Virtually everyone finds it difficult to understand health information.

“A majority of U.S. adults do not have the literacy skills needed to use health-related print materials and tools with accuracy and consistency.” This is a conclusion of research presented to the Connecticut Health Foundation (CT Health) in 2007, compiled by Rima Rudd, Sc.D. (doctor of science), of the Harvard School of Public Health.

“Even those who are highly educated are challenged to understand and use health information at some point,” notes Elizabeth Krause, CT Health program officer and former Harvard graduate student health literacy researcher.

The Institute of Medicine defines health literacy as “the degree to which individuals have the capacity to obtain, process and understand health information and services needed to make appropriate health decisions.” But health literacy also includes the ability of medical professionals and institutions to communicate effectively with those they serve, says Krause.

“Anyone who has ever weighed the potential risks and benefits of elective surgery, helped an elderly relative enroll in Medicare Part D, or needed a second medical opinion knows how difficult it can be to interpret and apply health information,” adds Krause. Even simpler tasks, like managing a health savings account, monitoring dietary intake of saturated fat or using sunscreen correctly, can be challenging.

Yet the challenge is greater for some than others, says Krause. “The elderly, those with cognitive limitations, racial and ethnic minority groups, immigrants and the poor disproportionately exhibit lower health literacy.” And this affects patient safety, according to a 2007 paper by The Joint Commission, an independent, not-for-profit organization that certifies U.S. health care organizations and programs.

The paper, “What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety,” notes: “The safety of patients cannot be assured without mitigating the negative effects of low health literacy and ineffective communications on patient care.”

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The initiative was a partnership between CT Health and six adult education sites, which are ideal for improving health literacy among those at risk for health disparities. Participating centers were:

- Capitol Region Education Council (Hartford)
- JUNTA for Progressive Action, Inc. (New Haven)
- Mercy Learning Center (Bridgeport)
- New Haven Adult and Continuing Education
- Norwich Adult Education
- Stamford Public School Adult Education

Each center received intensive professional development and a 15-month CT Health grant of about $72,000 in October 2007. In addition to English as a second language, centers provided health literacy instruction in adult basic education, employment training, life skills and general equivalency diploma classes.

Twenty teachers trained in a “study circle” approach, a concept developed by Rima Rudd, Sc.D. (doctor of science), of the Harvard School of Public Health in response to research linking low health literacy to health inequities. Winston Lawrence, Ed.D., a facilitator from the Literacy Assistance Center in New York City, helped teachers review research and resources, develop lesson plans and share classroom experiences around three themes:

- Health care access and navigation
- Chronic disease management
- Disease prevention and screening

Previous efforts to increase people’s health literacy focused on building knowledge about diseases and body parts. These study circles, however, focused on health-related skills (e.g., critical thinking, asking questions) and tasks (e.g., making appointments, navigating a hospital).

Teachers did not become health experts. Instead, they improved student reading, writing, math, computer and communications skills, and taught students how to apply them to health-related situations.

CT Health estimates 2,000 students from 50 classes benefited over two semesters and an optional summer session. “Students have responded enthusiastically because these lessons speak directly to their needs,” says Roslyn Nessin, Stamford Adult Education administrator.

Along with developing health literacy skills, interim results of an evaluation, pre- and post-test, show students were “more comfortable asking questions of their health providers and more confident managing their health after being exposed to the curriculum for one semester,” says initiative evaluator Kien Lee, Ph.D., principal associate with the Association for the Study and Development of Community.

One teacher from the Capitol Region Education Council adds, “My students in both classes have told me they were more comfortable speaking with health care providers.”

As a result of the health literacy project:

- Each center has increased its capacity to teach health literacy.
- Students are more comfortable navigating the health system, managing their health and seeking preventive care.
- Participating teachers are sharing their knowledge and skills with their colleagues.

Lee also noted that “thirty-five partnerships were developed with various types of health care organizations.”

Although the formal program will end in December 2008, a passion for health literacy has been ignited among the grantees. Each site plans sustained health literacy instruction and will continue partnering with health care organizations in their communities beyond the grant period.

The evidence is clear: U.S. health care systems demand high health literacy that is well beyond the average person’s skills.

This was documented in 2006 when the results of the National Assessment of Adult Literacy (NAAL), conducted by the U.S. Department of Education, were published. This first national study to examine the health literacy of U.S. adults measured health literacy on four levels:

- Below basic
- Basic
- Intermediate
- Proficient

The NAAL study found:

- Only 12 percent of all adults have health literacy skills proficient enough to complete everyday health tasks, such as taking medications and reading nutrition labels.
- All racial and ethnic minority groups demonstrate lower health literacy levels than whites.
- Notably, 58 percent of African-Americans and 66 percent of Latinos score at basic or below.

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Why is health literacy such a challenge for most? “The reasons are multiple and interconnected,” Krause explains.

“One reason is that the systems driving health care are exceptionally complicated, with increasing demands shifting to patients and consumers,” says Krause. This is supported by research highlighted by Rudd, which shows “health sector expectations and demands exceed adults’ literacy skills.”

“Health literacy challenges also are linked to education, the digital divide as health information moves into the realm of technology, and cultural differences in how people communicate,” adds Krause. But the problem can be solved.

“If health care systems reduce the sophisticated literacy demands they require of patients, and communities work to increase individuals’ health literacy skills, the hope is that these simultaneous efforts will have greater total effect than they would separately,” Krause explains.

**Health Literacy: A Family Profile**

Managing the sickle cell disease affecting two of the three Jean-Baptiste* children is a family challenge in health literacy on several fronts.

In addition to understanding how to guard against possible complications of this genetically inherited blood disorder, the Haitian-born parents also must ensure their health literacy is sufficient to interact with the Connecticut health care system at least four times each month and educate extended family members about the disease's genetic implications.

They also must coordinate appointments; communicate with an orthopedist and ophthalmologist, a pediatrician, hematologist and pulmonologist; deal with multiple surgeries and three separate daily pain medications; handle paperwork and health-related finances.

Ensuring they are health literate is critical. It means that when the children's pain becomes unmanageable they can knowledgeably advocate for the treatment they know their children need. And they can help family members who pursue testing, education and counseling better understand their risk for passing on a sickle cell trait or the disease.

*Pseudonym for an actual Connecticut family*
The study also concluded that adults with below basic or basic health literacy were less likely than adults with higher health literacy to get information about health issues from written sources and more likely than adults with higher health literacy to learn about health issues from radio and television.

Other studies confirm that in Connecticut and nationally:

• Racial and ethnic minority groups experience more health problems and die earlier than the majority population.

• Racial and ethnic health literacy disparities may contribute to other racial and ethnic disparities in health outcomes and health care quality (see Family Profile, page 3).

• Low health literacy affects a person’s ability to prevent health problems and is a barrier to improving health for those with existing health problems.

In addition, many studies associate low health literacy with inequities in:

• Health care costs
• Prevention and screening behavior
• Health knowledge
• Access to care
• Health service use
• Overall health status

Studies also show individuals with low health literacy experience shame, stigma in health care environments (e.g., feeling inadequate because the individual did not know medical terminology; embarrassed to ask questions).

More information on these studies can be found at the following sites:


• Health disparities in Connecticut: www.dph.state.ct.us/PB/HISR/Hlth_Disparities.htm

• National health care disparities: www.ahrq.gov/qual/nhdr05/nhdr05.htm

What Does It Mean?

The fact that the NAAL study concluded that only 12 percent of U.S. adults have proficient health literacy skills is significant for the 88 percent whose skills are lower. For example, the study concludes:

• Adults with below basic health literacy would have trouble circling the date of a medical appointment on an appointment slip.

• After reading a short pamphlet about a disease, individuals with basic health literacy would struggle to provide two reasons why someone without symptoms should be tested for it.

• Adults with intermediate health literacy would have difficulty calculating their annual employee health insurance contribution using a table indicating monthly costs by family size and income.