Health literacy may be a recent addition to the health policy lexicon. But just as “computer literacy” became a rallying term for states wanting to strengthen their citizens’ ability to compete in the global economy, so will health literacy become a rallying cry for states that want relief from double-digit health care inflation and questions regarding quality of care.

Health literacy – the ability to read, understand, and act appropriately on health care information – directly affects an individual’s ability to access services and successfully communicate with his or her health care provider. Low 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, to poorer quality care, errors and omissions, as well as higher costs.

Low literacy’s impact

Inadequate health literacy costs the U.S. health care system an estimated $30 billion to $73 billion annually, according to a 1998 study by the National Academy on an Aging Society. When broken down to expenditures by payer, this means that Medicaid spends as much as $10 billion annually due to low health literacy – 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 1).

Low health literacy also affects patients’ access to care. Complicated forms and procedures, rules about in-
network and out-of-network providers, tiered co-payment structures, as well as other aspects of modern health care, act as barriers that prevent people with low health literacy from receiving care. And when consumers do not know what questions to ask about a test or procedure or don’t feel empowered to prevent medical errors before they happen, the level of care diminishes.

Who is affected?

To date, no national measure of health literacy has been taken. However, studies of specific patient populations and data from the 1992 National Adult Literacy Survey, which demonstrates that almost half of the U.S. adult population has low or marginal literacy skills, point to groups vulnerable for low health literacy. These at-risk groups include: seniors; people with chronic illness; non-English speakers; and low-income individuals eligible to participate in Medicaid, SCHIP, WIC, maternal/child health programs and other public programs.

This list, however, is not exhaustive. Given today’s complicated health care system, no one is immune from having difficulty accessing appropriate care, understanding health information and making informed health care decisions.

Why health literacy? Why now?

A number of trends in the American health care system highlight the importance of health literacy, especially among beneficiaries of public health-insurance programs:

- **Rising health care costs:** Because of the increased costs associated with low health literacy, providing appropriate information or increasing beneficiaries’ skills can increase efficiencies and decrease expenditures. In addition, state efforts to contain costs by encouraging consumers to act as guardians of quality and affordable care will only succeed among individuals who are health literate.

- **Managed care:** HMOs, PPOs and other forms of managed-care insurance plans assume that patients will play an active role in managing their health. Without the tools and skills they need to access and navigate these complex systems, however, individuals with low health literacy will be unable to take on these responsibilities.

  - **Innovations in treatment:** Although recent medical advances have done much to improve the quality of life, the increasing complexity of treatments affects a person’s ability to make informed health care decisions and follow doctors’ instructions.

  - **An aging population:** The growing number of seniors places an increased burden on the U.S. health-care system. 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:** As the U.S. population becomes more diverse, differences in language and cultural beliefs will act as a barrier to successful communication between physician and patient, health plan and member.

CSG’s national survey

With the support of Pfizer Inc., during the spring of 2002, The Council of State Governments conducted a national survey to find out what states are doing to improve health literacy or to make the health care system easier to navigate. CSG surveyed governors’ offices, departments of health, Medicaid and SCHIP offices, departments of education and offices of adult literacy. Information gleaned from this survey, as well as private-sector programs and academic research, is highlighted in CSG’s recently published *State Official’s Guide to Health Literacy* (see http://www.csg.org/healthliteracy).

Awareness

Throughout the country, awareness of health literacy and its role in providing quality health care services varies. Even among the state representatives who responded to CSG’s survey, the number of times they had heard or seen the term “health literacy” reflects this issue’s emerging status.

As Figures 3 and 4 show, education and adult literacy officials were much more likely to have heard the term “health literacy” six or more times than officials in gov-

---

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

<table>
<thead>
<tr>
<th>Payee</th>
<th>Billions of 1998 Dollars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>$28.3</td>
</tr>
<tr>
<td>Employers</td>
<td>$12.1</td>
</tr>
<tr>
<td>Patients</td>
<td>$11.5</td>
</tr>
<tr>
<td>Medicaid</td>
<td>$10.3</td>
</tr>
<tr>
<td>Other Public</td>
<td>$7.6</td>
</tr>
<tr>
<td>Other Private</td>
<td>$3.4</td>
</tr>
</tbody>
</table>

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.

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 who want to help specific populations access care. In 1999, the center sponsored a health literacy conference for national, state and local health care programs.

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 collaboration between schools, parents and the community.

Massachusetts’ medical assistance programs have been at the forefront of providing multilingual 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 use in 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.

What can policy-makers do?

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

- Hold hearings or convene conferences about health literacy.
- Establish a task force or advisory group to recommend state actions.
- Promote the use of plain language and simplify enrollment forms and procedures for accessing care, especially for plans serving at-risk populations, such as recipients of Medicaid, SCHIP, WIC and mater-

State initiatives

While CSG’s National Survey on Health Literacy Initiatives found few states that have addressed health literacy in a comprehensive, multifaceted manner, individual agencies in a handful of states have established programs, hired staff or created task forces to respond to low health literacy and its effects on health care delivery.

- 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 who want to help specific populations access care. In 1999, the center sponsored a health literacy conference for national, state and local health care programs.
- 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 collaboration between schools, parents and the community.
- Massachusetts’ medical assistance programs have been at the forefront of providing multilingual 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 use in adult literacy classes.
- Georgia’s Department of Adult and

Effects of low health literacy

The growing awareness of the difficulties so many people face in reading, understanding and acting on health information is underscored by an increase in media attention. In a recent ABCNews story, Louisiana State University’s Dr. Terry Davis, a leading health literacy researcher, discussed how cost-saving measures can sometimes increase the health care system’s complexity. The piece also highlighted a common problem associated with low health literacy – taking prescribed medicines incorrectly. For more information or to see a video of the segment, visit The Henry J. Kaiser Family Foundation Web site at http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=13501.
Reformat or rewrite written materials to increase their accessibility. Require documents to 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 people with low health literacy.

• Incorporate health materials and health education in the classroom at all levels – including K-12 and adult literacy classes. Giving individuals the skills to navigate today’s complex health care system should be a priority for educators and school officials. Basic health literacy can also help children and adolescents make better decisions about their health and avoid risky behaviors.

Conclusion

Navigating the modern health care environment demands that consumers be ready to learn about health conditions, how to get health insurance, what treatments are 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. Efforts by state officials to simplify health-related information and procedures or to improve a patient’s health literacy through education and training will likely lead to improved efficiency and effectiveness in health care delivery.

—Jenny Sewell is a health policy analyst at The Council of State Governments.

Health literacy resources

• Center for Health Care Strategies Inc. – http://www.chcs.org/resource/hl.html.
• Harvard School of Public Health – http://www.hsph.harvard.edu/healthliteracy.