plain language.
- Use a "teach-back" method when providing information. By asking a person to repeat back to you what was said, you can assess their level of understanding.
- Demonstrate an idea whenever possible.
- Rewrite and reformat written materials to make them easier for someone with low health literacy to understand.
- Screen individuals at-risk for low health literacy. Evaluation tools include the Rapid Estimate of Adult Literacy in Medicine (REALM) and The Test of Functional Health Literacy in Adults (TOFHLA).

Source:

- Foulk, D., Carroll, P., and Wood, S., "Addressing Health Literacy: A Description of the Intersection of Functional Literacy and Health Care." *American Journal of Health Studies*: v17.1, <<http://www.ches.ua.edu/health/ajhs/17-1/2.pdf>>.

### **The AMA Foundation Physician Education Program**

In June of 2000, the AMA Foundation announced a multiyear program to address the issue of health literacy. "Partnership in Health—Improving the Patient-Physician Relationship Through Health Literacy" is aimed at helping doctors better understand the problems caused by low health literacy and provide information on improving doctor-patient communication.

As part of the program, the AMA Foundation created a "Health Literacy Introductory Kit." In addition to fact sheets and a discussion guide, the kit includes a video showing individuals with low health literacy discuss how it affects them.

For more information, call the Health Literacy Hotline at (800) 262-3211, ext. 5297.

which the term is used or in written materials they provided to the patient. Also, patients may be too intimidated—or too ashamed—to ask questions when they don't understand.

Another barrier is how difficult it can be to recognize someone who is having problems understanding health information. While most doctors recognize that literacy poses a problem in communicating with their patients, their ability to judge which patients are having difficulties is poor.

Preliminary results of a study conducted by Dr. Dean Schillinger, a practicing general internist and Assistant Professor of Medicine at University of California at San Francisco, found that doctors correctly assessed the functional health literacy levels of their patients only 31 percent of the time. "Overall, physicians overestimated functional health literacy levels 55 percent of the time."<sup>6</sup> While several assessment tools exist to evaluate an individual's health literacy, their use is not widespread.

### **Nurses**

Nurses' participation in health care provision has become increasingly important in the United States. As health care expenditures grow, making better use of these skilled professionals to provide patient-specific service delivery is a win-win for both patients and health plans.

In a case study analysis of the care provided an elderly gentleman who had attended school only until the fourth grade, it was determined that the instructions he received during his discharge from the hospital were inadequate for his needs. A visiting nurse was able to spend time discussing his understanding of his diagnosis as well as his prescribed treatment, provide instructions and detailed information on how and when to take his medication, and work with his home health aide so she better understood the gentleman's dietary restrictions.<sup>7</sup>

### **Health educators and allied health professionals**

As states move to control health care expenditures through better management of chronic disease, health educators and allied health professionals such as dietitians and physical therapists will be increasingly important to health care delivery.

The treatment of diabetes illustrates the importance of having a variety of health care professionals participate in patient care. Through one-on-one interactions, nurses, dietitians and diabetes educators can work together to create an individualized treatment plan discussing diet, exercise, insulin regimens and how to recognize warning signs requiring a doctor's attentions. Each of these professionals needs to be aware of low health literacy and its affect on patient understanding and compliance.

### **Pharmacists**

Much of the research surrounding the effects of low health literacy on health outcomes relates to knowledge of medication therapy—which medicine is taken when,

<sup>6</sup>Schillinger; Dean. "Literacy and Health Care: A Hidden Vulnerability." Presentation made at the Institute of Healthcare Advancement's *Health Literacy Conference: State of the Art 2002*, May 9, 2002, Anaheim, California.

<sup>7</sup>Perdue, Bobbie Jean, Degazon, Cynthia., and Lunney, Margaret. "Case Study: Diagnoses and Interventions with Low Literacy." *Nursing Diagnosis*. January 1999, v 10 11.

how should it be taken, what is it for and what are the possible side effects. Pharmacists bring a wealth of knowledge to patient interactions and are able to counsel patients about appropriate use and predict possible drug interactions.

## Hospitals

One area where hospitals can improve patient communication is informed consent. Not only is it in the best interest of the patient to fully understand the nature of the procedure, its risks, its benefits and the alternatives, but true informed consent will help protect the hospital and attending physician from liability should something go wrong.

Hospitals also have the opportunity to improve patient education, especially as it relates to preparing a patient for self-care after leaving the facility. Discharge procedures match the medical diagnoses and the prescribed treatment with very little consideration given to how an individual learns and understands the best.<sup>8</sup> When factors such as low health literacy apply, evaluating success based on whether or not protocols were followed makes little sense. A system based on health outcomes—asking ‘Does the patient know what to do now?’ instead of ‘Was the patient told all relevant information?’—is much more effective.

## Health plans

Written materials designed by a health plan should be prepared at a level appropriate to its members. The effectiveness of enrollment forms, information on available benefits and how to access services, as well as procedures for filing a complaint or grievance depends on how well the reader understands the information.

Also, the data collected by health plans on their members offer a wonderful opportunity to provide targeted outreach to certain populations. Information available to health plans could include:

- The diagnosed condition of the member or his or her dependents.
- The number and purpose of prescribed medication.
- The education level of the member.
- The language spoken in the home.
- The number and age of any children in the household.

Using this data, health plans could make useful educational tools available to clients at risk for low health literacy, and even provide selected case management. These activities could significantly benefit plan members as well as serve to decrease overall costs. (See sidebar on Molina Healthcare of California).

## Pharmaceutical companies

As use of prescription drugs to treat and manage disease has increased, so too has the role of pharmaceutical companies in educating patients about appropriate use, adverse effects, and drug interaction problems. Because compliance with drug treatment is vital to good outcomes, these companies represent critical partners in efforts to address low health literacy.

### Molina Healthcare of California

In March 2001, Molina Healthcare of California, a managed care company primarily serving low-income populations, began a study to find out if providing health information written specifically for low literacy populations would result in decreased visits to the emergency room.

Molina divided its Medi-Cal members with children five years and younger into three groups—a control group (A), a group that received a copy of the book *What To Do When Your Child Gets Sick* (B), and a group that received a copy of the book plus reminders to use the book if they have questions about their child's health (C).

While more follow-up and analysis still needs to be performed, preliminary results show that making the information available did decrease inappropriate visits to the emergency room. For the eight months survey data is available, emergency room visits by groups B and C decreased 3.7 percent when compared to visits during the same period the previous year and taking into account changes in emergency room visits by the control group A. Parents who received copies of the book also showed a significant increase in parent self-efficacy—knowing how to care for common childhood complaints.

Source:

- Ryan, Marian, “Low Literacy Resources as a Demand Management Tool,” Presentation made at the Institute of Healthcare Advancement's *Health Literacy Conference: State of the Art 2002*, May 9, 2002, Anaheim, California.

<sup>8</sup>ibid.

In 2001, Florida's Agency for Health Care Administration announced a partnership with Pfizer, Inc., to assist Medicaid recipients suffering from four common chronic conditions: congestive heart failure, diabetes, asthma and hypertension. The program will take a three-pronged approach to disease management. First, specially trained nurses will conduct outreach and provide targeted case management. Second, community health centers will offer health education that is appropriate for their clients' literacy level and cultural background. Third, Pfizer will expand its drug donation program, offering prescriptions at no charge to Medicaid participants receiving care at a select number of community health care sites.

### **Federal government**

Resources made available by the federal government provide states with a good foundation for addressing the issue of health literacy.

#### ***Healthy People 2010***

The Department of Health and Human Services (HHS) has joined forces with a number of federal agencies and outside partners to create *Healthy People 2010*, a public health agenda for the nation. Among the focus areas in this plan are two directly related to health literacy: Educational and Community Based Programs and Health Communication. Goal 11-2 specifically states, "Improve the health literacy of persons with inadequate or marginal literacy skills."<sup>9</sup> (More information is available at [www.health.gov/healthypeople/default.htm](http://www.health.gov/healthypeople/default.htm).)

#### **National Adult Literacy Survey**

In 1992, the National Center for Education Statistics and the Division of Adult Education and Literacy conducted a national survey to determine literacy skills among adults in the United States. The survey results provide information about literacy rates for the nation. A follow-up survey—the National Assessment of Adult Literacy—is planned for 2002. This survey will have a health literacy component and will give state and federal decision-makers a baseline measure of health literacy levels around the nation. (For additional information, go to <http://nces.ed.gov/naal/>.)

#### **Simplifying Medicaid/SCHIP Enrollment and Retention Forms (SMERF)**

Sponsored by Health Care Financing Administration (now Centers for Medicare and Medicaid Services or CMS), this program provided grants to states to assist them in making the Medicaid/SCHIP enrollment and renewal process easier. In addition, the project created simplified forms and procedures as well as documents commonly used among all states.

### **National organizations and foundations**

A number of national organizations, foundations, think tanks and voluntary health associations have research and resources available regarding health literacy.

#### **Centers for Health Care Strategies, Inc. (CHCS)**

CHCS works to improve the quality of care available for low-income populations, the disabled, and the chronically ill participating in public health insurance programs.

<sup>9</sup>See [http://www.health.gov/healthypeople/document/html/volume1/11healthcom.htm#\\_ednref32](http://www.health.gov/healthypeople/document/html/volume1/11healthcom.htm#_ednref32).

Their website offers a number of resources and links relevant to those working in this arena. (More information available at [www.chcs.org/resource/hl.html](http://www.chcs.org/resource/hl.html).)

### **Center on an Aging Society**

The Center on an Aging Society examines the effect of demographic changes on society, acting as a source of useful information that will aid policy-makers in making decisions on a number of issues, especially Medicare and Medicaid. A number of reports are available on their websites, including “Health Literacy: Responding to the need for help” by Kristin Kiefer. (Visit [www.aging-society.org/](http://www.aging-society.org/) for more information.)

### **Robert Wood Johnson Foundation**

Dedicated to improving health and health care in the United States, the Robert Wood Johnson Foundation has funded a number of studies to examine the effect of low health literacy on quality of care. (Additional information available at [www.rwjf.org/index.jsp](http://www.rwjf.org/index.jsp).)

### **National Health Council**

Made up of voluntary health associations, business and industry groups, as well as other organizations interested in promoting health, the National Health Council works to improve health status in the U.S., particularly among the disabled and chronically ill. (For more information, visit [www.nationalhealthcouncil.org/](http://www.nationalhealthcouncil.org/).)

### **Institute for Healthcare Advancement**

The Institute for Healthcare Advancement recognizes the challenges posed by today’s health care system and works to educate both health care providers and health care consumers on crucial issues including accessing care. The Institute has published several resources, including the *What to Do For Health* textbook series. (Visit [www.ih4health.org](http://www.ih4health.org) for more information.)

### **Academia**

A number of resources on health literacy are available through academic institutions and researchers.

### **Harvard University’s National Center for the Study of Adult Learning and Literacy (NCSALL)**

A joint effort between Harvard University and World Education, NCSALL seeks to bridge the gap between researchers and practitioners in the field of adult education. The Health Literacy Studies program in the Department of Health and Social Behavior at the Harvard School of Public Health is a research program of NCSALL focused on studying the link between literacy and health. One tool made available by the program is the video “In Plain Language,” developed for medical and public health professionals who want to learn more about literacy and its effect on patient/provider communication. (For more information on The Health Literacy Studies program at Harvard University, including publications and research, go to [www.hsph.harvard.edu/healthliteracy/](http://www.hsph.harvard.edu/healthliteracy/). Information on NCSALL can be found at <http://ncsall.gse.harvard.edu/>.)

### California Literacy

California Literacy, the oldest and largest statewide adult volunteer literacy organization in the United States, hopes to tackle the issue of health literacy through its California Health Literacy Initiative. Only recently announced, this project will seek to improve health literacy among at-risk populations and increase awareness of the effect low health literacy has on health among health care providers and educators.

In the first two years, California Literacy hopes to implement several projects, including:

- Elevate the status of health literacy to make it a definite priority for major health care organizations.
- Create a clearinghouse of health literacy information and resources.
- Build awareness of the problems associated with low health literacy among health care providers.
- Participate in the development of a baseline standard of accessibility that will help communities evaluate whether the systems they have in place are suitable for someone with low health literacy.

For more information, visit [www.caliteracy.org/index.html](http://www.caliteracy.org/index.html).

### Emory University

Much of the research about the effect of low health literacy on health care outcomes has been performed at Emory University. Studies have looked at health literacy among Medicare managed care enrollees, the chronically ill and the elderly. This information is vital for policy-makers wishing to gauge the effect of low health literacy on costs and quality of care, as well as those wanting to know what works in addressing this issue.

### Louisiana State University

Research from LSU has also contributed to information available on the effect of literacy on health. One area of interest includes studies examining the usefulness of a variety of rapid assessment tools that evaluate patient literacy skills.

### Other players

In addition to the partners listed above, several other groups may assist in addressing the issue of low health literacy.

### Employers

With literacy a problem for over half of the adult population in the United States, government-sponsored health insurance programs aren't the only health plans faced with higher costs because of low health literacy. Employers can take an active role in addressing low health literacy among their employees. Strategies employers can adopt include:

- Simplifying enrollment procedures.
- Providing health information written at an appropriate level.
- Educating employees about health promotion activities.

### Advocacy groups

Local community groups working on behalf of those needing assistance can be important partners in improving health literacy among beneficiaries of state programs. In New York City, for example, the Managed Care Consumer Assistance Program provides information to help consumers understand their health plan and access the services they need. One-on-one assistance is provided in English, Spanish, Chinese, Russian, Yiddish, Korean and Haitian-Creole. (For more information, go to [www.mccapny.org/](http://www.mccapny.org/).)

### Literacy organizations

Organizations dedicated to improving literacy can assist in addressing the issue of low health literacy as well. Whether it is using health information to teach reading skills or making available materials written at a suitable level, these groups have access to those who inevitably struggle to communicate with their health care provider.

### Senior groups

Providing avenues for seniors to ask questions about health care, especially disease management, is important in addressing the problem of low health literacy. By inviting representatives from voluntary health organizations to discuss health issues, senior

groups give members the opportunity to learn about disease prevention and management, taking prescriptions, and knowing when to seek care.

## **Conclusion**

Solutions to the problem of low health literacy cross boundaries both within and between the health and the educational systems. Players range from local school districts and non-profit advocacy groups to national organizations and the federal government.

The impact state officials can have is tremendous. States are responsible for providing assistance to elderly, disadvantaged, low-income or low-literate individuals—exactly the individuals most at risk for low health literacy. Governors, state legislators and state agency administrators have the authority to establish programs and policies to aid individuals with low health literacy. Departments of education and offices of adult literacy, too, represent a mechanism for change. Health literacy represents both an opportunity for state officials and private sector leaders to make a difference, and a challenge because, as the next chapter will describe, few programs exist that directly address health literacy.



## Chapter Three



*What are states doing?*



## What are states doing?

Mrs. Walker is articulate and fully capable of participating in both her work and family life. She reads at a third-grade level.

*Mrs. Walker: Can you imagine what it's like being sick, and you know that you have limited skills, okay, and you're talking to an intelligent doctor like yourselves. And these people are using words that you really don't know because they're not speaking in layman's terms, okay? Most doctors are just presuming that everybody's as intelligent as they are. And that is just not the case. So . . . you come out of that room, that examination room with this intelligent man or woman thinking: God, I hope I don't make a mistake with my medicine, because I did not understand anything he or she said to me.<sup>1</sup>*

Early in 2002, CSG sent its *National Survey on Health Literacy Initiatives* to governors' offices, departments of public health, Medicaid and SCHIP offices, departments of education and offices of adult literacy. The survey elicited information on state officials' awareness of health literacy as an issue and identified any laws, rules or programs that assist individuals with low health literacy. This chapter provides an overview of the survey results and highlights innovative programs and best practices throughout the country. (Appendix B provides information on the survey methodology; Appendix C provides individual state responses to selected indicators.)

The survey results indicate that the roadmap for improving health literacy has yet to be drawn. A few states are beginning to be aware of the problems associated with low health literacy and to develop programs to address them specifically. Other states have made changes that aid individuals with low health literacy, such as simplifying enrollment materials or strengthening health education standards, but these efforts have not been recognized as addressing the problem of health literacy *per se*. As this chapter shows, states are taking steps forward, but health literacy is an issue that is ripe for public policy leadership.

### Awareness

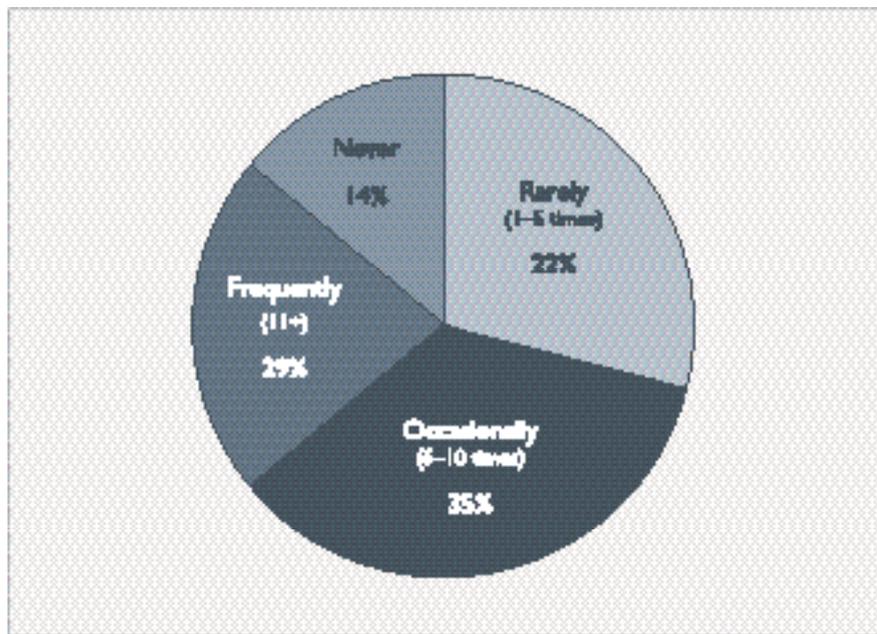
Awareness of health literacy and its role in the provision of quality health care services is mixed throughout the country. Even among the state representatives responding to CSG's survey, the number of times they had heard or seen the term "health literacy" reflects the emerging status of this issue.

As Figures 3-1 and 3-2 show, education and adult literacy officials are much more likely to have heard the term "health literacy" six times or more than officials in governors' offices, departments of public health and Medicaid and SCHIP offices (82.8 percent versus 64.6 percent).

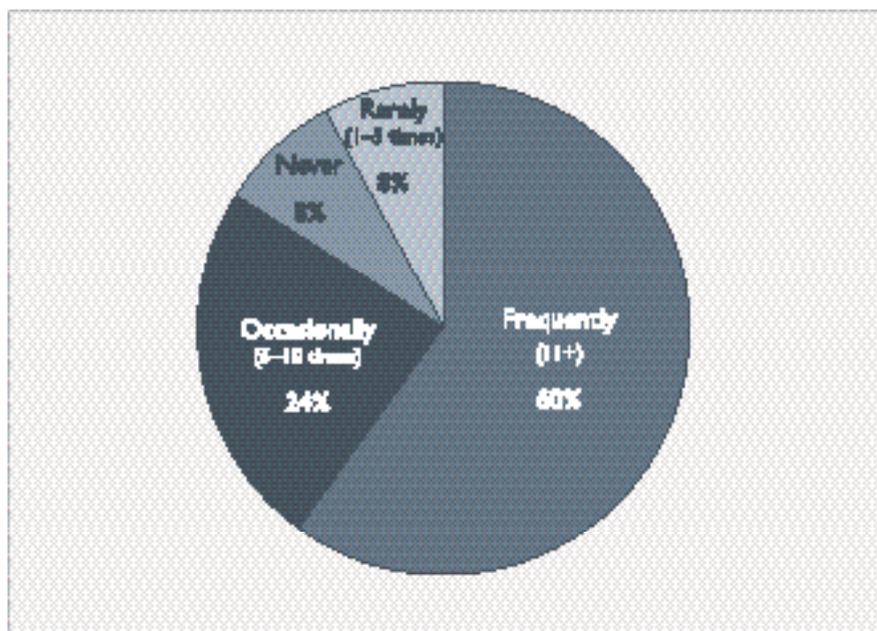
Several states have hired staff specifically to address this issue. Georgia's Department of Adult and Technical Information is one example. The department's health literacy coordinator is responsible for implementing a series of health literacy classes throughout the state, monitoring and providing technical training and support

<sup>1</sup>Schwartzberg, Joanne, and Lagay, Faith. "Health Literacy: What Patients Know When They Leave Your Office or Clinic." *Virtual Mentor*. June 2001. <<http://www.ama-assn.org/ama/pub/printcat/5154.html>>.

**Figure 3-1. Number of times seen or heard the term “health literacy” as reported by governors’ offices, departments of public health, Medicaid/SCHIP offices**



**Figure 3-2. Number of times seen or heard the term “health literacy” as reported by departments of education and offices of adult literacy**



when necessary. Still in its early stages, this program has hosted classes in hospitals, senior centers, mental health facilities and community centers. Doctors and other health care professionals such as emergency medical technicians refer individuals to the classes. Future plans include strengthening support for the program among physicians and developing a recruitment plan to increase enrollment.

Efforts to increase awareness among agency staff and health care service providers also vary. Connecticut, for example, mandates that managed care organizations with which it contracts train staff on how to communicate information to individuals with low literacy. The Louisiana Department of Health and Hospitals, Bureau of Health Services Financing, noted that ‘marketing’ the role low literacy has on behavior—such as completing Medicaid renewal forms—to Medicaid eligibility staff has played a role in improving retention rates.

The South Carolina Office of Minority Health reports that agency staff are required to complete a one-and-a-half-day cultural competency training. South Carolina’s Department of Health and Human Services also reports that one training session on writing in plain and simple language has been held and another is planned.

In Virginia, the Center for Primary Care and Rural Health, part of the Virginia Department of Health, works with a number of groups to build healthy communities. One facet of this work is the Virginia Health Access Network, a collaboration between organizations working to improve access to health care and health information throughout Virginia. Under this umbrella, the Health Literacy Network and the Multicultural Health Network both serve as resources to health care providers, agency staff, or any other Virginian wanting help in accessing care or assistance in working with specific populations.

### **Making Access Easier: Targeted Assistance**

CSG’s *National Survey on Health Literacy Initiatives* found that most states had made some effort to make the process for enrolling in and accessing care through state health insurance programs easier to understand. Of the states and territories responding to the survey, 95.9 percent had either simplified the language on enrollment forms for health care programs or the organization of enrollment forms to make them more understandable. Most—85.7 percent—had done both.

In addition, 87.8 percent had simplified the language in written materials used to help enrollees access care. More than three quarters had re-formatted written materials about accessing health care services to make them more user-friendly.

Alabama, for example, uses a joint application that is coordinated among Medicaid, Public Health (SCHIP) and the Alabama Caring Foundation. North Carolina has also instituted a joint application for its public health assistance programs. By combining the applications for both Medicaid and SCHIP, the state has been able to increase enrollment in both programs.

Montana’s Department of Public Health & Human Services reported that simplified Medicaid/SCHIP forms and materials have recently been introduced. These materials will be evaluated for their effectiveness in decreasing unnecessary visits to the emergency room, increasing preventive care measures and raising immunization rates.

To simplify the enrollment process in Wyoming, applicants for the adults with children and children’s Medicaid programs are no longer required to show proof of

### **California’s Healthy Families and Medi-Cal programs**

A 1998 report by the Medi-Cal Policy Institute titled “Opening Doors: Improving the Healthy Families/Medi-Cal Application Process,” offered several suggestions for simplifying the state’s 28-page joint SCHIP and Medicaid application. Out of these recommendations came Health-e-App, an Internet-based application that can be used by both clients and agency staff.

The application offers several user-friendly features, including: automatic error checking, computation of income and deductions, real-time determination of eligibility, information on providers, the ability to pay premiums electronically, confirmation that the application was received and the ability to track its progress, and the ability to move from English to Spanish versions.

A pilot test of the application showed that Health-e-App was faster, resulted in few errors and led to greater customer satisfaction.

For more information on Health-e-App, please go to [www.healthapp.org](http://www.healthapp.org).

income. By doing away with the resource test on these programs, it is easier for individuals to apply to the program and eliminates the interview requirement.

### **One-on-one assistance**

One-on-one assistance was consistently noted as one of the most effective methods for helping people understand enrollment and access procedures. Eighty-two percent of respondents offer one-on-one assistance in enrolling in state health insurance programs and 71.4 percent offer assistance for those having problems accessing care. This assistance took many forms:

- 69.4 percent provided on-site assistance at offices of state agencies.
- 55.1 percent made assistance available through clinics.
- 67.3 percent of states reported that counseling is offered at local non-profits or community centers.
- The vast majority of states—83.7 percent—provided a toll-free number for individuals to call if they had questions.

### **Non-English speakers**

State efforts to make information about enrolling in and accessing care more accessible to those populations whose primary language is something other than English vary across the country. According to the survey, 53.1 percent provide one-on-one assistance in multiple languages. For some states, this means staffing agencies or help lines with people who speak other languages. Other states contract with an interpreter service such as AT&T's LanguageLine Services, to provide health care providers and agency staff with a means of communication.

Massachusetts is one state that does both. Not only is their dedicated customer service line staffed by multi-lingual staff, the state's contract with AT&T provides people needing assistance access to interpreters who speak over 140 languages. In addition, all MassHealth (the state's combined Medicaid and SCHIP program) materials—including applications—are translated into English and Spanish. Certain materials are available in another nine languages: Arabic, Cambodian, Chinese, French, Haitian Creole, Laotian, Portuguese, Russian and Vietnamese.

The Massachusetts Division of Medical Assistance has also contracted with a community-based "Translation Bureau" that assists the state in meeting the needs of its culturally and linguistically diverse membership. The Bureau ensures MassHealth materials contain the linguistic and cultural elements to successfully convey the intended message.

In New York, Medicaid managed care plans are contractually required to provide information in a language if over 5 percent of a county's population speaks that language. This requirement is specified in the terms and conditions of the state's 1115 waiver.

### **Disease and health information: Educating for life**

Educating the public about health concerns is another area where states reach out to those with low health literacy. According to the survey, 71.4 percent have prepared written educational materials appropriate for someone who has difficulty reading and understanding health information.

The South Carolina Department of Health and Human Services, for example, has produced an educational activity booklet titled “Don’t Take Chances With Your Medication!” for seniors on understanding prescription drugs and the state’s SILVERxCARD drug assistance program. Crosswords and fill-in-the-blank exercises allow seniors to become familiar with medical terminology while at the same time reinforcing the importance of following a doctor’s instructions when taking medication. The booklet provides a place to list important contact information as well as a chart to write down all the medications the person is taking, the dosage instructions, and possible side effects.

### Pilot testing

Pilot testing materials offers states an opportunity to learn what works and what doesn’t when communicating complex information to individuals with low health literacy. However, few states responding to the CSG survey reported that they had tested their materials prior to implementation.

Alabama is a notable exception. Alabama’s Medicaid Agency reported that extensive tests have revealed that:

- Easy-to-read materials are preferred even by those with more advanced reading skills.
- Audio-visual materials must be evaluated for accessibility as well. However, audiotapes and videos that complement written materials can lead to increased understanding.
- Efforts to educate beneficiaries allow doctors to focus on health care and not the logistics of seeking care, ultimately strengthening the patient/provider relationship.
- Improvements to the layout of materials leads to greater utilization and retention.
- Use of medically-accurate photographs and artwork enhance patient compliance. Graphics that clearly illustrate the desired behavior reinforce the intended message.
- Materials translated into other languages are most effective when the dialect and cultural preferences of the audience are taken into consideration. Because individuals may be illiterate in their native language as well, use of artwork and other visuals is important.

Pilot tests in Florida and Virginia have also provided valuable feedback. The Florida Department of Health reported that pilot tests and evaluations of materials by focus groups found that mechanisms for communication that staff thought would work had to be modified. Interpretation of cartoons and pictographs, for example, vary depending on the audience. Florida’s research showed that pictures of ‘real’ people were preferred.

The Institute for Community Health at Virginia Tech, a partner in Virginia’s Health Access Network, reported that pilot tests provided feedback on appropriate wording. Terms such as ‘anger,’ ‘grief,’ and ‘depression’ were recommended over the more clinical ‘mental health.’

### **Kids are the key: Elementary and secondary health education**

There is growing recognition that health literacy begins with elementary and secondary education. Of the states responding to CSG’s *National Survey on Health Literacy Initiatives*, fifty percent indicated that health education had been established as

### **Illinois Secretary of State**

In 2000, Illinois Secretary of State Jesse White created a Health Literacy Task Force to spearhead “Health Literacy For All,” a program designed to aid parents in understanding health information. Members included key leaders from within state government as well as private sector leaders in health care and education.

The goals of the task force are:

- To help health care providers, hospitals and pharmacies improve their effectiveness in communicating with mothers who have low health literacy.
- To distribute easy-to-understand information about common childhood ailments.
- To assist “Reach Out and Read,” a program that encourages health care providers to ‘prescribe’ reading to parents as a method for improving health.
- To aid literacy offices in selecting and producing health information that is understandable to someone with low health literacy.

For more information about this program, please contact the Illinois Secretary of State’s Literacy Office at (217) 785-6921.

a core academic subject for grades K–12. Slightly more—61 percent—indicated that some form of health education is required in elementary schools. At the secondary school level, 69.6 percent require health education. Survey respondents noted, however, that what is outlined in state guidelines and what goes on in the classroom can vary greatly since curriculum decisions are usually made by local school districts.

Despite the potential for inconsistencies in delivery states are working hard to improve health education in the classroom. Many states have adopted health education frameworks to assist local school districts in designing health curriculums.

California's *Health Framework for California's Public Schools, Kindergarten Through Grade Twelve*, a tool to aid curriculum development at the local level, is one such framework. Adopted in 1994, the framework encourages school districts to create a health education curriculum that puts students first. Recognizing that health education begins at home, the framework promotes collaborations between schools, parents, and the community.

To complement the framework, California's Department of Education has also partnered with the state's Department of Health Services to create School Health Connections. Partially funded by the Centers for Disease Control and Prevention (CDC), this program seeks to:

- Make use of research and survey data to guide health and physical education activities.
- Promote partnerships among stakeholder groups.
- Encourage local decision-making in creating comprehensive school health systems.
- Provide technical assistance and support to local decision-makers.

Rhode Island has also adopted a framework to guide curriculum development. Based on the National Health Education Standards as well as additional input from the state's Health Education Framework Task Force members, Rhode Island's 'Healthy Schools! Healthy Kids!' seeks to reinforce health education. The state feels that promoting healthy students will increase academic achievement and, as these students enter the workforce, result in a stronger state economy.

### **Health education teachers**

Making teaching tools available to health education teachers and offering professional development training are other strategies states have adopted for improving health education in the classroom.

The state of Alaska has created "Healthy Reading Kits," one for second-through-fourth grade and one for fourth-through-eighth grade. The texts referenced in the kit have strong health content and the teacher's manual that accompanies the kit helps educators tie the books to Alaska's reading standards.

The New Mexico Department of Education offers an annual school health education institute to train educators. Similarly, Maine provides a year-long program of professional development for Comprehensive School Health Education. According to a representative from the Maine Department of Education, the various trainings and institutes offered to educators in Maine encourage enthusiasm about health education among teachers and the inclusion of health information in the classroom.

## Health information as a tool for learning: Adult literacy

Many states have already recognized the potential for improving health literacy by using health information to teach basic adult education. Health materials can be employed to teach all the skills participants in adult literacy programs seek: vocabulary building, language development, listening comprehension, critical analysis, writing and discussion. In addition, health topics offer a relevancy and an opportunity to apply classroom lessons to real life situations that may be missing in a traditional adult education curriculum.

Florida's Adult Education Practitioner's Task Force is developing a curriculum framework and student performance standards to encourage teachers to incorporate health information into other subject areas. Emphasis has also been placed on partnerships between the health care industry and educators.

Louisiana has created a curriculum guide for its adult literacy classes. Developed to complement the textbook *What to Do When Your Child Gets Sick*, published by The Institute for Healthcare Advancement, these self-contained lessons use health information to teach literacy. Emphasis is placed on lessons that are relevant to the students' lives, such as treating ear infections and getting all the required immunizations, as well as how to navigate the health care system.

In Texas, the El Paso Community College/Community Education Program has also created a health literacy curriculum for adult learners. The lessons were developed to meet the health and education needs of its students.

To download the curriculum developed by Louisiana, go to [www.iha4health.org/healthlit\\_curriculum.html](http://www.iha4health.org/healthlit_curriculum.html). For information about the curriculum created by El Paso Community College, go to [www.worlded.org/us/health/docs/el Paso/index.htm#health](http://www.worlded.org/us/health/docs/el Paso/index.htm#health).

### Picking up the tab:

#### Finding funding for health literacy efforts

State officials responding to CSG's *National Survey on Health Literacy Initiatives* listed a number of different funding sources for programs related to health literacy. Overall, 88.5 percent indicated state dollars funded these activities and 78.8 percent made use of federal monies. Income from the tobacco Master Settlement Agreement was used by 40.4 percent of the states and territories responding.

Among the federal agencies listed, the U.S. Department of Education and the CDC were referred to most often. State departments of education often cited funds available through the Division of Adolescent and School Health (DASH), part of the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). DASH dollars are dedicated to preventing those behaviors that would jeopardize the health of children and young adults.

In Kentucky, money from a Cardiovascular Health Grant from the CDC to the state's Department of Education and the Kentucky Public Health Department was used to develop a standards-based unit of study for K–12 educators. Physical activity, nutrition, and tobacco-use prevention were integrated into the units at all levels.

Using tobacco Master Settlement Agreement dollars, Hawaii's Department of Education and Department of Health teamed up to provide training to educators to support the implementation of the state's standards for health and physical education. This partnership resulted in the hiring of ten additional staff members.

States also make use of money available from private foundations and voluntary health associations. Both Wyoming and West Virginia have received funding from the Robert Wood Johnson Foundation. In Alabama, a grant from the March of Dimes helped pay for an independent study of the effectiveness of health materials the state put out in conjunction with the state's PT + 3 Family Planning Counseling Method.

### **Health literacy mandated: State laws and contractual requirements**

No state has passed legislation that identifies or addresses health literacy directly. There are, however, state laws and regulations pertaining to either improving health literacy or making it easier for someone with low health literacy to access and act on healthcare information that are part of other legislation.

For example, contractual requirements between states and their Medicaid/SCHIP service providers often set specific requirements concerning readability of enrollment forms and health care information. Illinois's Department of Public Aid is one such state. The contract uses the following language in contracts between the state and the managed care organizations with which they work:

Written materials described herein that are to be provided to Eligible Enrollees, Prospective Beneficiaries or Beneficiaries shall be easily understood by individuals who have a sixth-grade reading level. If five percent or more (according to Census Bureau data as determined by the Dept.) of those low-income households in the relevant Dept. of Human Services local office area are of a single language minority, the Contractor's written materials provided to Eligible Enrollees, Prospective Beneficiaries or Beneficiaries must be available in that language as well as English. Translations of written material are subject to prior approval by the Dept. and must be accompanied by a certification that the translation is accurate and complete. Written materials, as described herein, shall mean Marketing Materials, Beneficiary Handbooks and any information or notices required to be distributed to Eligible Enrollees, Prospective Beneficiaries or Beneficiaries by the Department or regulations promulgated from time to time under 42 C.F.R. Part 438.

In addition, the health education curriculum frameworks adopted by state departments of education are often part of a larger state education code. For more information on sample laws and contractual language, please see Appendix A.

### **Conclusion**

Despite the costs and inefficiencies of low health literacy, public policy that specifically and directly addresses this issue has only begun. As of yet, no state legislation directly addresses health literacy, and only a handful of programs confront this challenge head on. This is both a challenge and an opportunity for state leaders. State officials can learn a lot from changes instituted by Medicaid and SCHIP programs to make information more accessible and understandable to enrollees. State efforts to improve health literacy through elementary and secondary education and adult literacy classes are also noteworthy. In addition, states can rely on a number of resources available from academia, non-profit organizations and the federal government to inform policy decisions. The next chapter will address how state policy-makers can determine the extent of the problem in their respective states.

## Chapter Four



**What do you need to consider when addressing low health literacy?**



## What do you need to consider when addressing low health literacy?

Mrs. Stuart is a nurse's aide in a nursing home. She reads at a seventh-grade level.

(Mrs. Stuart and a researcher sit in front of about 15 over-the-counter medicines.)

*Researcher: Your two-year-old has a high fever. Okay. What would you do?*

*Mrs. Stuart: Well, I would probably go and get some Tylenol.*

*Researcher: Okay, so which one of these things would you pick out for a two-year-old?*

*Mrs. Stuart: Probably this one. (Mrs. Stuart has picked out a pediatric suspension form of Tylenol.)*

*Researcher: Okay. Let's take that. Now take a look at it, and tell me how much you'd give your two-year-old of that?*

*Mrs. Stuart: Probably a teaspoon (One teaspoon equals eight Adult Extra Strength Tylenol).<sup>1</sup>*

For state officials to successfully respond to the issue of low health literacy, they must take into consideration many factors that will help to determine the extent of the problem in their state as well as what an appropriate response would entail. Among the important factors are the state's demographic characteristics and literacy and education rates.

### Demographics

Many of the populations identified as at-risk for low health literacy qualify for assistance through Medicaid, SCHIP or Medicare. By targeting assistance to these individuals, states can improve the quality of services and decrease costs.

### Elderly

The current problems with Medicare, especially the lack of a prescription drug benefit, have resulted in states playing a significant role in elder care through Medicaid and senior drug-assistance programs.

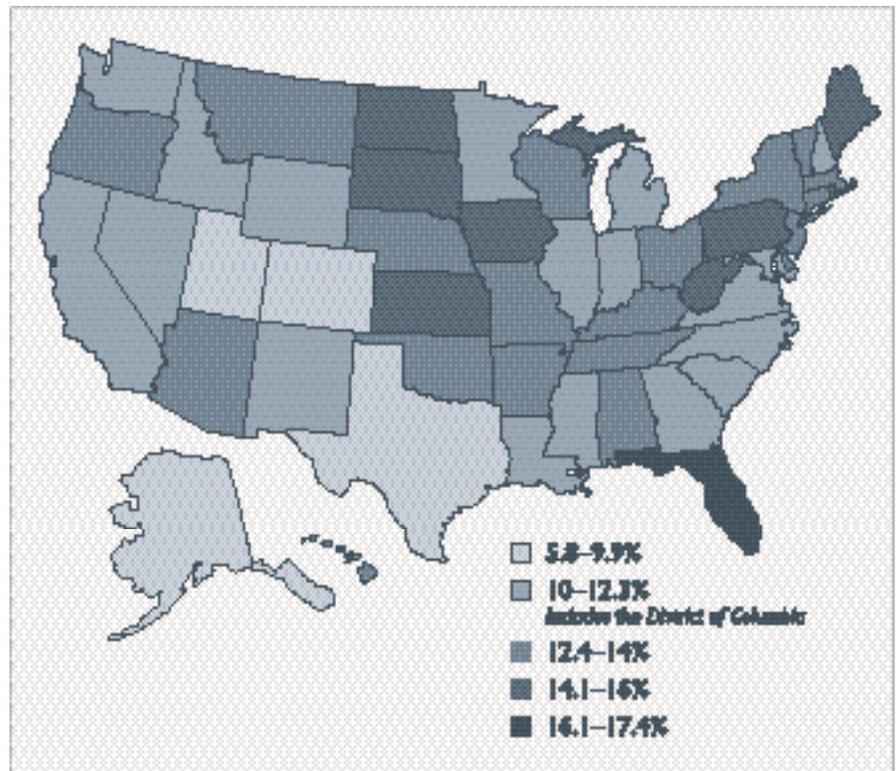
The diseases associated with aging—heart disease, cancer, osteoporosis, and dementia—are expensive and the treatments complicated. Programs that assist those over 65 to understand and manage their health conditions have great potential for keeping health expenditures down.

Questions policy-makers should ask:

- How many elderly live in my state (Figure 4-1)? What is the projected growth of this population?
- What health problems does this population suffer from?

<sup>1</sup>Schwartzberg, Joanne, and Lagay, Faith. "Health Literacy: What Patients Know When They Leave Your Office or Clinic." *Virtual Mentor*. June 2001. <<http://www.ama-assn.org/ama/pub/printcat/5154.html>>.

**Figure 4-1. Percent of residents per state age 65+, 2001**



Source: U.S. Census Bureau

- What type of care is required?
- Where is this population located (urban vs. rural)?
- How many seniors are enrolled in publicly-financed programs?
- How much does my state spend on this population?

**Low-income**

Studies show low-income populations are especially at risk for having difficulties understanding and acting on health information. State officials who are aware of the barrier created by low health literacy can take a two-pronged approach to addressing the issue: improve health literacy levels among public health insurance enrollees and revise program materials and procedures so they are more accessible to this population.

Questions policy-makers should ask:

- What are the poverty rates for my state (Figure 4-2)?
- What health problems is this group experiencing (drug abuse, infant mortality, low immunization rates, dental disease, etc.)?
- Where are these individuals located (rural vs. urban)?
- How many low-income individuals are enrolled in publicly-financed programs?
- How much does my state spend on this population?

**Figure 4-2. Percent of people in poverty by state, 1999–2000 average**

Ala. ....14.6%	Ky. ....11.9%	N.D. ....11.5%
Alaska .....7.8	La. ....18.3	Ohio .....11.1
Ariz. ....12.0	Maine .....9.5	Okla. ....14.0
Ark. ....16.4	Md. ....7.4	Ore. ....11.6
Calif. ....13.3	Mass. ....10.9	Pa. ....9.2
Colo. ....8.1	Mich. ....9.9	R.I. ....9.2
Conn. ....6.7	Minn. ....6.6	S.C. ....11.0
Del. ....9.5	Miss. ....14.5	S.D. ....8.6
D.C. ....14.8	Mo. ....9.7	Tenn. ....13.3
Fla. ....11.5	Mont. ....15.8	Texas .....14.9
Ga. ....12.1	Neb. ....9.8	Utah .....7.6
Hawaii .....10.3	Nev. ....9.7	Vt. ....10.2
Idaho .....13.5	N.H. ....6.3	Va. ....7.8
Ill. ....10.8	N.J. ....7.9	Wash. ....9.6
Ind. ....7.6	N.M. ....18.7	W.Va. ....14.8
Iowa .....7.3	N.Y. ....13.8	Wis. ....8.9
Kan. ....10.8	N.C. ....12.9	Wyo. ....11.2

Source: U.S. Census Bureau

### Non-English speakers

Individuals who do not speak, read or write in English—or who do so very poorly—often have difficulty processing health information, especially when translation services are not available. Providing assistance to non-English speakers is complicated by cultural differences and the fact that individuals may be illiterate in their native language as well.

Questions policy-makers should ask:

- What languages are spoken in my state? By how many? (See Figure 4-3.)
- How do cultural differences affect service provision?
- What health problems do these populations suffer from?
- Where is this population located (urban vs. rural)?
- How many non-English speakers are enrolled in publicly-financed programs?
- How much does my state spend on this population?

### Literacy rates

Results from the 1992 National Adult Literacy Survey (NALS) showed that 46–51 percent of the U.S. adult population scored at a Level 1 or a Level 2, based on a five-point scale. (See Figure 4-4 for state scores.) While it is difficult to generalize exactly what skills these individuals have—included in this group are those who cannot read or write at all, as well as non-English speakers—it is almost certain these individuals would face some difficulty in navigating through today’s complicated health care environment.

**Cultural competency:  
Communicating with diverse  
populations**

While many states offer written materials in multiple languages, tackling the issue of low health literacy among diverse populations is more complicated than just word-for-word translations. Taking into account cultural differences is critical for successfully communicating health information to consumers.

Providing health information—both written and oral communication—that is ‘culturally competent’ means creating materials that appeal to diverse communities on many levels. Culturally appropriate interactions reflect an awareness of differing attitudes and beliefs, as well as customs and communication patterns.

Adapted materials use examples that are appropriate for the audience, define new and unfamiliar concepts, avoid stereotypes, and are familiar with changes in a language—the addition of new phrases and terms—that will best convey the key health message.

**Resources:**

- “A Guide to Health Education Materials for Adults with Limited English Literacy Skills,” World Education <<http://www.worlded.org/us/health/docs/culture/>>.
- National Center for Cultural Competence, <<http://www.bphc.hrsa.gov/OMWH/default.htm>>.
- American Medical Association, <<http://www.ama-assn.org/ama/pub/category/2661.html>>.

**Figure 4-3. Language spoken at home, population five years and older, by state, 2000 U.S. Census**

	English	Spanish	Pacific Island	Indo-European
Ala.	96.1%	2.2%	0.5%	1.1%
Alaska	85.7	2.9	3.8	0.6
Ariz.	74.1	19.5	1.3	2.1
Ark.	95.0	3.3	0.6	0.9
Calif.	60.5	25.8	8.6	4.3
Colo.	84.9	10.5	1.6	2.5
Conn.	81.7	8.4	1.5	7.9
Del.	90.5	4.7	1.3	3.1
D.C.	83.2	9.2	1.7	4.4
Fla.	76.9	16.5	1.1	5.0
Ga.	90.1	5.6	1.5	2.2
Hawaii	73.4	1.7	23.6	1.3
Idaho	90.7	6.7	0.7	1.6
Ill.	80.8	10.9	2.2	5.5
Ind.	93.6	3.3	0.6	2.2
Iowa	94.2	2.9	0.9	1.8
Kan.	91.3	5.5	1.3	1.6
Ky.	96.1	1.9	0.6	1.4
La.	90.8	2.5	1.0	5.4
Maine	92.2	0.8	0.5	6.3
Md.	87.4	4.7	2.7	4.0
Mass.	81.3	6.2	2.9	8.9
Mich.	91.6	2.7	1.1	3.3
Minn.	91.5	2.9	2.3	2.4
Miss.	96.4	1.9	0.5	0.9
Mo.	94.9	2.1	0.8	1.9
Mont.	94.8	1.5	0.4	2.1
Neb.	92.1	4.9	0.9	1.7
Nev.	76.9	16.2	3.7	2.5
N.H.	91.7	1.6	0.9	5.5
N.J.	74.5	12.3	3.5	8.4
N.M.	63.5	28.7	0.7	1.3
N.Y.	72.0	13.6	3.8	9.3
N.C.	92.0	5.0	1.0	1.6
N.D.	93.7	1.4	0.3	4.0
Ohio	93.9	2.0	0.8	2.8
Okla.	92.6	4.4	1.1	1.1
Ore.	87.9	6.8	2.4	2.6
Pa.	91.6	3.1	1.2	3.7
R.I.	80.0	8.1	2.0	9.3
S.C.	94.8	2.9	0.7	1.5
S.D.	93.5	1.4	0.4	2.8
Tenn.	95.2	2.5	0.7	1.3
Texas	68.8	27.0	1.9	1.9
Utah	87.5	7.4	1.9	2.5
Vt.	94.1	1.0	0.5	4.2
Va.	88.9	4.8	2.6	3.0
Wash.	86.0	5.8	4.4	3.2
W.Va.	97.3	1.0	0.4	1.1
Wis.	92.7	3.4	1.2	2.5
Wyo.	93.6	4.0	0.5	1.4
<b>U.S. Summary</b>	<b>82.1</b>	<b>10.7</b>	<b>2.7</b>	<b>3.8</b>

Source: U.S. Census Bureau

For policy-makers, reading levels have important implications for designing written materials. In recent years, many states have redesigned and reformatted Medicaid and SCHIP enrollment materials, simplified the process for accessing care and made available public health information appropriate for those with low literacy.

Questions policy-makers should ask:

- What are the literacy rates among those eligible to participate in public programs in my state?
- At what reading level is current information provided?
- Have changes been made to simplify the process for enrolling in public programs in my state?
- Is it possible to create a coordinated application process to decrease the number of forms that need to be completed to receive medical assistance?
- Is public health information suitable for those with low literacy?
- What can be done to increase literacy in my state?

**Figure 4-4. Percent of population at Level 1 or 2 on NALS by state**

Ala. . . . .57%	Ky. . . . .54%	N.D. . . . .39%
Alaska . . . . .33	La. . . . .61	Ohio . . . . .45
Ariz. . . . .42	Maine . . . . .42	Okla. . . . .47
Ark. . . . .56	Md. . . . .45	Ore. . . . .38
Calif. . . . .46	Mass. . . . .40	Pa. . . . .48
Colo. . . . .32	Mich. . . . .44	R.I. . . . .47
Conn. . . . .41	Minn. . . . .35	S.C. . . . .56
Del. . . . .44	Miss. . . . .64	S.D. . . . .41
D.C. . . . .61	Mo. . . . .46	Tenn. . . . .53
Fla. . . . .51	Mont. . . . .39	Texas . . . . .51
Ga. . . . .54	Neb. . . . .36	Utah . . . . .33
Hawaii . . . . .40	Nev. . . . .40	Vt. . . . .37
Idaho . . . . .38	N.H. . . . .36	Va. . . . .47
Ill. . . . .44	N.J. . . . .48	Wash. . . . .35
Ind. . . . .43	N.M. . . . .46	W.Va. . . . .56
Iowa . . . . .38	N.Y. . . . .50	Wis. . . . .39
Kan. . . . .39	N.C. . . . .52	Wyo. . . . .34

Source: Portland State University, 1996, <<http://www.casas.org/lit/litcode/Search.cfm>>.

### High school completion rates

Overall educational attainment—especially high school graduation rates—in a state also influences a state’s health literacy levels. Individuals without a high school diploma are less likely to be employed, earn less when they are employed, and more likely to qualify for public assistance.<sup>2</sup>

<sup>2</sup>Kaufman, Phillip, Alt, Martha, and Chapman, Christopher: “Dropout Rates in the United States, 2000.” National Center for Education Statistics, November 2001.

Questions policy-makers should ask:

- What is the rate of high school completion for my state (Figure 4-5)?
- What percent of the population without a high school diploma are enrolled in public programs?
- Is educational attainment tracked during Medicaid/ SCHIP enrollment?
- What services may be made available to those without a high school diploma?
- Can this information be shared with Offices of Adult Education?

**Figure 4-5. High school completion rates among the population 25 years and older, by state, March 2000**

Ala. . . . .77.5%	Ky. . . . .78.7%	N.D. . . . .85.5%
Alaska . . . . .90.4	La. . . . .80.8	Ohio . . . . .87.0
Ariz. . . . .85.1	Maine . . . . .89.3	Okla. . . . .86.1
Ark. . . . .81.7	Md. . . . .85.7	Ore. . . . .88.1
Calif. . . . .81.2	Mass. . . . .85.1	Pa. . . . .85.7
Colo. . . . .89.7	Mich. . . . .86.2	R.I. . . . .81.3
Conn. . . . .88.2	Minn. . . . .90.8	S.C. . . . .83.0
Del. . . . .86.1	Miss. . . . .80.3	S.D. . . . .91.8
D.C. . . . .83.2	Mo. . . . .86.6	Tenn. . . . .79.9
Fla. . . . .84.0	Mont. . . . .89.6	Texas . . . . .79.2
Ga. . . . .82.6	Neb. . . . .90.4	Utah . . . . .90.7
Hawaii . . . . .87.4	Nev. . . . .82.8	Vt. . . . .90.0
Idaho . . . . .86.2	N.H. . . . .88.1	Va. . . . .86.6
Ill. . . . .85.5	N.J. . . . .87.3	Wash. . . . .91.8
Ind. . . . .84.6	N.M. . . . .82.2	W.Va. . . . .77.1
Iowa . . . . .89.7	N.Y. . . . .82.5	Wis. . . . .86.7
Kan. . . . .88.1	N.C. . . . .79.2	Wyo. . . . .90.0

Source: National Center for Education Statistics, "Dropout Rates in the United States: 2000," <<http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2002114>>.

**Potential barriers**

Addressing the issue of low health literacy may pose problems for state officials, especially given the changing nature of healthcare and the budget shortfalls that have plagued states in the last year.

**Costs**

Many of the initiatives highlighted in the report required only small investments by states and were supplemented by federal or foundation grants. Even so, costs remain a significant barrier to any new program. One-on-one assistance, for example, was identified as one of the most effective means for increasing understanding among Medicaid and SCHIP enrollees. It was also noted for being one of the most expensive.

Many of the state initiatives highlighted in Chapter Three are funded through partnerships with many agencies. At the federal level, states have used money available from the Centers for Disease Control and Prevention, U.S. Department of Education

and Centers for Medicaid and Medicare Services to name a few. Collaborations also took place with private foundations such as the Robert Wood Johnson Foundation and voluntary health associations like the March of Dimes.

States can be creative when seeking funding for health literacy initiatives, making use of all available resources. Also, policy-makers must consider that increases in the efficiency and effectiveness of both government programs and health care service delivery may substantially offset costs.

### **Shame and embarrassment**

Identifying individuals with low health literacy isn't easy. The shame and embarrassment associated with not understanding one's doctor may prevent someone from asking questions and revealing their difficulties. Add to the mix the numerous forms and written documents that must be completed and read in order to access care, and society is left with the possibility that a large percentage of the population will simply do without care.

Increasing awareness among agency staff, health care providers, and educators at all levels is vital for reaching a group of individuals who wear no nametags and cannot be identified by income level, educational attainment, or age. Certain statistical indicators as well as various studies and surveys point to certain populations that are almost certainly at risk—populations served by government programs such as Medicaid, SCHIP and Medicare—but agency staff and health care professionals need to exercise care so that no one is treated stereotypically. A comprehensive approach to addressing the issue of low health literacy should not be limited to any one group in recognition of the pervasiveness of this problem.

### **Health care providers**

Medical innovation and changes in the health care delivery system already pose significant challenges for physicians and other healthcare providers. Encouraging health care providers to teach and interpret health information and to evaluate patient understanding may be seen as simply one more burden on a system near the breaking point.

When addressing this issue, policy-makers must decide how best to involve health care providers in improving health literacy. Passing legislation that regulates physician practices is one option. Another is to require materials be written at a certain grade level, or be made available in any language spoken by a certain percentage of the population.

States may also choose to encourage such practices by offering incentives. Results of customer satisfaction surveys that show efforts were made to increase understanding may be used in the contract renewal process. States may also make dollars available to fund innovative approaches to communicating with at-risk populations.

### **Educators**

While most states require health education be taught in elementary and secondary schools, what happens at the district level is often outside the realm of state responsibility. When, where and how health education is covered during K–12 education will differ significantly within a state.

Funding health education programs, offering professional development for teachers, providing educational tools, and adopting curriculum standards can assist local school districts in better addressing health education.

### Where do we go from here?

Health care is often described as a three-legged stool. The legs—access, costs and quality—work together to keep the system upright. By improving health literacy, state officials have an opportunity to address all three components. Increasing a person's ability to understand and act on healthcare information will result in more efficient use of healthcare resources. Encouraging better provider/patient communication will increase quality. And, making the health care system easier to navigate for someone with low reading and listening comprehension skills will improve access to care.

The information provided in this report does many things:

- Defines health literacy.
- Identifies why low health literacy is a problem.
- Identifies populations at-risk for low health literacy.
- Identifies the people involved in addressing low health literacy.
- Identifies innovative solutions and best practices from states around the country.
- Provides guidance on what policy-makers should know to best address the issue in their state.

Armed with data, state officials must evaluate the problem of health literacy in their state, assess what efforts are already underway and identify additional solutions.

### Contact information

The Council of State Governments does not advocate any one approach to a given issue, but instead tries to identify emerging trends and innovative responses that may be important to state government.

For additional research and materials about health literacy, help in evaluating the seriousness of the health literacy problem in a given state, or for information on how to contact experts in health literacy, state officials are welcome to contact the following CSG staff:

- **Trudi L. Matthews**, Chief Health Policy Analyst  
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## **Appendices**

- **Sample language**
- **Methodology**
- **State profiles**
- **FAQs**
- **Glossary**
- **Additional resources and references**



## Appendix A: Sample language for state legislation, contracts and health education frameworks

Listed below are resources for state officials interested in developing legislation, contracts or educational standards and frameworks regarding health literacy.

### Legislative Language

*Comprehensive Health Education Programs*

*California Codes*

*Education Code*

*Section 51890-51891*

51890. For the purposes of this chapter, “comprehensive health education programs” are defined as all educational programs offered in kindergarten and grades 1 through 12, inclusive, in the public school system, including in-class and out-of-class activities designed to ensure that:

- (a) Pupils will receive instruction to aid them in making decisions in matters of personal, family, and community health, to include the following subjects:
  - (1) The use of health care services and products.
  - (2) Mental and emotional health and development.
  - (3) Drug use and misuse, including the misuse of tobacco and alcohol.
  - (4) Family health and child development, including the legal and financial aspects and responsibilities of marriage and parenthood.
  - (5) Oral health, vision, and hearing.
  - (6) Nutrition.
  - (7) Exercise, rest, and posture.
  - (8) Diseases and disorders, including sickle cell anemia and related genetic diseases and disorders.
  - (9) Environmental health and safety.
  - (10) Community health.
- (b) To the maximum extent possible, the instruction in health is structured to provide comprehensive education in health to include all the subjects in subdivision (a).
- (c) There is the maximum community participation in the teaching of health including classroom participation by practicing professional health and safety personnel in the community.
- (d) Pupils gain appreciation for the importance and value of lifelong health and the need for each individual’s personal responsibility for his or her own health.

51891. As used in this chapter, “community participation” means the active participation in the planning, implementation, and evaluation of comprehensive health education by parents, professional practicing health care and public safety personnel, and public and private health care and service agencies.

*Plain Language Requirements*

*Minnesota Statute*

*Chapter Title: Department of Health*

*Section 144.056 Plain language in written materials.*

- (a) To the extent reasonable and consistent with the goals of providing easily understandable and readable materials and complying with federal and state laws governing the program, all written materials relating to determinations of eligibility for or amounts of benefits that will be given to applicants for or recipients of assistance under a program administered or supervised by the commissioner of health must be understandable to a person who reads at the seventh-grade level, using the Flesch scale analysis readability score as determined under section 72C.09.
- (b) All written materials relating to services and determinations of eligibility for or amounts of benefits that will be given to applicants for or recipients of assistance under programs administered or supervised by the commissioner of health must be developed to satisfy the plain language requirements of the Plain Language Contract Act under sections 325G.29 to 325G.36. Materials may be submitted to the attorney general for review and certification. Notwithstanding section 325G.35, subdivision 1, the attorney general shall review submitted materials to determine whether they comply with the requirements of section 325G.31. The remedies available pursuant to sections 8.31 and 325G.33 to 325G.36 do not apply to these materials. Failure to comply with this section does not provide a basis for suspending the implementation or operation of other laws governing programs administered by the commissioner.
- (c) The requirements of this section apply to all materials modified or developed by the commissioner on or after July 1, 1988. The requirements of this section do not apply to materials that must be submitted to a federal agency for approval to the extent that application of the requirements prevents federal approval.
- (d) Nothing in this section may be construed to prohibit a lawsuit brought to require the commissioner to comply with this section or to affect individual appeal rights under the special supplemental food program for women, infants, and children granted pursuant to federal regulations under the Code of Federal Regulations, chapter 7, section 246.

**Contractual language**

The Illinois Department of Public Aid, the agency responsible for Medicaid and the Children's Health Insurance Program, uses the following language in contracts between the state and the managed care organizations with which they work:

Written materials described herein are to be provided to Eligible Enrollees, Prospective Beneficiaries or Beneficiaries shall be easily understood by individuals who have a sixth grade reading level. If five percent or more (according to Census Bureau data as determined by the Dept) of those low income households in the relevant Dept. of Human Services local office area are of a single language minority, the Contractor's written materials provided to Eligible Enrollees, Prospective Beneficiaries or Beneficiaries must be available in that language as well as English. Translations of written

material are subject to prior approval by the Dept. and must be accompanied by a certification that the translation is accurate and complete. Written materials, as described herein, shall mean Marketing Materials, Beneficiary Handbooks and any information or notices required to be distributed to Eligible Enrollees, Prospective Beneficiaries or Beneficiaries by the Department or regulations promulgated from time to time under 42 C.F.R. Part 438.

## **Health education framework information**

### ***National Health Education Standards***

Joint Committee on National Health Education Standards, National Health Education Standards: Achieving Health Literacy, Atlanta, GA: American Cancer Society, 1995.

### ***Alaska***

Skills for a Healthy Life Framework, Alaska Department of Education & Early Development, <http://www.educ.state.ak.us/tls/frameworks/health/1table.htm>

### ***California***

Health Framework for California Public Schools Kindergarten Through Grade 12, California Department of Education, <http://www.cde.ca.gov/cfir/health/>

### ***Massachusetts***

Comprehensive Health Curriculum Framework for K–12, <http://www.doe.mass.edu/frameworks/health99/toc.html>

Massachusetts Comprehensive Adult Basic Education for Health, <http://www.doe.mass.edu/acls/frameworks/health.pdf>

### ***Missouri***

Frameworks for Curriculum Development Health/Physical Education, <http://www.dese.state.mo.us/divimprove/curriculum/frameworks/over3.html>

### ***New Jersey***

New Jersey Core Curriculum Content Standards for Comprehensive Health and Physical Education, <http://www.state.nj.us/njded/cccs/07hpeintro.html>

### ***Rhode Island***

Health Literacy For All Children: The Rhode Island Health Education Framework, <http://www.ridoe.net/standards/frameworks/health/>



## **Appendix B: Methodology**

The Council of State Government's (CSG's) *National Survey on Health Literacy Initiatives* sought to gather qualitative and quantitative information from state officials on efforts to address the issue of low health literacy.

### **Survey design**

Two versions of the survey were created with the advice and assistance of experts in the fields of health literacy, education and survey design.

The first version was sent to governors' offices, departments of public health, and Medicaid/SCHIP offices to determine what government-sponsored health insurance and public health programs were doing to assist individuals with low health literacy. The questions posed elicited information on efforts to simplify the process for enrolling in and accessing care as well as those intended to make public health information more easily understood by someone with limited literacy skills.

The second version was sent to departments of education and offices of adult literacy and asked questions pertaining to health education goals and curriculum requirements affecting students in elementary and secondary schools, and those attending adult education classes.

Each survey asked for information on number of dedicated personnel and sources of funding. Also, information on any relevant state law or regulation was requested.

### **Survey recipients**

CSG made every effort to send the survey to the most relevant official at each of the state offices described above. Using information from CSG's membership files, as well as data gathered from state web sites and other sources, staff created an extensive mailing list.

Each person on this list was offered the chance to redirect the survey to the most appropriate individual in his or her department. For the convenience of respondents, the survey was offered on-line. CSG staff followed up with state officials by phone to encourage all states to respond. CSG staff also conducted follow-up interviews with selected respondents to gather further information on promising approaches.

### **State response**

Of the 56 states and territories that received a copy of either survey, CSG received responses from 52 states and territories. No response was received from Oregon, the District of Columbia, the U.S. Virgin Islands and the Northern Mariana Islands.

### **Disclaimer**

Information about state efforts was taken directly from survey responses. CSG takes no responsibility for incomplete or incorrect responses.



## Appendix C: State profiles

The following profiles capture each state's responses to CSG's *National Survey on Health Literacy Initiatives*. Two versions of the survey were sent to each state. The first version—sent to governors' offices, departments of public health, and Medicaid/SCHIP offices—asked questions pertaining to government-sponsored health insurance and public health programs. The second version—sent to departments of education and offices of adult literacy—asked questions about health education goals and curriculum requirements for both K–12 and adult education programs.

For each state, information is reported on:

- Simplifying the process for enrolling in and accessing care.
- Providing in-person, one-on-one assistance at state offices.
- Providing one-on-one assistance through toll-free helplines.
- Providing written materials suitable for someone with low literacy.
- Providing materials or assistance in multiple languages.
- Training agency staff or providers on communication strategies.
- Requiring health education for K–12 students.
- Using health materials in adult education classes.

The initial six items were taken from responses of health officials. The last two items were gleaned from responses of education officials.

A summary of the information provided by respondents concerning state activities, lessons learned, sources of funding and state laws or regulations is also offered. Responses have been edited.

Of the 56 states and territories that received a copy of the survey, CSG received 52 responses. No response was received from Oregon, the District of Columbia, the U.S. Virgin Islands and the Northern Mariana Islands.



## Alabama

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- Strategies reported by the Alabama Medicaid Agency include: use of a joint application that is coordinated among Medicaid, SCHIP, and the Alabama Child Caring Foundation; a toll-free telephone assistance line to direct applicants to community-based workers; and Medicaid eligibility counselors to assist applicants. The state has made use of graphics in written materials as well as audio-visual aids to assist enrollees in accessing care. Both agency staff and health care providers have received training in working with individuals with low health literacy.
- Materials must be written at a certain grade level (usually sixth-grade) using one of the widely recognized readability scales.
- The Alabama Department of Education reports that health education is considered a core subject and is integrated into the K–12 curricula.

### Lessons learned

- Use of easy-to-read materials that repeat key messages are highly effective and result in beneficiaries understanding when and how to access care, contributing to greater patient and provider satisfaction.
- Improvement in the layout of materials increases the utilization rate of education materials and increases retention of information because they are easier to understand.

### Sources of funding

- State and federal funds were identified.

### State laws and regulations

- None identified.

## Alaska

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.            |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                  |

### Activities

- “Healthy Reading Kits” are provided by the Department of Education. These kits provide teachers with hands-on materials and guidance for introducing health concepts into the classroom. Professional standards for health education teachers have been established.
- In contracting out services, the Division of Public Health requires health-related materials be prepared specifically for individuals with low literacy.
- The department works with teachers to keep assessment of student knowledge standard throughout the state. The strong working relationship between the Department of Education and the Department of Health and Social Services allows the two to partner on health promotion activities.

### Lessons learned

- Simplifying materials and forms decreased incidences of unrecorded data and increased user satisfaction.
- Translating materials into multiple languages increased provider satisfaction and, because of reduced translation time, simplified the enrollment process.

### Sources of funding

- State and federal funds were identified. Specifically, CDC Cooperative Agreement dollars and federal grants specific to combating Fetal Alcohol Syndrome.

### State laws and regulations

- Sec. 14.30.360 (encourages programs in health education).

## American Samoa

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.                   | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.                   | <input checked="" type="checkbox"/> Require health education for K–12 students.            |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                  |

### Activities

- The Department of Health identified the use of the Samoan language as effective in addressing health literacy issues. Audio-visual aids and one-on-one assistance were also found to be effective.
- According to the Department of Education, a Coordinated School Health Program is offered through the schools.

### Lessons learned

- More training for health care providers is needed.
- Partnerships between state agencies are not always successful. Domination by any one agency hampers success.

### Sources of funding

- None identified.

### State laws and regulations

- None identified.

## Arizona

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- Managed care organizations contracting with the Arizona Health Care Cost Containment System (AHCCCS) participate in community-based outreach such as health fairs.
- In contracting with managed care organizations, AHCCCS asks that the contractor attempt to make all materials available at a fourth-grade reading level.
- Pilot tests of materials have resulted in rewording certain questions based on client recommendations.

### Lessons learned

- Clients don't read materials as often as AHCCCS would like—even if they are written at a fourth-grade reading level.
- Member satisfaction surveys show one-on-one assistance is popular among clients.

### Sources of funding

- State general funds and federal funds were identified as sources of funding.

### State laws and regulations

- None identified.

## Arkansas

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.                   | <input type="checkbox"/> Require health education for K–12 students.                       |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.       |

### Activities

- Videos concerning services commonly used by non-English speaking clients were pilot-tested. Although helpful, this tool works best when staff have a basic understanding of Spanish.

### Lessons learned

- Training staff and health care providers hasn't been as effective because the training hasn't been offered to everyone. Spanish classes are available on a 'per request' basis.
- One-on-one assistance enhances consumer outreach efforts.

### Sources of funding

- Federal Department of Education monies were identified.

### State laws and regulations

- None identified.

## California

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Pilot-tested materials and TV ads using focus groups.
- Many materials are offered in California's 11 threshold languages.
- Established Health Education as a core academic subject.
- Require professional standards for health education teachers.
- Collaborate with other state and county government agencies, nonprofits and community-based organizations to promote health literacy.
- Passed in 1994, the Health Framework for California's Public Schools provides local school districts with guidance and support in designing a health education curriculum.
- In adult education, Health & Safety is one of the 10 program areas sponsored by state adult education funds. Since 1980, health has been one of the competency areas for ESL (English as a Second Language) and Adult Basic Education (ABE).

### Lessons learned

- The revised enrollment form has helped significantly but it could be further simplified.
- Inconsistent quality and support of health education among school districts. Funding is not always adequate to support health education.

### Sources of funding

- Tobacco Master Settlement Agreement dollars, state and federal funds were identified as a source of funding.

### State laws and regulations

- None identified.

## Colorado

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Consultants were used to help simplify the language and layout of materials. Reformatting has resulted in increased enrollment.
- The Colorado Certificates of Accomplishment curriculum guides offer suggestions for incorporating health education into adult basic education classes but are not required.
- Many local adult education programs partner with health care organizations in their areas but no state initiative to promote these collaborations was identified.

### Lessons learned

- High turnover among staff reduces the effectiveness of training eligibility workers in health literacy issues.
- One-on-one assistance efforts are very limited within the state.

### Sources of funding

- Both state and federal funds were identified.

### State laws and regulations

- None identified.

## Connecticut

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- |   |   |
|---|---|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Connecticut mandates managed care organizations with which it partners train staff and increase awareness of providing health and culturally appropriate information to individuals with low literacy.
- Health care materials and information are required to be written at a sixth-grade reading level.
- The Department of Education and the Department of Public Health have a strong collaboration around coordinated school health programs.

### Lessons learned

- One-on-one assistance was identified as improving access to care for clients.
- Although health education is required to be taught in grades K–12, content, materials and methods of instruction are determined locally, resulting in great variation between districts. No compliance reviews are conducted.

### Sources of funding

- Both state and federal funds were identified. HIV Prevention Cooperative Agreement dollars made available through the CDC were cited specifically.

### State laws and regulations

- None identified.

## Delaware

- Simplified the process for enrolling in and accessing care.
- Provide materials or assistance in multiple languages.
- Provide in-person, one-on-one assistance at state offices.
- Trained agency staff or providers on communication strategies.
- Provide one-on-one assistance through toll-free helplines.
- Require health education for K–12 students.
- Provide written materials suitable for someone with low literacy.
- Use health materials in adult education classes.

### Activities

- When contracting out services, Delaware requires materials be written at no more than a sixth-grade reading level. One-on-one assistance must also be provided.
- Delaware Dept. of Education approved standards for health education that guide class content.
- The Delaware Coalition for Literacy is collaborating with the Medical Pharmacists Association to develop information and materials written at a level suitable for someone with low literacy. These materials will be distributed to the public and used in adult literacy classes.

### Lessons learned

- Simplifying forms, reformatting materials and using graphics were credited with reducing the number of questions for those applying for assistance.
- Training staff and providers increases sensitivity to the issue of low health literacy, and leads to better client interviewing and service delivery.
- One-on-one assistance was identified as the most effective method for working with someone with low health literacy. This type of assistance ensures paperwork is completed correctly the first time, eliminating barriers.
- Providing materials and forms in an individual's native language helps that individual better understand the information and results in increased accuracy.

### Sources of funding

- Respondents identified federal, state and tobacco Master Settlement Agreement funds. At the federal level, funds from the CDC and the U.S. Dept. of Education were specifically mentioned. Client billing was also listed.

### State laws and regulations

- Health Education Reg. 851.

## Florida

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Contracted with a Hispanic provider to develop materials in Spanish specific to physical activity and arthritis. These were pilot-tested and use of some terminology was changed based on what was learned.
- Provide materials at a fifth-grade reading level.
- Under the leadership of the Adult Education Practitioners Task Force, a curriculum framework and student performance standards are being developed.

### Lessons learned

- Using graphics increased attendance and improved scores on post-tests given to individuals participating in WIC, abstinence education, etc.
- Audio-visual aids were especially effective communicating the importance of taking medication on time and condom use among non-native English speakers.
- Different people can interpret cartoons and pictographs differently. Consumers prefer use of ‘real’ pictures.
- When translating materials, ensuring that specific dialects are targeted increases effectiveness.
- Staff and provider training is needed but can be less effective due to high turnover.
- One-on-one assistance is the most effective - and most expensive - strategy.
- Increasing awareness and providing training for teachers are necessary to incorporate health education in the classroom.

### Sources of funding

- Federal, state and tobacco Master Settlement Agreement funds were all listed as sources of funding. At the federal level, Workforce Investment Act dollars were cited specifically.

### State laws and regulations

- Chapter 232.246 of the Florida Statute; Sunshine State Standards; Section 233.061 and 233.0612 of the Florida Statute; Section 231.17 of the Florida Statute.

## Georgia

- Simplified the process for enrolling in and accessing care.
- Provide materials or assistance in multiple languages.
- Provide in-person, one-on-one assistance at state offices.
- Trained agency staff or providers on communication strategies.
- Provide one-on-one assistance through toll-free helplines.
- Require health education for K–12 students.
- Provide written materials suitable for someone with low literacy.
- Use health materials in adult education classes.

### Activities

- Established six pilot health literacy sites throughout the state that hold health literacy classes. Educational information and public health concerns are included in the curriculum. The effectiveness of these efforts is still being evaluated.
- Offer a bi-lingual tobacco cessation helpline.
- ‘Patient navigators’ offer assistance to Asian and Hispanic women in enrolling in cancer screening programs.
- Established a health education curriculum framework (available at [www.gle.k12.ga.us](http://www.gle.k12.ga.us)).
- Partnerships between the Department of Education and Area Health Education Centers (AHEC) provide programs to educate both students and teachers.

### Lessons learned

- Making materials more user-friendly increases patient understanding and improves access to public health networks.
- Using graphics is helpful in educating patients about self-management procedures

### Sources of funding

- Respondents identified federal, state and tobacco Master Settlement Agreement funds as sources of funding.

### State laws and regulations

- O.C. GA 20-2-142; O.C. GA 20-2-143; State Rule IDB 160.

## Guam

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- |  |   |
|--|---|
| <input type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                    |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Created a proposal for a health literacy pilot course to be offered the fall of 2002 at the Adult Secondary Education and Adult Basic Education levels.
- Require a health regulations test for food handlers applying for permits. Applicants participate in a health/sanitation regulations class offered by Guam Community College.

### Lessons learned

- Partnership between the Guam Community College and the Dept. of Public Health has proved successful.

### Sources of funding

- None identified.

### State laws and regulations

- None identified.

## Hawaii

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- Created a professional development system to support the implementation of K–12 Standards for Health Education. These efforts included the creation of 10 new positions.
- Established assessment standards.

### Lessons learned

- The fact that Hawaii has a single unified school district is expected to help in the implementation of a set of standards, practices and strategies that all teachers will be able to use and understand.
- Partnerships with organizations like the American Cancer Society and the American Lung Association have proved effective.

### Sources of funding

- Respondents identified federal, state and tobacco Master Settlement Agreement funds as sources of funding.

### State laws and regulations

- None identified.

## Idaho

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- The state has developed courses of study for health education to be used by local school districts as they work to align their curriculum to state achievement standards.
- A Health Education Coordinator conducts workshops for health educators, school nurses and physical education teachers throughout the state.

### Lessons learned

- Strategies such as simplifying forms and reformatting materials were identified as effective because documents became more user-friendly.
- Translating materials is important to outreach efforts in those parts of the state with large populations of non-native English speakers.
- One-on-one assistance and training agency staff saves time because it prevents mistakes in the application process. It also prevents incorrect information from being given to applicants.

### Sources of funding

- Identified sources of funding were state funds, U.S. Dept. of Education dollars and CDC Safe and Drug Free School Program funds.

### State laws and regulations

- None identified.

## Illinois

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.  | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- In contracting out services, the state requires materials be written at a sixth-grade reading level. Also, if five percent or more of those qualifying for services in a particular location speak the same language, information must be provided in that language.
- Education about the state's senior drug assistance program is offered at senior centers.
- The state's Adult Education and Family Literacy Service Center Network is currently developing a plan for a systematic statewide approach to training teachers in health literacy.

### Lessons learned

- Outreach by the Illinois Dept. of Aging has increased participation in the state's senior drug assistance program.

### Sources of funding

- State general funds are used to match Title XIX funds. U.S. Department of Education and tobacco Master Settlement Agreement dollars were also listed.

### State laws and regulations

- None identified.

## Indiana

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- To assist individuals in accessing care through state programs, Indiana has developed multiple enrollment sites and additional ‘one-stop shopping’ sites.
- Materials are available in English and Spanish. The state has also prepared culturally sensitive materials to reach its Native American population.
- Benefit advocates are co-located with local family and social services offices to explain how managed care works, how to choose a primary care physician and how to access care.
- When contracting out services, the state requires all materials be written at a fifth-grade reading level or below and be culturally appropriate.
- Adopted state health education standards. Initiatives to support these standards are being developed.
- Collaborate with other agencies, non-profits, higher education and local companies to develop a wellness program for schools.

### Lessons learned

- Simplifying forms and reformatting materials resulted in reduced ER visits, better relationships with primary care providers and improved satisfaction ratings. Agency staff and health care providers also reported less confusion and better understanding of how to access care.

### Sources of funding

- Respondents identified state, federal and tobacco Master Settlement Agreement dollars. Specifically, the U.S. Department of Education and CDC were listed as sources of funding.

### State laws and regulations

- None identified.

## Iowa

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.                    |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.                   | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- When contracting out Informing and Care Coordination services, the Iowa Dept. of Public Health requires one-on-one service delivery.
- Recommend adoption of the National Health Education Standards by local school districts.

### Lessons learned

- None Identified.

### Sources of funding

- Respondents identified state dollars as a source of funding.

### State laws and regulations

- Iowa Code 256.11 Education Standards (1–6).

## Kansas

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|---|---|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.             | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.             | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input checked="" type="checkbox"/> Use health materials in adult education classes.    |

### Activities

- A new Health Education Curriculum Guide that will include health literacy is in development. It has not yet been approved by the state.
- Adult education teachers have attended workshops on incorporating real-life examples (forms, prescription drug bottles, health information brochures, etc.) into the classroom. However, no workshop has been developed that addresses all components of health literacy.

### Lessons learned

- None identified.

### Sources of funding

- Funding from the CDC dedicated to HIV/AIDS prevention was listed.

### State laws and regulations

- None identified.

## Kentucky

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|--|---|
| <input type="checkbox"/> Simplified the process for enrolling in and accessing care.           | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices. | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines. | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.     | <input checked="" type="checkbox"/> Use health materials in adult education classes.    |

### Activities

- When contracting out services, the state requires member materials be written at a sixth-grade reading level, published in at least a 14 point font, and comply with the ADA of 1990 (907KAR1:750).
- Through a Cardiovascular Health (CVH) Grant from the CDC, the state's Department of Education and the Department of Public Health developed 16 standards-based units of study for primary, intermediate and high school students.
- Development of a Life Skills Competency Curriculum for adult education.
- Disseminating information on health issues related to pregnancy and childbirth through the Governor's Office of Early Childhood.

### Lessons learned

- The toll-free helpline improves members' access to care and acts as a source for member education.
- Implementation of a web site isn't helpful to those without computer access.
- The adoption of a health education curriculum has proved effective because schools are required to teach health education and it is assessed in grades five, eight, and 10.
- While the training for teachers that was developed for the CVH unit is effective, too few teachers have had a chance to attend.

### Sources of funding

- State general funds and a Cardiovascular Health Grant from the CDC were identified.

### State laws and regulations

- KRS 158.6451.

## Louisiana

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.  | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Delivery of one-on-one assistance through a network of application assistance sites and at special events.
- The Department of Education developed health education content standards and benchmarks. These standards will be used to guide the development of a revised health education curriculum.
- The Department of Education offers a variety of training opportunities for teachers, including summer university courses and stand-alone workshops throughout the year.

### Lessons learned

- Making Medicaid eligibility staff aware of how low health literacy affects behavior (i.e. completing Medicaid renewal forms) has lead to improved retention rates.
- Simplifying materials and forms, reformatting materials, and using graphics was a major factor in increasing enrollment of children over the last three years.

### Sources of funding

- Respondents identified state and federal dollars, tobacco Master Settlement Agreement dollars, and license or usage fees as sources of funding.

### State laws and regulations

- None identified.

## Maine

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.             | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input checked="" type="checkbox"/> Require health education for K–12 students.            |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input checked="" type="checkbox"/> Use health materials in adult education classes.       |

### Activities

- New materials introduced during the summer of 2002 will be designed taking literacy issues into consideration.
- Adopted health education standards as part of Maine Learning Results.
- The University of New England has developed health-related pamphlets on various issues appropriate for individuals with low literacy.

### Lessons learned

- Training teachers and collaborating with health organizations improves the quality of health education.

### Sources of funding

- Tobacco Master Settlement Agreement, Maine Bureau of Health, Maine Nutrition Network, Department of Education and CDC/Division of Adolescent and School Health Cooperative Agreement dollars were all identified.

### State laws and regulations

- Chapter 127 of Maine Learning Results.

## Maryland

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Hire and deploy community-based individuals to assist individuals with low literacy.
- Facilitate effective communication and interaction among outreach workers and key players in the health care system.
- Utilize organizations that are sensitive to diversity to develop written materials and to translate materials into other languages.

### Lessons learned

- Community-based outreach workers have proven effective in assisting individuals with low health literacy.

### Sources of funding

- Both state and federal dollars were identified. In addition, the Maryland Tobacco Master Settlement legislation designated \$1.5 million be used to enable effective participation by minority populations. Attention must be given to all factors of diversity including literacy.

### State laws and regulations

- Annotated Code of Maryland 7-401.

## Massachusetts

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Provide Division of Medical Assistance staff with a resource guide that conveys health information in an easy-to-read and understand format.
- Require health materials be culturally and linguistically appropriate. All MassHealth materials are available in Spanish and certain materials are available in up to 10 languages.
- The Division of Medication Assistance has provided Health Access mini-grants to 84 community-based organizations to provide enrollment assistance.
- Developed a Health Curriculum Framework at both the K–12 and adult basic education (ABE) level.
- Department of Education provided Comprehensive Health Grants to ABE programs to undertake health activities using a peer leadership model.

### Lessons learned

- Translated materials must reflect the diversity of countries of origin and still be accessible by the greatest number of clients.
- Training has been invaluable in providing staff with the tools to recognize and work with individuals with low literacy.
- The ABE health curriculum framework has proved quite useful but is not consistently implemented across the state due to a focus on ‘core’ subjects.
- Partnerships between ABE and community health vans, police, fire, and community and neighborhood health centers are very successful.

### Sources of funding

- Respondents identified state and federal dollars, as well as tobacco Master Settlement Agreements funds. CDC funds and money from the state tobacco tax were also cited.

### State laws and regulations

- None identified.

## Michigan

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|--|---|
| <input type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- The K–12 Assessment Component currently under development calls for health education to be integrated into the curriculum.

### Lessons learned

- Partnering between the Department of Education and other state agencies has proved ineffective.

### Sources of funding

- State funds were identified as a source of funding.

### State laws and regulations

- None identified.

## Minnesota

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Simplified materials and forms under the state's Plain Language Act.
- The Department of Health's communications staff and health educators have worked hard to increase awareness of low health literacy, including preparing displays and conducting presentation to health professionals.
- In preparation for large-scale public health campaigns, the state conducts market research to determine what type of communication is most effective for the target audience.

### Lessons learned

- Simplifying materials and forms works best if they are tested with the targeted audience. One-on-one assistance makes them more effective.
- Reformatting materials can be very effective because first impressions are critical. Materials that come across as overwhelming are ignored.
- Translating materials into multiple languages is a first step. However, to be effective, the translation must be accurate and written at a level understood by the target audience.
- One-on-one assistance is effective because the health professional can ensure understanding.

### Sources of funding

- Respondents identified state and federal dollars as funding sources.

### State laws and regulations

- Plain Language Act.

## Mississippi

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Prepared managed care program materials and forms specifically for individuals with low or marginal literacy skills.
- Health literacy is stressed in staff development meetings with Adult Basic Education (ABE) instructors.
- A partnership between the Department of Health and ABE instructors has resulted in the dissemination of information about immunizations and other health-related issues to adult students.

### Lessons learned

- Translating materials into multiple languages helps staff work with non-English speaking patients and serves as a good vehicle for health education.

### Sources of funding

- Both state and federal funds were identified.

### State laws and regulations

- None identified.

## Missouri

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.  | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.             | <input checked="" type="checkbox"/> Require health education for K–12 students.            |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input type="checkbox"/> Use health materials in adult education classes.                  |

### Activities

- As a result of statewide assessment, all schools must have a written health curriculum.
- Health education assessments are performed in the fifth and ninth grades.

### Lessons learned

- None identified.

### Sources of funding

- State, federal and tobacco Master Settlement Agreement dollars were identified.

### State laws and regulations

- None identified.

## Montana

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- |   |   |
|---|---|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.                   | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Implemented simplified materials and forms. These materials will be evaluated to determine if they affect number of ER visits, preventive care visits, immunization rates, etc.
- Content standards addressing health education and health literacy have been established.

### Lessons learned

- Revised materials resulted in higher voluntary managed care enrollment rates.
- Establishing a health education curriculum is positive but depends on knowledge of teacher.

### Sources of funding

- State and federal funds were identified.

### State laws and regulations

- Montana School Accreditation Standards 10.54.7010.

## Nebraska

- |   |   |
|---|---|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.  | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.             | <input type="checkbox"/> Require health education for K–12 students.                    |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Medicaid managed care plans use educational materials that must be written at a fourth-grade level and provided in the primary language.
- Health promotion materials are designed to reach a broad audience.

### Lessons learned

- Simplification of materials and forms is helpful but it still assumes a fourth-grade reading level.
- Translating materials into multiple language isn't helpful if an individual is illiterate in their native language.
- One-on-one assistance is the most effective way to communicate but is expensive.

### Sources of funding

- Both state and federal funds were identified.

### State laws and regulations

- None identified.

## Nevada

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Developed health education standards. State law requires school districts to implement these standards.
- The Department of Education reports collaborations with other agencies—especially the Department of Human Resources, Health Division.

### Lessons learned

- Despite efforts to simplify forms and materials, program complexity is still the greatest barrier to enrollment.
- One-on-one assistance is the most effective tool for communicating with individuals with low literacy.
- Despite ongoing professional development activities, many teachers feel they are limited in the time they have to devote to health education due to school reform and testing pressures.

### Sources of funding

- Respondents identified state and federal funds. This includes CDC/Division of Adolescent and School Health Cooperative Agreement funds to fund physical activity and nutrition programs and state tobacco Master Settlement Agreement dollars for tobacco prevention campaigns.

### State laws and regulations

- NRS 389.110, NRS 389.063, NRS 392.450, and NRS 389.060.

## New Hampshire

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Standards and related activities developed by adult education practitioners include information about increasing awareness about health and nutrition issues.
- Is in the beginning stages of a collaboration between adult education programs and Area Health Education Centers that looks promising.

### Lessons learned

- After reformatting and simplifying materials and forms, more people have applied for the Healthy Kids program (SCHIP and Medicaid).

### Sources of funding

- Respondents identified Federal Department of Education dollars.

### State laws and regulations

- None identified.

## New Jersey

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|---|---|
| <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.</li> <li><input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.</li> <li><input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.</li> <li><input type="checkbox"/> Provide written materials suitable for someone with low literacy.</li> </ul> | <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.</li> <li><input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies.</li> <li><input type="checkbox"/> Require health education for K–12 students.</li> <li><input type="checkbox"/> Use health materials in adult education classes.</li> </ul> |
|---|---|

### Activities

- None Identified.

### Lessons learned

- None Identified.

### Sources of funding

- None identified.

### State laws and regulations

- None identified.

## New Mexico

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.  | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- New Mexico offers both a client services hotline and a behavioral health hotline. In addition, Medicaid managed care participants benefit from a contract with the AT&T's LanguageLine Services.
- Materials must be written at a sixth-grade reading level using the Fleisch-Kincaid Readability Index.
- All materials are available in English and Spanish because of New Mexico's large Spanish-speaking population.
- Providers, health educators and other agency staff are trained in providing presumptive eligibility and application assistance.

### Lessons learned

- Television advertising and direct mailings proved highly effective in increasing client enrollment.
- Collaborations between the Department of Education and other state agencies have been very effective in addressing school health issues.

### Sources of funding

- Both state and federal dollars were identified as well as private foundation grant monies.

### State laws and regulations

- Even Start Program 22.13.3-1; State standards 6.30.2 NMAC.

## New York

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- Conduct focus group tests of Medicaid materials. Consumer satisfaction studies also look at accessibility of information.
- Materials are written between a fourth- and sixth-grade reading level. Information is provided in a language if more than 5 percent of the county's population speaks that language.

### Lessons learned

- One-on-one assistance has proved to be an effective tool for increasing enrollment.
- Notices, advertisements, posters, etc., in other languages increase call rates.
- While it is difficult to assess its effectiveness, training of providers is essential since many consumers turn to their doctor for advice.

### Sources of funding

- Tobacco Master Settlement Agreement dollars and state and federal funds were identified.

### State laws and regulations

- None identified.

## North Carolina

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.             | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input checked="" type="checkbox"/> Require health education for K–12 students.            |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input type="checkbox"/> Use health materials in adult education classes.                  |

### Activities

- The state evaluates any materials prepared by its contracted HMOs or HBMs. Readability is one of the criteria for approval.
- The Division of Public Health considers health literacy when designing its materials.
- Community-based, grass roots organizations have been contacted to assist in enrollment.

### Lessons learned

- Outreach efforts, including creating one simple application for both Medicaid and SCHIP, increased enrollment.
- Collaborations between the Department of Public Instruction and health organizations have proved helpful in understanding the terminology used in health information.

### Sources of funding

- Respondents identified both state and federal funding.

### State laws and regulations

- None identified.

## North Dakota

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|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Counties with high refugee settlement rates offer translators to help people apply for assistance.
- On American Indian Reservations, health outreach workers assist individuals with low health literacy access services.
- Offer several professional development opportunities for educators: 14 summer courses, a large health conference and teacher trainings in research-based programs.

### Lessons learned

- None identified.

### Sources of funding

- Client fees and state and federal funds were identified.

### State laws and regulations

- Accreditation Rules in North Dakota's Century Code 67-19-01-3

## Ohio

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|---|---|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.             | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input checked="" type="checkbox"/> Use health materials in adult education classes.    |

### Activities

- Representatives from the Ohio Literacy Network report a strong focus on health literacy in its work with literacy professionals around the state as well as in its work with Ohio State University and the Ohio Department of Health.

### Lessons learned

- Implementation of Ohio’s health education curriculum must be supported by training and professional development if it is to be affective in improving health literacy.
- Creating guidelines for health literacy education in the schools is a good “first step” in getting the appropriate agencies and departments involved.
- Comprehensive health literacy efforts need the support of partnering agencies in order to be effective.
- Raising awareness among Adult Basic Education instructors has resulted in an increase of activities designed to improve health literacy.
- Collaborating with health organizations is very helpful. Representatives from these groups who speak to classes are able to explain terms and answer student questions that enable learners to make better health decisions.

### Sources of funding

- State funds were identified as a source of funding.

### State laws and regulations

- None identified.

## Oklahoma

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                       |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                  |

### Activities

- The Oklahoma Health Care Authority reports that it purchased easy-to-understand booklets for mothers of small children to help them understand common childhood illnesses and the care that is needed.
- A 24/7 nurses' advice line is available to assist enrollees in addressing health care needs.
- Materials and forms are written at a fifth-grade reading level.
- Outbound calling campaigns ensure training and assistance of members on accessing care. These campaigns also help identify barriers to program enrollment and access.

### Lessons learned

- Simplifying materials and forms is helpful but still have potential for being misunderstood or discarded.
- Translated materials are helpful but identifying the populations that would find them useful can be challenging.
- One-on-one enrollment assistance replaced mail-in enrollment cards. Before, members had to write their name and enrollment numbers on the card. Now, members can call a Helpline to determine program eligibility and participating providers.

### Sources of funding

- State and federal funds were identified.

### State laws and regulations

- None identified.

## Pennsylvania

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.                    |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.                   | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- None identified.

### Lessons learned

- None identified.

### Sources of funding

- None identified.

### State laws and regulations

- None identified.

## Puerto Rico

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- One-on-one assistance allows program eligibility staff to gauge understanding. When needed, one-on-one assistance is provided in English. All managed care service brochures are translated into English.

### Lessons learned

- Simplifying forms and materials has lead to fewer errors in data collection and transmittal.
- Training staff leads to more effective communication with clients.

### Sources of funding

- State funds were identified.

### State laws and regulations

- None identified.

## Rhode Island

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages. |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.  | <input type="checkbox"/> Trained agency staff or providers on communication strategies.    |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input checked="" type="checkbox"/> Require health education for K–12 students.            |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input checked="" type="checkbox"/> Use health materials in adult education classes.       |

### Activities

- Changed certification requirements for health and physical education teachers to include more health-related courses.
- Instituted assessments during eighth grade.
- Adopted “Healthy Schools! Healthy Kids!” - Rhode Island’s plan for comprehensive school health.
- Department of Education staff work with local schools to develop health education curriculum.
- Adult education programs use curriculum materials developed by World Education. A lot of emphasis is placed on nutrition and issues associated with mental health and cancer.
- Created partnerships with health organizations and other state agencies. The Department of Health, for example, assists in improving health literacy among young parents with a lead hazard curriculum.

### Lessons learned

- The framework is an important tool in curriculum development and instructional change. It also supports statewide health education assessment.
- Professional development on standards-based health education curriculum improves instruction.

### Sources of funding

- State and federal funds were identified.

### State laws and regulations

- Section 3.0 Title 16 General Laws on Education.

## South Carolina

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Educational materials are currently being revised to comply with program requirements.
- The Office of Minority Health notes that Department of Health and Environmental Control staff is required to complete a one-and-a-half day cultural competency training.
- Prepared an educational activity booklet to help older people manage their medications. The booklet also provides information about South Carolina's SILVERxCARD drug-purchasing assistance program.
- The Department of Health and Human Services offers a training session for staff on how to write using plain language.
- South Carolina's SCHIP program—Partners for Healthy Children—offers a video that promotes and explains the program.

### Lessons learned

- The state is using a multi-agency approach to the use of interpreters. The primary need is for Spanish-translators. Although the need has been identified, there are not many materials available yet.
- Training has improved awareness among Department of Health and Human Services staff. They are beginning to ask for help in assessing readability.

### Sources of funding

- Respondents identified state and federal dollars a sources of funding.

### State laws and regulations

- None identified.

## South Dakota

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- |   |   |
|---|---|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care. | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.  | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.  | <input type="checkbox"/> Require health education for K–12 students.                    |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy.      | <input checked="" type="checkbox"/> Use health materials in adult education classes.    |

### Activities

- None identified.

### Lessons learned

- Offering one-on-one assistance increases client satisfaction.

### Sources of funding

- State and federal funds were identified.

### State laws and regulations

- None identified.

## Tennessee

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- |   |   |
|---|---|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Provide materials written at a sixth-grade reading level. In reformatting materials, notices are being revised so the information flows better. Attempts have been made to place the most important information on the first page, or as close to the beginning as possible.
- All enrollee-directed notices and materials are translated into Spanish. There is a five-language card that goes into each notice indicating help is available in those languages if needed. All posters are in English and Spanish.
- National Health Education Standards are used for K–12 curriculum.
- Training opportunities for health education teachers and other teachers in curriculum standards and health education.

### Lessons learned

- None identified.

### Sources of funding

- Respondents identified state and federal dollars.

### State laws and regulations

- None identified.

## Texas

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Video scripts, brochures, and handouts designed for the Texas WIC program are routinely pilot-tested with the target audience.
- All clinics offer one-on-one assistance in Spanish and many offer help in Vietnamese as well. A contract with AT&T's LanguageLine Services enables communication in practically any language.
- Texas Department of Health (TDH) is in the process of designing a study to evaluate the literacy levels of key target populations. Findings will influence decisions on how best to communicate with clients. In addition, TDH is developing publishing standards and guidelines that provide clear guidance on how to create materials written in plain language.
- The Texas Education Agency is actively working on a number of relevant projects such as professional development for teachers, collaborating with health organizations, and partnering with other agencies such as TDH and El Paso Community College.

### Lessons learned

- Materials that make use of graphics have been shown to be more acceptable to clients and enhance readability.
- Clients are more motivated to change unhealthy behaviors if they can identify with a 'real' person. This has increased the value of using videos to provide information.
- Although health education varies across the state, those schools that are most effective are making a difference.

### Sources of funding

- None identified.

### State laws and regulations

- None identified.

## Utah

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input type="checkbox"/> Require health education for K–12 students.                               |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Materials produced by contracting health plans must be written at or below a sixth-grade reading level. All materials are reviewed prior to publication.

### Lessons learned

- Pilot-testing materials proved difficult because it was hard to find a good cross-section of clients. However, what they were able to do resulted in re-wording phrases to improve clarity.

### Sources of funding

- Respondents identified state and federal dollars as sources of funding.

### State laws and regulations

- Core Curriculum R277-733-7.

## Vermont

- Simplified the process for enrolling in and accessing care.
- Provide materials or assistance in multiple languages.
- Provide in-person, one-on-one assistance at state offices.
- Trained agency staff or providers on communication strategies.
- Provide one-on-one assistance through toll-free helplines.
- Require health education for K–12 students.
- Provide written materials suitable for someone with low literacy.
- Use health materials in adult education classes.

### Activities

- The Office of Health Promotion, part of the Virginia Department of Health, has offered several staff training opportunities.

### Lessons learned

- Translating materials into other languages is positive but only if the person is literate in his or her native language.
- The more colorful brochures are used more quickly.
- When done well, training teachers provides resources and encourages collaboration.
- Partnerships between the Department of Education and other state agencies enhance regional programs by ensuring support at the state level.
- Guidelines for health literacy provide schools with a menu of important concepts and skills to focus on within their health education program.
- Collaborations between schools and health organizations such as the American Cancer Society bring expertise, advocacy and funding to improve and support a variety of school health initiatives.

### Sources of funding

- Respondents identified tobacco Master Settlement Agreement funds, state and federal dollars. CDC/Division of Adolescent and School Health funds were cited specifically.

### State laws and regulations

- None identified.

## Virginia

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input checked="" type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- The Institute for Community Health at Virginia Tech has developed a plain language curriculum it has used in direct training and train-the-trainer workshops for staff enrolling families in Medicaid and SCHIP.
- Incorporating easy-to-understand health articles in newsletters distributed to residents of public housing.
- Conducted recipient open house to answer questions about managed care expansion.
- Information sent to Medicaid recipients by managed care organizations must meet low literacy standards.
- The Center for Primary Care and Rural Health has supported and funded projects with various organizations to promote health literacy and cultural competency to community health care providers. In 1999, the Center sponsored a health literacy conference.
- Health literacy is a required element for English as a Second Language classes.

### Lessons learned

- In pilot-tested materials, the Institute for Community Health at Virginia Tech received helpful feedback on word choices. For example, the test audience preferred terms such as ‘anger’ and ‘depression’ instead of ‘mental health.’
- Although many Department of Health programs have access to multi-language materials, there is a lack of consistency in the availability of materials in languages other than Spanish.

### Sources of funding

- State funds were identified.

### State laws and regulations

- None identified.

## Washington

- Simplified the process for enrolling in and accessing care.
- Provide materials or assistance in multiple languages.
- Provide in-person, one-on-one assistance at state offices.
- Trained agency staff or providers on communication strategies.
- Provide one-on-one assistance through toll-free helplines.
- Require health education for K–12 students.
- Provide written materials suitable for someone with low literacy.
- Use health materials in adult education classes.

### Activities

- Created online enrollment forms that can be completed and submitted to a centralized eligibility office.
- Developed guidelines for health literacy based on the National Health Education Standards.
- The Office of Superintendent of Public Instruction works with the Department of Health to support school health education. Other partners include the Comprehensive Health Education Foundation and the American Cancer Society.

### Lessons learned

- One-on-one outreach is very successful in Hispanic communities.
- Translating information into other languages is helpful unless the person is illiterate in his or her native language.
- Pilot-testing concepts and messages with the target population is very important.

### Sources of funding

- Respondents identified state, federal and tobacco Master Settlement Agreement dollars. CDC funds were cited specifically.

### State laws and regulations

- WAC 388-472, RWC 28A.150.210 Basic Education Act.

## West Virginia

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- |  |   |
|--|---|
| <input type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.         |
| <input type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.               |

### Activities

- Health education is offered every year during K–8 with one full unit required for high school graduation.

### Lessons learned

- None Identified.

### Sources of funding

- Respondents identified state, federal and tobacco Master Settlement Agreement dollars. CDC funds were cited specifically.

### State laws and regulations

- None identified.

## Wisconsin

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- The state has a variety of helplines available, providing information on maternal and child health, tobacco-use prevention and women's health.
- A health education class is required for the state's High School Equivalency Diploma.
- Adopted statewide health education standards.

### Lessons learned

- Partnerships between adult education programs and health organizations have been successful. More could be done to collaborate with the state Department of Health and Social Services.

### Sources of funding

- State and federal funds were identified. At the state level, local technical college matching funds support health literacy.

### State laws and regulations

- None identified.

## Wyoming

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- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Simplified the process for enrolling in and accessing care.       | <input checked="" type="checkbox"/> Provide materials or assistance in multiple languages.         |
| <input checked="" type="checkbox"/> Provide in-person, one-on-one assistance at state offices.        | <input checked="" type="checkbox"/> Trained agency staff or providers on communication strategies. |
| <input checked="" type="checkbox"/> Provide one-on-one assistance through toll-free helplines.        | <input checked="" type="checkbox"/> Require health education for K–12 students.                    |
| <input checked="" type="checkbox"/> Provide written materials suitable for someone with low literacy. | <input type="checkbox"/> Use health materials in adult education classes.                          |

### Activities

- The Department of Health, Office of Medicaid, reports that the state no longer requires income verification for applicants for programs serving families with children, children and pregnant women.
- The state requires all recipient bulletins be written at a sixth-grade reading level.
- The Department of Education offers teachers a lending library including health education resources.
- The state has adopted K–12 health education standards.

### Lessons learned

- No longer requiring a resource test on certain programs makes it easier for individuals applying for these programs.

### Sources of funding

- Respondents identified state and federal dollars. Specifically, CDC/Division of Adolescent and School Health funds. Also, the state has received funding from the Robert Wood Johnson Foundation to assist Medicaid enrollees and individuals without insurance.

### State laws and regulations

- None identified.

## Appendix D: FAQs

### What is health literacy?

Health literacy is the set of skills an individual needs in order to read, understand and act on health care information.

### Why is health literacy important?

Low health literacy affects health care by increasing costs. The National Academy on an Aging Society estimates that low health literacy cost \$30 to \$73 billion dollars annually.

Quality and access to care are also compromised by low health literacy. Many studies have demonstrated that individuals with low health literacy are less likely to understand instructions on how to take their medications properly, more likely to require longer hospital stays, and less likely to understand eligibility requirements for medical assistance programs.

### Who is affected by low health literacy?

Low health literacy is a problem for individuals in every socio-economic category. However, because of the relationship between educational attainment and economic status, low-income populations are especially at risk. Seniors and individuals whose first language is not English are also vulnerable.

### Who can make a difference?

Efforts to address the problems associated with low health literacy involve many sectors:

- **State government:** governors and other constitutional officers; legislators; administrators such as heads of departments of public health, Medicaid/SCHIP directors, departments of education, and offices of adult literacy.
- **Federal government:** through programs such as Healthy People 2010, the National Adult Literacy Survey, and Simplifying Medicaid/SCHIP Enrollment and Retention Forms (SMERF).
- **Health care providers:** physicians, nurses, pharmacists and other allied health professionals.
- **Hospitals.**
- **Health plans.**
- **Pharmaceutical companies.**
- **National organizations and foundations.**
- **Academia.**
- **Employers.**
- **Advocacy groups.**
- **Senior groups.**
- **Literacy organizations.**

**What can be done?**

Opportunities for simplifying the health care system, providing targeted assistance or improving health literacy rates abound. Suggested actions include:

- Simplify enrollment forms and procedures for accessing care, especially for plans serving populations at risk for low health literacy.
- Reformat or rewrite written materials to increase their accessibility. Require documents be written at a sixth-grade reading level or below. Incorporate graphics and white space, and increase font sizes to make materials more user-friendly.
- Translate relevant information—either written or verbal—into an individual's native language. When translating documents, ensure that the message isn't lost in translation and is relevant to the reader.
- Train agency staff and health care providers in effective communication strategies for individuals with low health literacy.
- Incorporate health materials and health education in the classroom at all levels—K–12 and adult. Giving individuals the skills to navigate today's complex health care system should be a priority for educators and school officials.

## Appendix E: Glossary

**Access**—The ability to navigate the health care system in order to obtain appropriate care.

**Adult basic education (ABE)**—Classes designed for adults that teach reading, writing, and math skills. Coursework is taught at levels ranging from basic—pre-high school—to high school, and includes English for speakers of other languages.

**Chronic disease**—A debilitating health condition that is of long duration and requires continuous medical treatment. Examples include diabetes, arthritis, kidney failure, and congestive heart failure.

**Culturally appropriate**—Takes into consideration the attitudes, beliefs, behaviors, practices, and communication patterns of diverse populations. Differences could be based on race, ethnicity, religion, socioeconomic status, historical or social context, physical or mental ability, age, gender, sexual orientation, or generational or acculturation status. The role these differences play in attitudes toward health and health care delivery is especially relevant.

**Cultural competence**—Taking into account the effects of ethnicity, racial and linguistic differences, educational attainment, and physical abilities when designing, implementing, and evaluating communication strategies.

**Enroll**—The ability to navigate the health care system in order to become a member of a private or public health insurance plan.

**Federal poverty level**—This scale provides policymakers with an idea of the level of income needed to ensure basic needs are met.

**Functional literacy**—A level of literacy sufficient to meet only the everyday demands of reading and writing.

**Health**—In addition to absence of disease or disabling condition, being of sound body and mind.

**Health communication**—Providing data about health issues to individuals and institutions in a manner that informs, influences and motivates behavior.

**Health education**—Lessons designed to teach and promote behaviors leading to better health.

**Health literacy**—The ability to read, understand and act appropriately on health information.

**Health promotion**—Actions encouraging and supporting the health of individuals and communities.

**High school completion rates**—The percentage of individuals 18 years and older not currently enrolled in high school who report that they have received a high school diploma or its equivalent.

**Illiteracy**—The inability to read or write.

**Linguistically competent**—Having the skills necessary to communicate effectively in the native language or dialect of the targeted population. Language preferences, educational attainment and literacy level are taken into consideration.

**Literacy**—Having the reading, writing, speaking, computation and problem-solving skills needed to perform the functions of daily living, to reach personal goals, and to maximize personal potential.

**Low literacy**—Reading or writing at a seventh-grade reading level. At this level, performing daily tasks would present difficulties.

**Managed care organizations (MCOs)**—Organizations that provide health care services to members by integrating the financing and delivery aspects of care. Services are provided through a pre-determined network of providers. Health maintenance organizations, preferred provider organizations and point-of-service plans are all considered managed care organizations.

**Marginal literacy**—A level of literacy that only adequately meets the needs for communication in reading and writing.

**Medicaid**—A joint effort by state and federal governments to provide health insurance to populations below a certain-income level.

**Medical errors**—Preventable adverse events resulting from medical management as opposed to the disease or condition of the patient.

**Medicare**—A federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with end-stage renal disease.

**Outcome evaluation**—Assessment of the results of an intervention, especially changes in knowledge, attitudes and beliefs.

**Pilot testing**—The evaluation of the effectiveness of a tool or program prior to full implementation.

**Plain language**—Phrase describing materials written below an 8th grade reading level. Other components of plain language documents include use of a large font and lots of white space. Plain language materials take readers' background knowledge and interests into consideration.

**Public health**—An organized effort to protect and improve a community's overall health status. Efforts include education outreach and prevention efforts, as well as treatment.

**Quality of care**—The standard of services available.

**Quality of Life**—A measure of a person's capacity to experience a full life based on level of disability. Factors that are taken into consideration include one's ability to perform tasks of daily living.

**SCHIP (State Children's Health Insurance Programs)**—A joint state and federal program created by the 1997 Balanced Budget Act. This program provides health insurance to children 18 years and under who do not qualify for Medicaid and yet live in families who lack the resources to purchase private health insurance.

## Appendix F: Additional resources and references

Braddock, C., Edwards, K., Hasenberg, N., Laidley, T., and Levinson, W. "Informed Decision Making in Outpatient Practice." *JAMA*, December 22/29, 1999: v282 n24.

This study reviewed 3,552 clinical decisions made during 1,057 encounters between a physician and a patient to determine what types of decisions were made and whether they could truly be considered "informed" decisions. The study found that only nine percent of decisions met the criteria.

Collins, K., Hughes, D., Doty, M., Ives, B., Edwards, J., and Tenney, K. "Diverse Communities, Common Concerns: Assessing Health Care Quality for Minority Americans." The Commonwealth Fund, March 2002. <<http://www.cmwf.org/publist/publist2.asp?CategoryID=11>>.

Results from *The Commonwealth Fund 2001 Health Care Quality Survey* show the quality of health care for minority Americans is below that of non-Hispanic white Americans. Identified problems included level of respect, patient-physician communication and number of insured.

D'Alessandro, Donna M., Kingsley, Peggy, and Johnson-West, Jill. "The Readability of Pediatric Patient Education Materials on the World Wide Web." *Archives of Pediatrics & Adolescent Medicine*, July 2001: v155 i7 p807.

This study evaluated the general readability of pediatric patient education materials designed for adults on the World Wide Web. Results indicated that information on the Web is generally written at a level higher than the level at which the average adult reads.

Davis, T., Arnold, C., Berkel, H., Nandy, I., Jackson, R., and Glass, J. "Knowledge and Attitude on Screening Mammography Among Low-literate, Low-income Women." *Cancer*, November 1, 1996: v78 n9.

In this study of the relationship between reading ability and knowledge and attitudes about getting a mammogram, of those women claiming to know what a mammogram was, only one in four were able to describe it correctly. Often, it was confused with a Pap smear.

"Educational and Community-Based Programs." *Healthy People 2010*. U.S. Department of Health and Human Services, <<http://www.health.gov/healthypeople/>>.

This chapter discusses the Health People 2010 goal to "increase the quality, availability, and effectiveness of educational and community-based programs designed to prevent disease and improve health and quality of life." According to the report, those communities most successfully addressing health issues do so through collaborations between a variety of organizations, including nonprofits, schools, public health offices, businesses and civic organizations.

Feinberg, E., Swartz, K., Zaslavsky, A., et al. "Language Proficiency and the Enrollment of Medicaid-eligible children in publicly funded health insurance programs." *Maternal and Child Health Journal*. March 2002: v6 n1.

In this study, parents of children participating in a State Children's Health Insurance Program were surveyed to find out how they learned about the program, how they enrolled, and the barriers to enrollment they felt existed. Results showed that families that did not speak English at home were significantly more likely to learn about the program from a service provider and to receive in-person assistance with enrollment (versus a toll-free telephone information line).

Foulk, D., Carroll, P., and Wood, S. "Addressing Health Literacy: A Description of the Intersection of Functional Literacy and Health Care." *American Journal of Health Studies*: v17.1. <<http://www.ches.ua.edu/health/ajhs/17-1/2.pdf>>.

This paper explores the issue of illiteracy and examines the points at which literacy and health cross. Suggestions on how literacy and health professionals can address the issue of health literacy are offered.

Gazmararian, J., Baker, D., Williams, M., Parker, R., Scott, T., Green, D., Fehrenbach, S., Ren, J., Koplan, J. "Health Literacy Among Medicare Enrollees in a Managed Care Organization." *JAMA*, February 10, 1999: v281 n6.

Medicare enrollees participating in four Prudential HealthCare plans were interviewed to determine levels of health literacy. The study used the Short Test of Functional Health Literacy in Adults. Results showed that health literacy was a significant problem for 33.9 percent of English-speaking enrollees and 53.9 percent of Spanish-speaking enrollees.

Greenberg, Daphne. "A Critical Look at Health Literacy." *Adult Basic Education*. Summer 2001: v11 i2 p67-79.

This article critically looks at the types of studies reported in medical journals, the definitions that are utilized, health literacy assessment and communication issues, and the role of adult literacy classrooms.

Greenberg, Jennifer. "An Updated Overview of Medical and Public Health Literature Addressing Literacy Issues: An Annotated Bibliography of Articles Published in 2000." National Center for the Study of Adult Learning and Literacy, Harvard University, 2001. <<http://www.hsph.harvard.edu/healthliteracy/annotations.html>>.

A comprehensive overview of articles relating to health literacy published from January 2000 to January 2001.

"Health Literacy: Report of the Council on Scientific Affairs." Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. *JAMA*, February 10, 1999: v281, n6, p552 (6).

This article uses past research to reflect on the effects of low literacy on patient/physician communication.

"Healthy Communication." *Healthy People 2010*. U.S. Department of Health and Human Services. <<http://www.health.gov/healthypeople/>>.

This chapter discusses the *Healthy People 2010* goal to "use communication strategically to improve health." Communication about health issues contributes to disease prevention and health promotion by raising awareness and providing individuals with the knowledge and motivation to make better decisions.

"Helping New Yorkers with Health Insurance and Health Plan Problems: The Managed Care Consumer Assistance Program (MCCAP)." Community Service Society of New York, March 2001.

This report provides demographic information on the clients served by the Managed Care Consumer Assistance Program (MCCAP), and the types of problems clients present. MCCAP provides outreach, consumer education and basic consumer assistance.

Hohn, Marcia Drew. "Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers, and Funders." National Institute for Literacy. <<http://www.nifl.gov/nifl/fellowship/reports/hohn/HOHN.HTM>>.

This report is the result of a two-year investigation of the problem of health education for low literacy groups. The report identifies a model that links health and literacy learning together in a power-sharing environment, utilizing the naturally occurring social contexts of adult literacy classrooms.

Hohn, Marcia Drew. "Literacy, Health, and Health Literacy" State Policy Considerations." *Focus on the Basics*, a quarterly publication of the National Center for the Study of Adult Learning and Literacy. February 2002: v5 iC. <<http://ncsall.gse.harvard.edu/fob/2002/hohn.html>>.

This article discusses the policies and supports instituted by state adult basic education policy-makers that will aid educators in improving health literacy.

"Increasing Medicare Beneficiary Knowledge Through Improved Communications: Summary Report on the Limited Education/Low Literacy Medicare Population." Prepared by Barents Group LLC for Health Care Financing Administration, March 1999. <<http://www.medicare.gov/nmep/publications&reports/pdfs/sum4.pdf>>.

This report was designed to answer two questions: what information do beneficiaries want or need from Medicare and what are the best ways to communicate that information to them. Key findings include Medicare beneficiaries with limited education and low literacy have a greater need for basic Medicare program information, are less knowledgeable of the specifics of the Medicare programs, and prefer informal and familiar sources and modes of communication.

Irvine, Cindy. "Health and Literacy Compendium: An annotated bibliography of print and Web-based health materials for use with limited-literacy adults." Developed by World Education in collaboration with the National Institute for Literacy, 1999. <<http://www.worlded.org/us/health/docs/comp/index.html>>.

A comprehensive overview of easy-to-read health materials available to health literacy educators and health care practitioners. The compendium provides information on resources written on a level accessible for those with low health literacy.

Jacobson, T., Thomas, D., Morton, F., Offutt, G., Shevlin, J., and Ray, S. "Use of Low-Literacy Patient Education Tool to Enhance Pneumococcal Vaccination Rates." *JAMA*, August 18, 1999: v 282 n7.

The study sought to determine if distributing information about the pneumococcal vaccine written for someone reading below a fifth-grade level increased immunization rates. Results showed that, when compared to the control group, patients receiving the information were four times more likely to have discussed the vaccine with their doctor and five times as likely to have been vaccinated.

Kalichman, S., Ramachandran, B., and Catz, S. "Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy." *Journal of General Internal Medicine*, May 1999: v14 n5.

This study found that individuals with low health literacy who had tested positive for HIV were four times more likely to be non-compliant with their medication.

Kaplan, S., Greene, J., Molnar, C., Bernstein, A., and Ghanbarpour, S. "Educating Medicaid Beneficiaries About Managed Care: Approaches in 13 Cities." The Commonwealth Fund, May 2000. <[http://www.cmwf.org/programs/quality/kaplan\\_educat\\_fr\\_380.pdf](http://www.cmwf.org/programs/quality/kaplan_educat_fr_380.pdf)>.

A review of Medicaid managed care educational efforts in 13 cities across the country. The intent of the study is to help policymakers develop and sustain programs that will teach beneficiaries to understand, use, and benefit from Medicaid managed care.

Kerka, Sandra. "Health and Adult Literacy." ERIC Practice Application Brief No. 7, 2000. <<http://ericacve.org/docs/pab00016.pdf>>.

An educational brief discussing the role of low literacy in determining health outcomes. Four solutions mentioned in the *Healthy People 2010* report—readability of health materials, improving health communications, changing individual behaviors and using approaches that empower the patient—are discussed.

Kiefer, Kristen. "Health Literacy: Responding to the Need for Help." Center for Medicare Education, February 2001. <<http://www.medicareed.org/cmepublications.html>>.

An in-depth discussion of health literacy including the problems low health literacy poses for individuals attempting to both enroll in and access Medicare. Efforts to address this issue are highlighted. Recommendations include assessment of health literacy skills by healthcare providers, one-on-one and group assistance, visual tools and training programs. Funding opportunities for these types of programs are also discussed.

Kilker, Kristin. "Considering Health Literacy." Center for Medicare Education, Issue Brief Vol. 1, No. 6, 2000. <<http://www.medicareed.org/pdfs/papers58.pdf>>.

A brief overview of health literacy—its definition, the effect of low health literacy on Medicare and Medicaid populations, and the costs associated with low health literacy. Examples of programs that address this problem are provided.

"Low Health Literacy Harms Patient Health, Increases Health Care Costs." Pfizer's *Views Making News*. January 2001. <<http://www.viewsmakingnews.com/policy/literacy.shtml>>.

An illustration of how low health literacy affects doctor/patient communication. The article recommends, among other activities, customizing drug schedules to the patient and color coding medicine label. Efforts by Pfizer to address this issue are highlighted.

"Low Health Literacy Skills Increases Annual Health Care Expenditures by \$73 Billion." National Academy on an Aging Society. <<http://www.agingociety.org/healthlit.htm>>.

The economic consequences of low health literacy are briefly discussed. According to the findings, the estimated additional health care expenditures due to low health literacy skills roughly equal what Medicare pays to finance physician services, dental services, home health care, prescription drugs and nursing home care combined.

Mann, C., Rousseau, D., Garfield, R., and O'Malley, M. "Reaching Uninsured Children through Medicaid: If you Build it Right, They Will Come." Kaiser Commission on Medicaid and the Uninsured, June 2002. <<http://www.kff.org/content/2002/20020611/4040.pdf>>.

This report discusses the changes in attitude resulting from the de-linking of welfare and Medicaid, and the creation of SCHIP.

Marsa, Linda. "Illiteracy Can Be Hazardous to Your Health." *Los Angeles Times*, July 31, 2000, p1.

An overview of the issues surrounding health illiteracy. A profile of one clinic in Los Angeles working to help patients overcome the barriers posed by low health literacy skills is given.

McComb, T., Duffy, M., and Pearson, I. "Making Handouts Easy to Read." *Contemporary Pediatrics*, April 2000: v17 i4 p145.

A review of methods for creating health education materials intended for individuals with lower reading levels.

Mechanic, Dave. "How Should Hamsters Run? Some observations about sufficient patient time in primary care." *BMJ*, August 4, 2001: v323 p266 (2).

This article discusses trends in the amount of time physicians spend interacting with patients. Although research shows the length of office visits has increased over the years, doctors continue to be dissatisfied with the amount of time available with a patient. Several possible explanations are provided.

"Medicaid and Children: Overcoming Barriers to Enrollment." The Kaiser Commission on Medicaid and the Uninsured, January 2000.

The results of a national survey intended to better understand the barriers to Medicaid enrollment and test the usefulness of ideas to facilitate enrollment by low-income parents. Survey findings include that the majority of children eligible for enrollment but not enrolled are in two-parent, working families with little welfare participation and that a complex, burdensome enrollment process is the greatest barrier to enrollment.

Molnar, Christine. "The Next Steps in Fostering Consumer Participation in Medicaid and S-CHIP Managed Care." *Journal of Ambulatory Care Management*, July 2001.

This article provides an overview of the difficulties families face in participating in Medicaid managed care. Identified challenges include: lack of support, education and information to aid in the decision-making process; barriers to accessing primary care and preventing services; and lack of information concerning a patient's right to appeal decisions.

"Non-English Language & Health Literacy Resources." Consumer Health Reference Center, Massachusetts General Hospital. <<http://www.mgh.harvard.edu/library/chrc/noneng.html>>.

A directory of websites offering easy-to-read health education materials in English and a number of other languages.

Perdue, B., Degazon, C., and Lunney, M. "Case Study: Diagnoses and Interventions With Low Literacy." *Nursing Diagnosis*, Jan 1999: v10 i1 p4(1).

A case study illustrating the effects of low literacy on patient understanding. Results point to the need for nurses to be aware of cues indicating low literacy, to assess functional health literacy when appropriate and to tailor patient education to the abilities of the patient. In this case, the home health aide also needed to assist in following the special diet and proper use of medications.

Root, Jane, and Stableford, Sue. "Easy-to-read consumer communications: A missing link in Medicaid managed care." *Journal of Health Politics, Policy and Law*. Feb. 1999: v24 i1 p1–26.

Article highlights the Maine Area Health Education Center Health Literacy Center's efforts to educate Medicaid patients with easy-to-read materials. The center sponsored three national skills training workshops titled "Writing for the Medicaid Market."

Ross, Donna Cohen, and Cox, Laura. "Enrolling Children and Families in Health Coverage: The Promise of Doing More." Kaiser Commission on Medicaid and the Uninsured, June 2002. <<http://www.kff.org/content/2002/20020611/4046.pdf>>.

This report details the result of a National Survey of Enrollment and Renewal Procedures in Medicaid and SCHIP. The most recent survey shows that, overall, states have designed programs that are easier to navigate than traditional Medicaid programs.

Rudd, Rima. "A Maturing Partnership." *Focus on the Basics*, a quarterly publication of the National Center for the Study of Adult Learning and Literacy. February 2002: v5 iC. <<http://ncsall.gse.harvard.edu/fob/2002/rudd.html>>.

This article traces the history of "health literacy," providing information on how the partnership between literacy and health professionals developed. Current initiatives as well as future activities in the field of health literacy are discussed.

Rudd, R., Colton, T., Schacht, R. "An Overview of Medical and Public Health Literature Addressing Literacy Issues: An Annotated Bibliography." National Center for the Study of Adult Learning and Literacy, Harvard University, 2000. <<http://www.hsph.harvard.edu/healthliteracy/literature2.html>>.

A comprehensive overview of articles relating to health literacy published from 1990 to 1999.

Rudd, R., Moeykens, B., Colton, T. "Health and Literacy: A Review of Medical and Public Health Literature." *The Annual Review of Adult Learning and Literacy*, Volume 1, edited by John Comings, Barbara Garner, and Cristine Smith, 1999. <[http://www.hsph.harvard.edu/healthliteracy/litreview\\_final.pdf](http://www.hsph.harvard.edu/healthliteracy/litreview_final.pdf)>.

This article discusses research exploring the link between the literacy level of patients and health outcomes. Barriers to health communication are highlighted as well as strategies for improving communication.

Rudd, R., Zahner, L., Bahn, M.. "Findings from a National Survey of State Directors of Adult Education." National Center for the Study of Adult Learning and Literacy, Harvard University, 1999. <<http://www.hsph.harvard.edu/healthliteracy/report9.pdf>>.

Results of a survey of State Directors of Adult Education. Respondents were asked to consider health within the context of adult learning. Priority ratings are offered for health as a content area through which other skills may be taught, as a subject of study, as a skill area, and as a barrier to learning.

Schillinger, Dean. "Improving the Quality of Chronic Disease Management for Populations with Low Functional Health Literacy: A Call to Action." *Disease Management*, Fall 2001, v4 i3 p103–109.

A discussion of the role of effective communication in chronic disease management and the challenges of low health literacy.

Selden, C., Zorn, M., Ratzan, S., Parker, R. "Current Bibliographies in Medicine: Health Literacy." <<http://www.nlm.nih.gov/pubs/cbm/hliteracy.pdf>>.

Sponsored by the National Library of Medicine, this bibliography provides citations for 479 articles relating to Health Literacy published between 1990 and 1999.

Sherer, Richard A. "Inadequate Health Literacy Raises Costs, Compromises Care." *Mental Health Economics*, a supplement to *Psychiatric Times*. June 2001, <<http://www.mhsource.com/pt/mhe17.pdf>>.

A brief discussion of the effects of health illiteracy on health care costs and delivery. Sherer points out that low health literacy is found among all populations and that doctors can't assume patients' ability to understand health information based on income or education level achieved.

Shutan, Bruce. "ABCs of Health Care: Educational campaigns are afoot to improve patient understanding and save on unnecessary care and costs." *Risk & Insurance*, November 2001: v12 i15 p50(4).

A discussion of efforts by the various organizations—including the AMA, Pfizer, risk management company FutureHealth Corp., and medical management company Intracorp—to address the issue of health literacy.

Slocum, W., Ryan, G., Gallina, D., Ferguson, S., Ernst, K. "Literacy Assessment in an Urban, Municipal Hospital Diabetes Clinic." *Diabetes*, May 1999: v48 i5 pSA158.

Results of a study done at an urban, municipal hospital diabetes clinic that studied the relationship between literacy and health outcomes.

Stevens, B., Yee, D., and Oritz, J. "Developing Culturally Appropriate Medicare Education Materials." Center for Medicare Education, Issue Brief Vol. 2, No. 4, 2001. <<http://www.medicareed.org/pdfs/papers51.pdf>>.

This brief explores the lessons learned from an effort to provide culturally appropriate materials to Medicare beneficiaries. CME discovered that: 1) culturally appropriate Medicare education is more than translation, 2) the differences within ethnic groups are as important—and as difficult—to deal with as the differences among ethnic groups, and 3) the process through which educational materials are developed needs to be guided by cultural expectations and behaviors.

"Unequal Treatment: Confronting racial and ethnic disparities in health care." Ed. By Smedley, B., Stith, A., and Nelson, A. Institute of Medicine, March 2002. <<http://www.nap.edu/books/030908265X/html/>>.

This report discusses the effect of race and ethnicity on quality of health care services received. Several solutions for improving the quality of care for these populations are given, including: increasing awareness of the differences, instituting protocols to ensure equal treatment and establishing uniform patient protection measures for enrollees in public health insurance programs.

Williams, M., Baker, D., Honig, E., Lee, T., Nowlan, A. "Inadequate Literacy Is a Barrier to Asthma Knowledge and Self-Care." *CHEST: The Cardiopulmonary and Critical Care Journal*, October 1998: v114 n4.

In this study of 483 asthma sufferers, researchers found that knowledge of asthma and proper self-care was directly related to reading level.

Williams, M., Baker, D., Parker, R., and Nurss, J. "Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease." *JAMA*, January 26, 1998: v158 n2.

The article reports the results of a study of the relationship between a person's knowledge of their disease and their level of health literacy. The study found that low health literacy presents a barrier to patient education.

Williams M., Parker R., Baker D., Parikh N., Pitkin K., Coates W., Nurss J. "Inadequate functional health literacy among patients at two public hospitals." *JAMA*, December 6, 1995: v274 n21.

According to this study of patients at two public hospitals, 33 percent of English-speaking patients could not read basic health materials; 42 percent of patients did not know what "taking medication on an empty stomach" meant, 26 percent did not understand the information on an appointment slip, and 43 percent and 60 percent respectively could not understand the rights and responsibilities section of a Medicaid application or an informed consent document.

Woodring, Barbara C. "If You Have Taught—Have the Child and Family Learned?" *Pediatric Nursing*. September 2000: v26 i5 p505.

A discussion of key concepts nurses should consider when educating the child and family. Topics include individual learning styles and readiness to learn, content of communications, and evaluation. Examples of clinically appropriate, easy-to-use assessment tools are included.

Zarcadoolas, Christina, and Blanco, Mercedes. "Lost in Translation: Each Word Accurate, Yet. . . ." *Managed Care Magazine*, August 2000. <<http://www.managed-caremag.com/archives/0008/0008.translate.html>>.

This article highlights the importance of creating documents that are not only correctly translated but culturally competent in contributing to patient understanding. The authors discuss translations versus adaptations of materials.