

ISSUE BRIEF  
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# Considering Health Literacy

## ABOUT THIS BRIEF

Older adults face many decisions as they navigate the complex health-care system. For people with low health literacy skills, making such decisions can be daunting. This brief discusses health literacy and describes techniques your organization or program can use to reach out to those with low levels of health literacy.

## What Is Health Literacy?

The 1992 National Adult Literacy Survey (NALS) reported that some 40 to 44 million of the 191 million adults in the United States are *functionally* illiterate. Another 50 million are only *marginally* literate. Functional literacy represents more than just the ability to read. It involves reading comprehension as well as the ability to compute, communicate, write and solve problems. These skills are important for us in acquiring general information and applying it to specific circumstances in our everyday lives.

When applied to the health and long-term care systems, low functional literacy translates into low health literacy. Health literacy is defined as our ability to obtain, interpret and understand basic health information and services, as well as our competence and motivation to use such information and services in ways that enhance our health.<sup>1</sup> Most health education campaigns use simplified printed materials to convey information, assuming that people can read. Most adults do read, but many have difficulty understanding what they read and applying generalized information to their own specific situation.

## How Is Functional Literacy Measured?

Past studies have considered literacy as a "condition" that people either have or do not have. The NALS takes a different approach however. This survey assesses the English literacy of adults in the U.S. based on their performance along three separate dimensions of literacy—understanding simple prose, filling out documents and applying simple quantitative tasks, such as arithmetic operations. The survey assigns a score ranging from zero to 500 for each dimension. People with scores of 225 or less are considered functionally illiterate, those with scores of 226 to 275 only marginally literate and those with scores of 376 or above highly literate, in that dimension of literacy.

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## Why Should I Be Concerned About Health Literacy?

The inability to navigate the complex health-care system due to low health literacy can have dire individual consequences for your clients. For example, people who cannot read or comprehend prescription drug labels may take medications incorrectly, or not at all. The consequences of uninformed decisions go beyond the choices made by consumers about their own health care. These same people may be making choices on behalf of their spouses or their children, or they may be helping their parents with health and long-term care decisions.

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These consequences also have implications for the payers of health care. Overall, there may have been

between \$35 and \$73 billion in wasted health-care expenditures in 1998 due to more frequent doctor visits and longer hospital stays associated with low health literacy.<sup>2</sup> The Medicare and Medicaid programs finance more than 50 percent of these costs. So it makes both good health care *and* financial sense to invest in ways to assist people with low health literacy in making informed health-care decisions.

## Why Is Health Literacy a Critical Issue for Medicare Beneficiaries?

While health literacy is important for anyone dealing with the health care system, it can be especially critical for people on Medicare who are dealing with the complexities of that program. Some examples of areas where Medicare beneficiaries with low health literacy levels may experience problems are listed below.

**UNDERSTANDING MEDICARE.** Understanding the differences in coverage, financing and enrollment between Medicare Parts A and B can be difficult for anyone, but especially for those with low functional literacy. People must be able to under-

stand the enrollment processes and premiums associated with Parts A and B. In addition, beneficiaries who have problems with Medicare have rights and an appeals process, which also requires understanding complex terms and administrative procedures.

**FILLING IN THE GAPS.** Medigap insurance is available to fill gaps in coverage under traditional Medicare. But in order to obtain that coverage, people must first identify the insurance companies that offer Medigap policies in their state. Then they must choose from among 10 standardized plans, each with a different set of benefits. Comparing the benefits and premiums under each plan, completing the application for Medigap coverage and sorting out claims paid by the Medigap policy can be confusing, particularly for people with low health literacy skills.

**CHOOSING MEDICARE COVERAGE.** Medicare Part C, or Medicare+Choice, further complicates things by offering new managed care and other health plan choices. People on Medicare must first decide whether to stay with the traditional Medicare coverage or participate in a managed care plan. If they choose managed care, they must then be able to choose among the plans available to them. Consumers must understand the benefits and costs associated with each managed care plan in order to choose the best plan for their needs.

**ASSISTANCE FOR LOW-INCOME BENEFICIARIES.** Many Medicare beneficiaries with low incomes and limited financial resources are eligible for full Medicaid coverage. Others may be eligible for partial coverage of Medicare premium and cost-sharing requirements through Medicare buy-in programs (such as the QMB, SLMB, and QI programs).<sup>3</sup> Yet, many who are eligible for these programs are not enrolled. Some states conduct outreach to educate consumers about these buy-in programs, but most of these efforts involve the use of printed materials. These materials are of very limited value to those with low levels of functional literacy because they are unable to read or comprehend them. As a result, many beneficiaries who should have their Medicare premiums subsidized by the buy-in programs are instead paying the premiums out of pocket, leaving them with less money for other necessities such as food and prescription drugs.

**HEALTH CONDITIONS AND THEIR TREATMENT.** The continued growth in the number of older people—as baby boomers age and people live longer—will cause an increase in the number of people who are most vulnerable to and most affected by health conditions. People with low levels of functional literacy often find it difficult to understand conditions and their treatments. An inability to

*“People with low levels of functional literacy often find it difficult to understand conditions and their treatments.”*

communicate with you (or their other health-care providers or insurance

counselors) or to understand what you are saying affects the prevention, diagnosis and treatment of acute and chronic conditions. Some conditions may be prevented or at least detected earlier if people on Medicare can communicate their symptoms appropriately or if they understand preventive health measures (especially those covered by Medicare) and how to access care.

## **How Has Health Literacy Been Addressed?**

Currently, very few health literacy efforts exist because of a lack of resources and a lack of awareness of the problem. But some effective techniques have been developed to assess and assist people with low health literacy skills. While the techniques described

in this Issue Brief do not target Medicare beneficiaries specifically, they can be adapted for that population.

## **How Can I Determine If My Clients Need Help?**

Identifying those with low functional literacy skills is an important first step in addressing the issue, but it can be difficult. Many people do not want their literacy level to be discovered. The shame often associated with low functional literacy promotes silence and discourages people from seeking information or asking for your assistance.

## **TESTS FOR FUNCTIONAL LITERACY**

Some tests have been developed to screen for low levels of functional literacy. These tests can measure reading comprehension, numerical ability, word recognition and pronunciation.

Currently, some organizations use formal screening tests to determine health literacy levels. Others use less formal methods.

- MetroHealth Medical Center at Case Western Reserve University in Cleveland, Ohio, administers tests that are easy to use and generally accepted by consumers. Upon arrival at the emergency room, people with congestive heart failure undergo a one-on-one assessment,

## **Targeting**

One common assumption is that certain populations have low levels of functional literacy. For example, traditionally “underserved” populations such as those with low incomes are labeled as having low levels of functional literacy simply because they are, on average, less educated. However, low functional literacy is not defined by race, class or even educational attainment.

Only focusing on the traditionally underserved in addressing low functional literacy is problematic for three reasons. First, targeting only the traditionally underserved is viewed by many as discriminatory. Second, valuable resources may be directed unnecessarily toward people who do not need help. Third, others who are not part of the target group may miss their chance to obtain information and assistance as they make health-care choices.

the Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM is a word recognition and pronunciation test in which people read aloud a list of 66 medically related words and receive one point for each word that they pronounce correctly. If staff discover that people have low levels of functional literacy, they alert doctors and nurses prior to their appointments to ensure that medical personnel take care in talking with them.

- The Southside Area Health Education Center in Farmville, Virginia, received a one-year grant to survey seniors for health literacy levels and to provide group health education programs to improve their health literacy. Southside used the Short Test of Functional Health Literacy of Adults (S-TOFHLA), a seven-minute reading comprehension and numerical ability test, as its screening instrument. Health educators and trained nurses from a local nursing school administered the tests in community centers, restaurants, libraries, area agencies on aging and hospitals. Staff at the center then designed health education programs to help people with low functional literacy understand their health care.

## LESS FORMAL ASSESSMENTS

Asking your clients to undergo formal screening tests may foster distrust and suspicion on their part. Structured but less formal assessments provide an opportunity for you to develop a sense of your patients' comfort levels with different modes of communication.

By assessing everyone, you empower clients to take responsibility for their own health care. This is effective because people with low levels of functional literacy no longer fear being "singled out" and are more likely to receive the health-care services they need. The trust established between you and your clients through these less formal assessments allows them to communicate their concerns.

- The first step in working with clients at the To Help Everyone (T.H.E.) Clinic in Los Angeles, California, is to sit with them and determine the ways in which they are the most comfortable learning. Nurses and health professionals speak one-on-one with patients upon their arrival in the health clinic to determine whether patients prefer to use written materials, pictures, verbal counseling or some other technique to learn. After determining a person's preferred learning style, the staff puts the appropriate personnel and equipment into place. Clients are also asked who in the household generally gets and uses the printed materials to ensure that information falls into the right hands.
- Another less formal type of assessment is the use of non-health-related objects to gain a sense of reading and comprehension ability. This helps to distinguish whether someone is just having difficulty with certain medical language or insurance terminology or whether they cannot read words or numbers at all. Physicians or pharmacists at the Brownsville Community Health Center in Brownsville, Texas, sit with patients and ask them to read certain words and numbers on an ordinary object such as a Coca-Cola can. This provides staff with a sense of whether consumers will understand instructions on medication bottles or other written instructions for care.

## *How Can I Help People With Low Health Literacy Skills?*

Unfortunately, at this point, few organizations specifically assist people with low health literacy skills as they make health-care decisions. Yet, those that do use a variety of techniques to assist this population.

### ONE-ON-ONE ASSISTANCE

Many of the techniques commonly used to help people with low literacy skills involve one-on-one assistance. In addition to helping people gain a better understanding of the health-care system and their own health problems, this approach can foster trust between you and your clients.

- Staff at T.H.E. Clinic sit with clients after their appointments to give them the opportunity to ask additional questions. Outreach workers talk with them about what the nurse or doctor said and what it meant to them. They also discuss the dosage and timing of medications. These one-on-one conversations can help to make sure consumers leave their appointments with a clear understanding of the nature of their conditions and treatments.
- The MetroHealth Medical Center at Case Western Reserve University tailors its assistance to the individual needs of those with low levels of

*“ . . . if clients do not appear to understand oral instructions for taking their medications, a nurse may make a cardboard clock using suns and moons as symbols for when they should take them.”*

functional literacy. After administering screening tests to determine literacy levels, heart failure nurses, acting as both health

educators and case managers, determine what people know about their condition and what they do to deal with it. Nurses then design an educational program to teach each person about the condition and techniques for self-management. For example, if clients do not appear to understand oral instructions for taking their medications, a nurse may make a cardboard clock using suns and moons as symbols for when they should take them.

- One-on-one assistance for people with low functional literacy skills is also provided in settings other than clinics and hospitals. The Lafayette Adult Reading Academy (LARA), an adult basic education program in Lafayette, Indiana, uses an interactive approach between its adult learners and pharmacy students to ensure that prescription medications are taken correctly. LARA, in collaboration with Purdue University’s Pharmacy Department, offers a program in which pharmacy students meet on a weekly basis with adult learners who have chronic conditions. The goal of this program is to increase pharmacy students’ understanding of the medication-related needs and perspectives of people with low levels of functional literacy, while at the same

time encouraging learners to voice any concerns or questions they may have about their medications. During each weekly visit, pharmacy students count all medications, both over-the-counter and prescription, and record them on a medication sheet along with the data from the pharmacy label. They then conduct a three-step oral interview that uses open-ended questions to assess each client’s habits and perspectives. With each week of working with their adult learners, the pharmacy students sense attitudinal changes on the part of the learners, as shown through more faithful medication compliance and a willingness to discuss their health and medication-related problems.

- Volunteers at the Brownsville Community Health Center, known as “promotoras,” conduct door-to-door visits within their community. Promotoras are generally women between ages 40 and 67 with families and grown children. They visit people’s homes to answer questions such as where to go for health care or how to get transportation to the doctor’s office. They often accompany people to doctor’s appointments. Promotoras also provide information regarding health-care rights or eligibility for programs that offer financial assistance for health care, such as the Medicare buy-in programs. Through a “Medicaid Sign-Up” campaign, promotoras help people determine whether they are eligible for Medicaid coverage and assist those who are eligible with program enrollment. They help people fill out application forms, compile the correct documentation and ensure that the forms are mailed to the appropriate place.
- One-on-one assistance can also occur on a less personal level. State health insurance assistance programs (SHIPs) and the Health Care Financing Administration offer toll-free hotlines that Medicare beneficiaries can call if they have questions about their insurance coverage. These hotlines can be helpful to older people who would like to determine whether they are eligible for QMB, SLMB or QI assistance but do not want to reveal their income and assets to others within their community. Telephone counseling provides information just one time, however, and assumes a person can take that information

and apply it immediately. For some, reinforcing instructions or providing the opportunity for more discussion may be necessary.

## GROUP ASSISTANCE

Group assistance offers an arena in which people can obtain information from educators and through the questions asked by others in the group.

- Southside Area Health Education Center arranges programs and activities for older people through partnerships with community health centers, area agencies on aging and hospitals. A health educator from Southside presents information to groups on health care issues that are important to older adults, such as medication use, nutrition, vitamins, how to talk to doctors and how to decide whether to go to the emergency room. At the end of the program, the health educator answers questions.
- The El Paso Community Education Program in El Paso, Texas, has developed a health literacy program to help academically and economically disadvantaged adults have a better understanding of health-care issues, such as preventive care and access to services. Instruction is provided at all of El Paso Community College's sites, which include four campuses, five elementary schools, six public housing complexes, one church and two community centers. Staff from El Paso Community College visit each site and, with student input, determine health topics to be discussed during classes. Instructors may be, for example, representatives from a Medicaid agency who instruct students on financial assistance they may be eligible for and how to apply. Class members may even visit the Medicaid office. Instructors may then present Medicaid application forms to the class, go through them step by step with students, and discuss certain definitions and how to complete the forms.

## VISUAL TOOLS

You can also use visual tools as supplements to one-on-one or group assistance. Visual tools are designed to simplify concepts such as instructions for care that are too complicated to understand in written form or

through verbal communication.

- The Johns Hopkins University Pictograph Research Project developed hundreds of pictographs that show how to manage certain conditions and how to



*Take medicines on a schedule as directed by the doctor*

understand medications and the treatment of chronic conditions. A pictograph is a picture that represents an idea. The goal of pictographs is to develop effective and efficient ways to communicate complex ideas to people who cannot read or who have limited reading skills. The results of an evaluation from the Pictograph Research Project show that pictographs combined with spoken explanations can increase information available to people for managing symptoms and problems related to complex illnesses.



*Don't eat fried foods*

- At the Southside Area Health Education Center, a health educator color-codes bottles of

*“Visual tools are particularly useful to those who cannot read at all.”*

medications. On a cardboard clock, she places the color of the bottle at the time that a certain medication is to be taken. Visual tools are particularly useful to those who cannot

read at all. You must take care to ensure that your clients really understand the idea behind the color-coding, or they may not use their medications properly.

- The Health Care Financing Administration produces videotapes that describe programs such as QMB, SLMB and QI to inform older people about potential sources of financial assistance for their health care. Some organizations, such as the North Carolina Seniors Health Insurance Counseling Program, make their own videotapes on specific topics of interest to Medicare beneficiaries. Videotapes are useful when supplementing other techniques to assist people

with low health literacy. Yet, too often videotapes are used alone because they are so easy. Without follow-up, these videos may fail to reach out and inform people, particularly those with low literacy skills. The videotapes may present information in a manner that is still much too difficult to understand, or the information may be presented in such a simplistic way that it is insulting to people of any educational level. Even videotapes that are inviting and appropriate may not be effective if viewers do not have the opportunity to discuss the content or to ask questions and if there is no reinforcement of the information presented in the tape.

## TRAINING PROGRAMS

The main reason organizations say they do not respond to problems related to health literacy is that they do not have the resources. The idea of incorpo-

rating health literacy into the current structure at first may seem overwhelming. Teaching health professionals how to work with people with low health literacy skills early in their careers may help this problem. If hospitals, medical schools, nursing programs and other health and social service programs make students aware of the problem and teach techniques for responding to it, then students will be equipped with the tools they need to deal with this population when they enter the labor force.

- The Southside Area Health Clinic provides inservice training to hospital staff to make them aware of the problem of health literacy and to help them recognize the cues for those who have difficulty reading or understanding what they read or are told. As a result of Southside's effort, more hospitals in the area are including health literacy staff training, and a local nursing school teaches students how to administer health literacy screening tests.

### *Where Can I Get More Information About Health Literacy?*

The National Academy on an Aging Society is working with the Center for Medicare Education to identify efforts to help people with low functional literacy navigate the health-care system. A final report with the Academy's findings will be available in fall 2000. This report will address the problems associated with low functional literacy in a health-care environment and highlight techniques used by various organizations and programs to identify and assist beneficiaries with low levels of functional literacy. For more information, contact Kristen Kilker at the Academy by telephone at (202) 408-3375 or by email at [kkilker@agingsociety.org](mailto:kkilker@agingsociety.org).

The National Institute for Literacy offers a health and literacy discussion list for literacy practitioners, health care providers, health educators, researchers, policy makers and others interested in exploring the links between health and literacy. The list features targeted discussion and information exchange about literacy issues in health education and in health care. To subscribe, go to [http://www.nifl.gov/lincs/discussions/nifl-health/health\\_literacy.html](http://www.nifl.gov/lincs/discussions/nifl-health/health_literacy.html).

<sup>1</sup> Definition was modified from a National Institute for Literacy discussion list, in response to the question of what is health literacy.

<sup>2</sup> National Academy on an Aging Society. *Understanding Health Literacy: New Estimates of the Costs of Inadequate Health Literacy*. Presented at the Pfizer Conference on Health Literacy, "Promoting Health Literacy: A Call to Action." October 7-8, 1998; Washington, DC.

<sup>3</sup> Starting in 1988, Congress enacted a series of Medicaid-financed provisions, or Medicare buy-in programs, to provide partial coverage to low and moderate-income Medicare beneficiaries not entitled to full Medicaid coverage. Medicare buy-in programs are also called the Qualified Medicare Beneficiary (QMB), Specified Low-Income Medicare Beneficiary (SLMB) or Qualifying Individual (QI) programs.

*To learn more about any of the programs mentioned in this brief, please contact the people listed below:*

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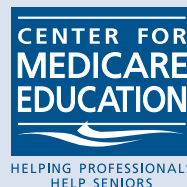
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The National Academy on an Aging Society is a Washington-based nonpartisan policy institute of The Gerontological Society of America. The Academy studies the impact of demographic changes on public and private institutions and on the economic and health security of families and people of all ages.



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