

HELPING PROFESSIONALS
HELP SENIORS

Health Literacy: **Responding to the Need for Help**

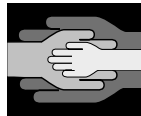
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Center on an Aging Society

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EXECUTIVE SUMMARY

The complexity of today's health-care system can be daunting for the large number of American adults who have difficulty reading or understanding what they read. People with low health literacy may not know where to go to seek appropriate care, which measures to take in order to prevent the onset of conditions or how to properly take their prescription drugs. They may forego enrolling in a health insurance plan or may not select the plan best suited for them because they do not understand their options. The consequences of low health literacy can be dire on both an individual and a societal basis.

Many sophisticated health education campaigns are underway to make the information in printed materials more consumer-friendly and easier to understand. While these simplified materials may be helpful for some, they generally do not help those with low health literacy skills as they navigate the health-care system. Few health plans, health-care providers or consumer assistance programs have implemented efforts to assist this population in making health-care and insurance decisions. Lack of awareness of the issue, difficulty detecting those with low health literacy and lack of funding or guidance in developing health literacy programs are a few reasons these programs may not exist.

Some clinics, hospitals, adult education programs and insurance counseling programs have developed innovative ways either to identify people with low functional literacy or to assist them with their health-care and insurance decisions. While these efforts have not been evaluated formally for effectiveness, they can act as catalysts for discussions on how to address health literacy now and in the future.

In this report, we will examine the issue of health literacy in greater detail. This report defines health literacy and discusses the individual and societal consequences of inadequate health literacy. It also highlights programs and efforts that address the needs of people with low health literacy and illustrates the techniques they use to identify and assist this population. Finally, this report provides guidelines for program administrators or coordinators to follow in establishing health literacy efforts of their own.

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. Some view low functional literacy as the inability to read. Others perceive it as a cultural issue affecting populations that cannot understand materials written in English. Yet, functional literacy encompasses more than just the ability to read. It involves reading comprehension and the ability to compute, communicate, write and solve problems. The constellation of these skills is vital for acquiring and applying general information to specific circumstances.

When applied to the health and long-term care systems, low functional literacy is tantamount to low health literacy. Health literacy is defined as the capacity of individuals to obtain, interpret and understand basic health information and services, as well as the competence and motivation to use such information and services in ways that enhance their health.¹ Information to make these decisions is often provided in printed form containing complex terms and concepts. A common assumption is not only that most adults can read these materials, but also that they can understand what they read.

Most adults do read, but based on the results of the NALS and results from tests of health literacy tests from specific health plans or clinics, it is apparent that many people have difficulty understanding what they read and applying that information to their particular situation. It is also likely that many in this situation are either too intimidated to say that they do not understand or too uncertain to know what to ask. It does not help that the delivery of health care generally and long-term care in particular is so fragmented or that health plans generally do not finance coordination and patient assistance.

The consequences of uninformed decisions go beyond the choices made by patients regarding their own health care. These same adults may also be making choices on behalf of their spouses or their children or they may be advising their parents on health-care decisions. Missed opportunities and additional use of health-care services associated with low health literacy can have dire individual consequences. The consequences also have implications for the payers of health care. Overall, there may have been between \$35 billion and \$73 billion dollars in wasted health-care expenditures in 1998 due to more frequent doctor visits and longer hospital stays generally associated with low health literacy (Friedland, 1998). The Medicare and Medicaid programs financed more than 50 percent of these costs. Estimates of this magnitude suggest that it makes both good financial sense and good health-care sense to invest in ways to better assist people with low health literacy in making informed and better motivated health-care decisions.

¹Definition was modified from a National Institute for Literacy Health Action Listserv response to the question of what is health literacy.

How is Literacy Measured?

Past studies have considered literacy as a “condition” that people either have or do not have. NALS takes a different approach. It assessed the English literacy of adults in the United States 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 of the three literacy dimensions and categorizes respondents using five levels of literacy. People with scores of 376 or above are considered highly literate. Those with scores of 225 or less are considered functionally illiterate and those with scores of 226 to 275 are only marginally literate.

HEALTH LITERACY AND THE MEDICARE POPULATION

Medicare beneficiaries with low levels of functional literacy encounter many obstacles in navigating the health-care system. Although no national studies have been conducted, smaller studies indicate that low health literacy is particularly problematic for the Medicare population. A study conducted at two public hospitals found that 81 percent of patients age 60 and older have inadequate or marginal functional health literacy (Williams, 1995). Another study by researchers at the Prudential Center for Health Care Research and two university medical schools examined the health literacy levels among Medicare enrollees in a national managed care organization (Gazmararian, 1999). Approximately one-third of the enrollees had inadequate health literacy. These findings suggest that many Medicare beneficiaries lack the basic skills required to make informed insurance and health-care decisions.

Medicare Beneficiaries and Health Insurance Coverage

The Medicare program is complex. People with Medicare need to be able to know which benefits are available and how to select health plans. They should also have an understanding of Medicare Savings programs, also known as the Qualified Medicare Beneficiary (QMB), Specified Low-Income Medicare Beneficiary (SLMB), and Qualifying Individual (QI) programs, which provide additional assistance to beneficiaries with low incomes and few financial resources. Beneficiaries must also recognize that the Medicare program does not cover all health-care expenses and that they may need to seek additional coverage to fill in the gaps in their coverage.

Enrolling in Medicare

Traditional Medicare consists of two parts: hospital insurance (known as Part A) and supplemental medical insurance (known as Part B). Medicare Part A covers inpatient hospital services, skilled nursing care, home health care and hospice care. Medicare Part B covers physician services, outpatient hospital services and other medical services. Understanding the differences in coverage, financing and enrollment between Parts A and B can be difficult, particularly for those with low functional literacy. They must be able to understand that they are enrolled automatically in Part A if they are eligible for Social Security benefits. Unlike Part A, however, enrollment in Part B is voluntary. Therefore, beneficiaries must determine whether they need Part B coverage and, if so, they must be able to understand the enrollment process. They also must realize that they are responsible for paying a monthly premium for Part B coverage. Beneficiaries who have problems with Medicare must know about their rights and know that an appeals process exists to maneuver disputes. This process can be particularly problematic for those with low levels of functional literacy since it requires understanding complex terms and administrative procedures.

Choosing Medicare Coverage

The implementation of Medicare Part C, or Medicare+Choice, further complicates the Medicare system for beneficiaries. Medicare+Choice offers some new managed care and other health plan choices that are more similar to those available in the private sector. With more health plan options available to them, beneficiaries must make numerous decisions. They must first be able to identify the options available to them in their area. They must then decide whether to participate in managed care plans or to stay with the traditional program. If they choose managed care, they must be able to choose among the plans available to them and must know that the plan may stop participating in Medicare+Choice at any time. Consumers need to understand benefits and costs associated with each managed care plan in order to evaluate their choices reasonably. The additional costs and benefits under the new plans are not standardized, making it difficult to decipher differences across plans. Since most of the information regarding benefits and costs under managed care plans is found in summary brochures and policy booklets, beneficiaries with low levels of functional literacy are likely to find choosing the appropriate health plan extremely difficult. Those who do not understand the potentially higher costs of certain plans may not fully realize the financial consequences that may ensue. The inability to make an informed decision may also diminish their quality of care.

Additional Assistance for Low-Income Beneficiaries

Many Medicare beneficiaries with low incomes and few financial resources are eligible for full Medicaid coverage. Others may be eligible for partial coverage of Medicare premium and cost-sharing requirements through Medicare Savings programs. To provide partial protection to low and moderate-income Medicare beneficiaries not entitled to full Medicaid coverage, Congress enacted a series of Medicaid-financed provisions, starting in 1988. The QMB, SLMB and QI programs provide various premium and Medicare cost-sharing protections to Medicare beneficiaries with low incomes and few financial resources. If Medicare beneficiaries are aware of and understand Medicare Savings programs, they can receive assistance in meeting their health-care needs. Yet, many who are eligible for these programs are not enrolled.

Before applying for Medicare Savings programs, beneficiaries must understand the eligibility criteria, such as income and resource limits. Those with low levels of functional literacy may not have the computational skills to make the necessary assessments to determine whether they are eligible to apply. The enrollment process for these programs is confusing and varies from state to state. While states use a combination of outreach strategies to educate consumers about the value of Medicare Savings programs, most involve the use of printed materials which are of limited value to those with low levels of functional literacy. As a result, beneficiaries who should have their Medicare premiums subsidized by these programs instead are paying the premiums out of pocket, leaving fewer resources for other necessities such as food and prescription drugs. The long-term effects of not having these medical necessities may result in even larger out-of-pocket health-care costs for beneficiaries and may place a larger burden on state and federal governments.²

Filling in the Gaps

Although Medicare provides health insurance coverage for 39 million people, it is not a comprehensive program. On average, about one-half of older adults' total health-care expenses are estimated to be paid by Medicare. Beneficiaries must understand that Medigap is available to fill gaps in coverage under traditional Medicare and to curb the financial distress caused by high out-of-pocket expenses. Beneficiaries must first determine which companies offer Medigap policies and then decide which one to buy. Each company offers up to 10 standardized plans, each with a different set of benefits. Comparing the benefits under each plan, completing the application for Medigap coverage and sorting out claims paid by the Medigap policy can be confusing to anyone. Beneficiaries must be aware that they have rights intended to protect them from unethical practices in the sale of these policies.

Medicare Beneficiaries and Access to Health Care

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.³ People with Medicare with low levels of functional literacy often encounter problems in obtaining medical care. Many times they do not receive the appropriate care simply because they do not know who to call to make an appointment. If they have an appointment, they may not know how to arrange for transportation to it. Beneficiaries with low levels of functional literacy may also have trouble filling out required paperwork, such as medical history questionnaires.

During their appointments, these people find communication with the health-care provider to be an obstacle. They may not be able to relay symptoms to the provider,

²The Medicaid program offers substantial assistance to low-income Medicare beneficiaries, but not all poor Medicare beneficiaries qualify or are fully aware of their eligibility for assistance. Medicare beneficiaries with a full year of Medicaid coverage have out-of-pocket expenses of 5 percent of their income or \$280. About one-half of all poor Medicare beneficiaries, however, do not receive assistance from Medicaid. These beneficiaries were estimated, on average, to have out-of-pocket expenses for primary and acute care of a staggering 49 percent of their income in 1999. Among Medicare beneficiaries enrolled in the QMB program all year, out-of-pocket expenditures for 1999 are estimated to be 13 percent of income.

³More than 40 percent of individuals with chronic illnesses are functionally illiterate (1992 National Adult Literacy Survey, funded by the U.S. Department of Education and administered by the Educational Testing Service and Westat, Inc.).

which could result in a condition not being diagnosed. They may not understand what test results mean and may be afraid to ask questions or may not know which questions to ask. Unclear communication might affect a beneficiary's treatment in that he or she could misunderstand instructions. For example, someone's inability to read or comprehend instructions on prescription drug labels such as when and how much to take of the medication may result in improper use or no use at all. People with Medicare may also be unaware of promising treatments and therapies or preventive health measures available to them.⁴ The consequences of foregoing preventive measures or not following treatment plans correctly can be devastating to the health and financial well-being of beneficiaries in the future. Poor communication can lead to missed opportunities for beneficiaries when they do access health care.

RESPONDING TO LOW LITERACY IN THE HEALTH-CARE SETTING

Health plans, health-care providers and consumer assistance programs are just beginning to recognize the importance of health literacy in the delivery of health care. Due to limited resources or lack of awareness of the problem, few organizations have attempted to address the issue directly. The existing culture and orientation of organizations, the ways in which organizations are financed and the lack of examples of best practices are a few of the barriers organizations encounter when they attempt to respond to the needs of the population with low health literacy.

This report describes practices that have been used to assess functional literacy and to help people with low health literacy skills. To date, many health education campaigns have used simplified printed materials or videotapes to convey information. These modifications to educational materials are often necessary but are not, in themselves, always sufficient.

The seven efforts featured in this report go beyond the use of simplified reading materials in reaching out to a population with low health literacy skills. Although the efforts described here do not necessarily target people with Medicare, they can be adapted for them.

Experts from many nationally recognized advocacy and research organizations, state health insurance assistance programs, state literacy centers, and community health clinics and hospitals were interviewed to identify programs that reach out to those with low levels of functional literacy as they navigate the health-care system. Administrators from these organizations and programs either detailed their own attempts to reach this population or assisted in identifying others. A second round of interviews was conducted to obtain in-depth information on the seven efforts highlighted in this report. They were selected based on the diversity in their settings, the populations they serve and the techniques they utilize to assess and assist people with low health literacy skills.

⁴A Dartmouth University study found that the vast majority of older Americans fail to get many preventive health services that could keep them healthier. Goldstein, Amy. The Washington Post, April 19, 1999, page A2. "Despite Medicare, Elderly Fail to Have Preventive Care Exams."

Three of the featured efforts are located in hospital or clinical settings: MetroHealth Medical Center, To Help Everyone (T.H.E.) Clinic and Brownsville Community Health Center. Two organizations are in adult learning settings: Lafayette Adult Reading Academy and the El Paso Community College Education Program. One, Southside Area Health Education Center, is located in a health education setting and one, Johns Hopkins University Pictograph Research project, is located in a research environment. These organizations and programs are located in both urban and rural areas and represent all regions of the United States. The populations served across these organizations and programs range from older adults to people of all ages, those with chronic conditions, the academically and economically disadvantaged, and those of different cultures. Appendix A describes the seven organizations in more detail.

ASSESSING HEALTH LITERACY SKILLS

Identifying those with low functional literacy skills may be an important first step in addressing the issue. Low functional literacy is difficult to detect, however. Many people do not want their literacy level to be discovered. The associated shame often promotes silence, hampers disclosure and discourages people from seeking information or requesting assistance. One common presumption is that only certain populations have low levels of functional literacy; however, many people who are well dressed or well educated may also have low levels of functional literacy.

Two main approaches have been used to address low functional literacy in the health-care environment. One is to recognize the need for assessment and use tests to assess levels of functional literacy. The second approach does not involve the administration of tests but assesses functional literacy on a less formal basis.

Administering Tests to Assess Functional Literacy Levels

Specific tests have been developed to screen for low levels of functional literacy. Different types of screening instruments test for certain skills related to functional literacy such as reading comprehension, numerical ability, word recognition and pronunciation. Persuading the older adults to participate in the screening poses a challenge. Distrust and suspicion may result when people are asked by health professionals or counselors to take tests. Incentives, such as free grocery certificates, have been offered unsuccessfully by some organizations to encourage people to participate in screenings. While the intent of screening tools is to identify and subsequently assist those with low levels of functional literacy, they may in fact do just the opposite. Those with low levels of functional literacy fear being “discovered” and view screening tests as threatening. The use of screening tools in a health-care setting may lead those with low levels of functional literacy to forego seeking appropriate health-care services altogether.

Many program administrators or health professionals who use these screening tools find they are able to overcome these obstacles, however. They spend time with people to describe how these tests can have a positive impact on their health. They discuss how these tests are meant to ensure that the health professional provides appropriate and adequate information to help people care for themselves. For example, patients with congestive heart failure at the MetroHealth Medical Center at Case Western Reserve University undergo a one-on-one assessment upon arrival at the emergency room. The Rapid Estimate of Adult Literacy in Medicine (REALM) is administered to assess the patients’

word recognition and pronunciation skills. The REALM is a screening instrument designed to identify patients who have difficulty reading common medical and lay terms that are used routinely in primary care patient education materials. This test has patients read aloud a list of 66 medically related words and gives one point for each that is pronounced correctly. Because the REALM takes only five minutes to administer, it is useful at MetroHealth. Since 60 to 80 percent of congestive heart failure patients are older adults and more likely to have cognitive impairments than those who are younger, MetroHealth also administers the Mini-Mental State Examination (MMSE) to assess for dementia. The MMSE is a five-minute test that quantitatively assesses the cognitive functioning of patients. Staff members provide this test to assess whether the problem is related to patients' health literacy levels or their cognitive functioning. If staff members discover that the problem is health literacy-related, they alert doctors and nurses before they see the patients to ensure that care is taken in talking with them.

The Southside Area Health Education Center received a one-year grant to survey seniors for health literacy levels and to provide group health education programs to improve their health literacy. The Test of Functional Health Literacy in Adults (TOFHLA), a seven-minute reading comprehension and numerical ability test, was used as a screening instrument at Southside. The TOFHLA tests patients' ability to read passages and phrases containing numbers using real materials from the health-care environment. Health educators from Southside and trained nurses from a local nursing school administered the tests in community centers, restaurants, libraries, area agencies on aging and hospitals. Health education programs were then designed to help those with low functional literacy understand their care.

Examples of Screening Instruments

The **Test of Functional Health Literacy in Adults** (TOFHLA) is the first available tool to measure functional health literacy. The TOFHLA tests patients' ability to read passages and phrases containing numbers using real materials from the health-care environment. It is a 50-item reading comprehension and 17-item numerical ability test and takes up to 22 minutes to administer. A Spanish version of the TOFHLA is available.

The **Short Test of Functional Health Literacy in Adults** (S-TOFHLA) is a shortened version of the TOFHLA. The S-TOFHLA measures the same skills, but takes only 7 minutes to administer.

The **Rapid Estimate of Adult Literacy in Medicine** (REALM) is a word recognition and pronunciation test. Patients read aloud a list of 66 medically related words and are given one point for each that is pronounced correctly. Scores are categorized into four literacy levels that are judged equivalent to grades zero through 12. It takes about five minutes to administer. The REALM is not a valid indicator of reading ability in Spanish.

The **Mini-Mental State Examination** (MMSE) was developed to quantitatively test the cognitive functioning of patients and to document cognitive changes that occur over time. It consists of many questions and ordinarily can be administered in 5 to 10 minutes. The MMSE is used as a supplement to tests such as the TOFHLA and the REALM in assessing the older adult population, which is more likely to have cognitive impairments than younger populations. The MMSE is offered in several languages.

Conducting Less Formal Assessments

Structured but less formal assessments provide an opportunity for health professionals to develop a sense of their patients' comfort levels with certain modes of communication. By assessing everyone, health-care professionals empower everyone to take responsibility for their own health care. This approach is seen as effective because those with low levels of functional literacy no longer fear being singled out or having their literacy levels discovered and are thus more likely to receive health-care services. The trust established between them and health professionals or counselors allows them to communicate their concerns. If they feel more comfortable speaking with their physician or health insurance counselor, those with low levels of functional literacy are more apt to ask questions and better understand their care or health insurance coverage.

For example, the first step in working with patients at T.H.E. Clinic 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 their patients prefer to use written materials, pictures, verbal coun-

selling or some other technique to learn. After determining the patient's preferred learning style, the clinic puts the appropriate personnel and equipment into place. At the end of the one-on-one interactions at T.H.E. Clinic, patients are also asked who in the household generally gets and uses the materials to ensure that information falls into the right hands. After their appointments, patients are asked by clinic staff to discuss what occurred and what it meant to them.

Another less formal type of assessment is the use of non-health-related objects to gain a sense of the ability to read and comprehend. 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. For example, physicians or pharmacists at the Brownsville Community Health Center sit with patients and ask them to read certain words and numbers on an ordinary object such as a Coca-Cola can. This allows the staff to assess patients' understanding of simple words and numbers and provides a sense of whether patients can understand instructions on medication bottles or other written instructions for care. If pharmacists feel that patients do not understand their prescriptions, they alert social workers who then make home visits to discuss the situation with patients and their families.

ASSISTING PEOPLE WITH LOW HEALTH LITERACY SKILLS

Few organizations specifically assist those with health literacy as they make health-care decisions, and those that do use different techniques. One-on-one assistance is the most effective technique. Group assistance and visual tools are less personal techniques that often supplement one-on-one counseling. Organizations that do not assist the population with low health literacy skills might begin by implementing training programs in order to prepare professionals for dealing appropriately with this population.

One-on-One Assistance

In addition to helping people gain a better understanding of the health-care system and their own health problems, one-on-one assistance fosters trust between patients and the counselors or health-care professionals who help them. For example, staff at T.H.E. Clinic sit with patients after their appointments to give them the opportunity to ask additional questions. These outreach workers talk to patients about what the nurse or doctor said and what it meant to them. They also discuss the dosage and time they are to take medications. If the outreach worker finds that the patient does not understand explanations or directions, he or she speaks with the nurse or doctor about what was discussed during the appointment. The outreach worker then works with the patient until he or she has a complete understanding of what the nurse or doctor said. These one-on-one conversations use reinforcement to make sure patients leave their appointments with a clear understanding of the nature of their disease and its treatment. For instance, one patient at T.H.E. Clinic had difficulty adhering to her medication schedule. A physician asked numerous questions of the patient regarding her daily routine to understand where the trouble occurred with the patient's medication. The physician then fit "the pill to the person, not the person to the pill," meaning he was able to determine a medication schedule that fit into the person's daily routine while, at the same time, ensuring the patient's medication was administered appropriately.

MetroHealth Medical Center also adjusts its assistance to the individual needs of those with low levels of functional literacy. Most of these patients are older adults with conges-

tive heart failure who often take five or more prescription drugs at a time. Therefore, it is crucial that they completely understand why it is important to take their medications and how to take them correctly. After administering screening tests to determine patient literacy levels, the heart failure nurse, acting as both health educator and case manager, provides special attention to those with low levels of functional literacy. In talking one-on-one with patients, the nurse determines what they know about their condition and what they do to deal with it. She then designs an intensive educational program for each patient to learn about the disease and techniques for self-management. Each program is unique to the patient's level of understanding and health-care needs. For example, if a patient does not appear to understand oral instructions for taking medications, she may make a cardboard clock using suns and moons as symbols for when patients should take them. After patients are discharged from the hospital, the nurse follows up with them to see if the individualized education programs seem to be working for them.

One-on-one assistance for those 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, 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 patients with low functional literacy levels, while at the same time encouraging learners to bring up any concerns or questions they may have with 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 an oral interview that features open-ended questions to assess each patient's use habits and perspectives. For example, the pharmacy student asks how and when patients were told to take their medication, what they know about their health condition and who they ask if they have questions about their medication. These questions are communicated in short sentences using common words. With each week of working with their adult learners, the pharmacy students sense attitudinal changes, generally exemplified by more faithful medication compliance. This one-on-one assistance also contributes to the learners' increased confidence in discussing their health and medication-related problems with their physicians.

Some one-on-one counseling involves door-to-door visits to determine individual and household health-care needs. Volunteers at the Brownsville Community Health Center, known as "promotoras" (ones who promote), conduct door-to-door visits within their community. Promotoras are generally women between ages 40 and 67 with families and grown children. They visit homes to answer questions that household members have about their health care such as where to go for 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 Medicare Savings 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 the application forms, compile the correct documentation and ensure that the forms are mailed to the appropriate place. The success of this campaign is evident by the fact that 90 percent of the forms filled out with one-on-one assistance from promotoras are filled out correctly.

Pharmacists at Brownsville also use one-on-one assistance with members of the community. They first ask each patient to bring in all of their pill bottles. Specialized pharmacy software tells the pharmacist how many pills were issued and when. With this information, the pharmacist matches the number of remaining pills to the renewal date on the prescription bottle to determine whether patients are taking medications properly. If the pharmacist finds that the patient is not taking his or her medications properly, he or she contacts the doctor, who then speaks with the patient or their family. The doctor determines whether a promotora should visit the home to assist the patient and ensure that he or she is taking their medications correctly. Four booths are also available at the health center for patients to talk one-on-one with pharmacists about their medications.

Sometimes one-on-one assistance occurs on a less personal level. An example of this approach is telephone hotlines. 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 the older adults who would like to see whether they are eligible for some form of QMB, SLMB or QI assistance but do not want to reveal their income and assets to others within their community. The one-on-one counseling offered through less personal methods may not be effective in all cases. Telephone counseling provides information just one time 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 is somewhat less personal than one-on-one assistance, yet it offers an arena in which people can obtain information through the discussions held and through questions asked by others in the group. For example, Southside Area Health Education Center arranges programs and activities for the older adults through partnerships with community health centers, area agencies on aging and local hospitals. Program administrators or activities coordinators in places such as low-income housing projects announce the education programs in newsletters. A health educator from Southside goes to these sites to teach programs on health-care issues that older people want to learn more about, 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 has developed a health literacy program to serve academically and economically disadvantaged adults so they have a better understanding of health issues, such as preventive care and access to services. Instruction is provided at all of the college's sites, which include four campuses, five elementary schools, six public housing complexes, one church and two community centers. Staff members 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. Classes can also involve other activities, such as a site visit to the Medicaid office. An instructor may then present Medicaid application forms to the class, go through them step-by-step, and discuss certain definitions and how to complete the forms.

Group assistance may take on forms other than group discussions. For instance, the California Health Insurance Counseling and Advocacy Program uses skits to teach people about Medicare choices and benefits. Similarly, the Brownsville Community Health Center

uses churches as vehicles to provide information through the use of role-playing. Members of surrounding churches volunteer to act out what a condition may physically do to a person and what may happen if people do not appropriately follow instructions for care.

Visual Tools

Visual tools are often used as supplements to one-on-one or group assistance. They can help simplify concepts such as instructions for care that are too complicated to understand in written form or through verbal communication. For example, 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 Johns Hopkins University Pictograph Research Project developed hundreds of pictographs containing actions that show how to manage certain conditions and how to understand medications and the treatment of chronic conditions (see Appendix C for pictograph examples). The results of an evaluation from the project show that pictographs, combined with spoken explanations, can increase information available to people with low health literacy skills for managing symptoms and problems related to complex illnesses. The project recruited 29 adults with reading skills below the fifth-grade level from an inner city job-training program. The subjects were shown the pictograph and, at the same time, told orally what it meant. Immediately after training and one month later, subjects were shown the pictograph again and asked to explain its meaning. Twenty-one of the adults completed both the training and the one-month recall. Recall of the pictograph immediately after training averaged 85 percent and, after a month, averaged 71 percent.

Simple visual tools are used to assist those with low health literacy in managing their medications. At MetroHealth Medical Center, a heart failure nurse tapes pills onto a cardboard clock and puts sun and moons on it to designate the time of day the medications are to be taken. Similarly, a health educator at the Southside Area Health Education Center color-codes bottles of various 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. However, care must be taken to ensure that the patient really understands them, or improper medication use may result.

Videotapes also are often used to teach people about health care and health insurance. For example, the Health Care Financing Administration which oversees the Medicare and Medicaid programs, produces videotapes that describe programs such as QMB, SLMB and QI to inform beneficiaries about potential sources of financial assistance for health care. Some organizations, such as the North Carolina Seniors Health Insurance Information Program (SHIIP), make their own videotapes on specific topics of interest to Medicare beneficiaries. For example, the North Carolina SHIIP produced an 18-minute videotape describing long-term care and explaining how people pay for it. 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. In those instances they may fail to really 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 comprehend, or the information may be presented in such a simplistic way that it is insulting to anyone. 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.

Helping Stanley (Hussey, 1991)

Stanley has medical problems that include temporal arthritis, gout, hypertension, angina and hypothyroidism. His medication regimen includes 10 pills that are to be taken at different times of the day and in different quantities. Stanley visits a nurse practitioner on an outpatient basis twice a month. Even though extensive written and verbal instructions were being given, Stanley did not adhere to his medication schedule appropriately. He stated that he only took medications when he could remember. The nurse practitioner then simplified Stanley's medication schedule by creating daily pill containers and labeled egg cartons. However, Stanley still came to his clinic visits with nearly as many tablets in each container as he had at the last visit. The nurse practitioner learned that Stanley was unable to explain or question what he did not understand.

A picture schedule has since been put into place to remind Stanley to take his medications at the correct time. The picture schedule consists of five simple line drawings that represent key events of the day: meal times, rising, going to bed, etc. A clock and three lines were placed to the right of each picture. Each of his medications was assigned a colored sticker. For example, Stanley said the best time to take his morning medications was at breakfast. Next to the breakfast picture, seven blue dots (prednisone), one red dot (furosemide), one green dot (thyroxine), etc., were placed. The other doses were indicated at the proper times of day to be taken. The picture schedule was enclosed in a plastic sheet protector with a non-permanent marker. Stanley was told to mark a line through each dosage after taking it, to avoid double dosing. Two weeks after the picture schedule was implemented for Stanley, his medication counts were exact. Stanley continues to comply with his medication schedule using this tool. If he is given a new prescription or a refill, he immediately brings his medication to the nurse practitioner to provide a new colored dot.

Training Programs

The main reason organizations say they do not respond to problems related to health literacy is that they lack resources. One technique that some administrators use to improve services for people with low levels of functional literacy over the longer term is to teach health-care professionals how to work with this population early in their careers. If hospitals and medical schools make students aware of the problems associated with low levels of health literacy and teach techniques for responding to the problems, then professionals and paraprofessionals will be equipped with the tools they need to deal with this population when they enter the labor force. For example, the Southside Area Health Education Center provides in-service 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. Nursing students are taught how to administer screening tests and are introduced to verbal and other techniques that can be used to

assist this population. As a result of Southside's effort, more hospitals in the area are including health literacy in staff training, and a nursing school teaches students how to administer health literacy screening tests.

Organizations such as the Medicare Rights Center (MRC) are specifically geared to provide education and training programs to professionals who assist Medicare beneficiaries. For example, staff at the MRC launched CityNET, a Medicare education and training program for community-based organizations serving hard-to-reach populations on Medicare in New York City. The MRC staff is implementing NationalNET to expand its training efforts across the United States. The goals of this project include: creating a network of community-based organizations and individuals in local communities that can provide information and assistance to beneficiaries; ensuring that Medicare beneficiaries not targeted by public education campaigns will receive the information and assistance they need to make informed health-care choices; and providing a testing ground for the development of effective educational messages and materials tailored to meeting the needs of beneficiaries in different regions of the United States. It would be useful to add those with low health literacy to efforts such as NationalNET, since low functional literacy overlaps with many hard-to-reach populations.

ESTABLISHING AND OPERATING HEALTH LITERACY PROGRAMS

Program administrators interested in implementing health literacy efforts face challenges. As efforts described in this report demonstrate, however, these challenges are not insurmountable. Established health literacy efforts can serve as guides for creating, operating and sustaining new programs.

Financing Health Literacy Programs

One reason that so few health literacy efforts exist is the lack of funding directed toward these activities. The staff time needed to work with Medicare beneficiaries with low health literacy is often not available, nor do the staff necessarily have the skills to provide intense one-on-one communication. There are, however, ways to find the appropriate resources to promote health literacy efforts.

Grants are one avenue to help organizations address low health literacy. For instance, Pfizer has become very active in promoting awareness of the issue of low health literacy. Pfizer's 2000 Health Literacy Grant Program is designed to stimulate efforts to address low literacy through community-based research and interventions.

Health literacy activities can be funded as part of broader efforts. For example, a quality improvement project was created at MetroHealth Medical Center to decrease in-hospital mortality and re-admissions for patients with congestive heart failure. Health literacy efforts are part of that project. Administrators of the project believe that the best way to achieve its objectives is to determine the functional literacy levels of patients and then to develop individualized educational programs. The hospital has always had an extensive cadre of case managers, but they have not always been involved in clinical activities. The position of heart failure nurse was created; the nurse spends time developing individualized educational programs.

At T.H.E. Clinic, health literacy efforts are a part of clinical operations. The clinic receives federal, state, county and city funds to support clinical services. Some of these resources are used to pay case managers or community health workers. These staff members are trained to identify patients' preferred way of learning, provide the resources to meet these needs, and follow up with patients to ensure that they understand what they have been told and that they properly manage their care. In addition, T.H.E. Clinic applies for funding from private foundations to support case management for populations with special needs, such as those with low levels of functional literacy.

Health literacy efforts may also build on other projects. For example, the El Paso Community Education Program received a grant from Laubach Women in Literacy USA in 1997 to begin a health literacy curriculum and to teach health literacy classes to women. Once funding for this project ended, staff at El Paso developed a curriculum pertinent to both men and women and added an evaluative component to measure its effectiveness. Staff were able to interest Pfizer in funding the project by building upon what was learned through the Laubach experience. The coordinator of program was also awarded a grant from the Kellogg Foundation to provide health care to the indigent in El Paso and applied for other grants to increase access to other populations.

The techniques developed by staff at the Brownsville Community Health Center also built upon another project. In 1994, an outbreak of ancephalis panicked the community of Brownsville, Texas. The "One Border Foundation" was created to provide outreach and research on this condition and was funded by the Centers for Disease Control and private funders, such as the March of Dimes and Levi Strauss. The concept of promotoras evolved from this effort and now stands as a permanent technique used by the Brownsville Community Health Center to meet the health-care and insurance needs of people in the community. The Robert Wood Johnson Foundation awarded a grant to Brownsville to enroll people in the community in the Medicaid program. The Medicaid sign-up campaign is designed to help parents understand Medicaid and to determine whether they are eligible for coverage. The promotoras at Brownsville assist those who are eligible for Medicaid to complete their applications and understand their rights. Although the grant was not specifically targeted to those with low levels of functional literacy, many people who needed assistance because they lacked literacy skills received help from promotoras.

Promoting Community Support for Health Literacy Programs

Program administrators who have established health literacy efforts stress the importance of community support. The use of volunteers allows many organizations to provide assistance to the population with low health literacy skills. People who understand their communities can help that population. Members of a community trust and may feel more comfortable with someone who knows them and understands their needs. For instance, promotoras who volunteer at the Brownsville Community Health Center have been particularly successful in identifying and addressing the health-care needs of their community. Program administrators assert that community workers may be able to identify those with low levels of functional literacy if people feel comfortable enough to share this information with someone who has helped them with their health-care needs for an extended period of time. Similarly, staff at the North Carolina Seniors' Health Insurance Counseling Program and other insurance counseling programs recruit and train retirees to serve as health counselors in local communities. Staff find that Medicare beneficiaries are more receptive to counseling from peers who receive Medicare and need to understand the benefits and options themselves.

Discussions with program administrators and their staffs show how community partnerships bring together many areas of expertise and can contribute to the effectiveness of programs that reach people with low health literacy. For instance, the collaboration between the Lafayette Adult Reading Academy and the School of Pharmacy at Purdue University benefits both parties. Future pharmacists are given a first-hand opportunity to be sensitive to the needs and perspectives of those with low health literacy skills. At the same time, students from the academy develop a relationship with their pharmacist and learn how to ask questions if they do not understand.

Collaborations between health and educational organizations might also provide increased visibility of the need to work with the population with low health literacy. For example, the El Paso Community Education Program built partnerships with the Thomason County Hospital, Planned Parenthood, and the Texas Department of Human Services and Department of Health into its grant for developing and implementing its health literacy curriculum. Each partner contributes certain components, such as providing materials or free screenings for students, or assisting people with enrolling for health insurance. According to the coordinator, this collaboration allows for additional visibility and reaches more people through partnerships with the departments of health and human services, which promote the program through their clients.

Many of those interviewed for this report say that health literacy efforts perhaps would be more successful if services were available in a variety of settings throughout the community. For example, community centers, a hospital, restaurants and Area Agencies on Aging served as screening sites when the Southside Area Health Education Center administered tests to assess for health literacy levels. Educators from Southside also worked with administrators at housing centers to present educational programs on health topics.

EVALUATING HEALTH LITERACY EFFORTS

The health literacy efforts discussed in this report are not evaluated formally. Rather, evaluation of the programs' effectiveness is often done on a more subjective and informal basis. For instance, the staff at T.H.E. Clinic considers its efforts successful if loyalty has been developed between its patients and its providers and if patients feel comfortable enough to ask questions regarding their care.

Efforts may also be evaluated as effective based on how many people seek health-care services or how many call a hotline after receiving assistance. Instructors at the El Paso Health Literacy Project speak with nearly 500 students about what they learned about their health and which services they sought and received after the classes. Some 400 people were screened for diabetes and 160 enrolled for private health insurance after going through 24 hours of El Paso's health education instruction.

Recall or repetition methods are also used to determine whether health literacy efforts are reaching the intended population. For example, patients are shown pictographs and taught their meanings and are re-tested a month or two later to evaluate recall. Pharmacy students at the Lafayette Adult Reading Academy use different wording of the same questions regarding medication compliance with each visit. If patients' responses remain consistent, pharmacists determine that their communication with patients is effective.

SUSTAINING HEALTH LITERACY PROGRAMS

Once health literacy efforts are established and operational, program administrators must determine how they will be sustained. Some view the incorporation of health literacy efforts into daily routines as one way to sustain efforts over time. For example, nursing and medical school curricula and hospital in-service training can sensitize health-care professionals and equip them with the skills needed to assist with people with low health literacy.

Sustaining health literacy efforts also means having necessary financial resources. Program administrators understand the importance of showing that their efforts are effective, particularly cost-effective, so funders remain interested in financing their efforts. For this reason, evaluation will increasingly become an important element of health literacy programs.

CONCLUSION

The complexity of today's health-care system causes confusion for consumers. Many sophisticated health education campaigns are underway, but most of them use printed materials to educate consumers about their health insurance options or health conditions and treatments. While these materials are helpful for some, they may not meet the needs of others, such as those with low health literacy skills.

Very few efforts exist to address specifically the needs of those with low functional literacy as they navigate the health-care system. This may, in part, be attributed to a lack of awareness of the problem and its impact on individuals and society. It is important to make the people who work with the population with low health literacy aware of the problem and sensitive and responsive to their needs.

The question that remains is how best to address the issue. The seven programs discussed in this report can serve as a catalyst for this discussion. The techniques used in these efforts can be replicated and adapted to assist individuals with low health literacy. At the same time, efforts to increase awareness of the problem among health professionals and policy makers are needed. As more programs are implemented, the need for evaluation will be even greater.

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APPENDIX A—Program Descriptions

CLINICAL SETTING

MetroHealth Medical Center at Case Western Reserve University

Cleveland, Ohio

Case Western Reserve University's MetroHealth Medical Center is a public hospital. Its health literacy effort began as part of a quality improvement project. Patients of all ages (though primarily the older adults) who are hospitalized with congestive heart failure undergo an intensive education program about their disease and techniques for self-management. They are first screened to assess their literacy level. If patients are found to have low levels of health literacy, the heart failure nurse alerts doctors and nurses so they take special care in communicating with them. The heart failure nurse then determines the most effective methods of communicating information to the patient and creates an individualized education program. The nurse follows up with patients after they are discharged from the hospital.

T.H.E. Clinic

(To Help Everyone)
Los Angeles, California

T.H.E. Clinic is a 25-year-old nonprofit, primary care clinic. In general, this clinic serves populations that tend to have low levels of health literacy. The key to T.H.E. Clinic's health literacy efforts is the personal approach used. When patients arrive at the clinic, outreach workers talk to them about the most comfortable way for them to understand health-care information (i.e., videotapes, printed materials, etc.). After determining the patient's preferred learning style, outreach workers put the appropriate personnel and equipment into place. They also ask patients who in the household generally gets and uses the materials to ensure that information falls into the right hands. Outreach workers also work with patients after their appointments to ensure that they have a complete understanding of what the doctor or nurse said regarding their medications or other instructions for care.

ADULT LEARNING SETTING

El Paso Community College Education Program

El Paso, Texas

The El Paso Community College (EPCC) Literacy Center was created in 1985 to assist educationally and economically disadvantaged members of the El Paso community, one of the poorest in the nation. The center teaches over 1,000 students annually at four of its campuses and over 15 community sites, such as churches and housing complexes. In 1998, EPCC was funded for one year to develop and implement a health literacy program to help academically and economically disadvantaged residents better understand health-related issues, take an active role in preventing health problems, access available health services and better understand the entire health-care system. A health literacy curriculum was developed for students to receive 24 hours of instruction on various facets of health care. Partnerships were formed with agencies within the community, such as Thomason County Hospital and Planned Parenthood, to assist with student instruction or to provide health services to students, such as free screenings at health fairs.

Lafayette Adult Reading Academy

Lafayette, Indiana

The Lafayette Adult Reading Academy (LARA) is an adult basic education program serving approximately 1,150 learners of all ages in Northwest Indiana. Years ago, LARA collaborated with the Purdue University pharmacy department to develop a program to help low-literate adults understand their chronic condition and medications, and to assist them in working with their physician or pharmacist. One to 10 pharmacy students work with LARA learners on a weekly basis for one college semester. A three-step oral interview process in which interviewers ask questions to assess each patient's medication use habits and perspectives is used. Pharmacy students also count all medications at the weekly meetings to ensure that the medications are being taken properly.

HEALTH EDUCATION SETTING

Brownsville Community Health Center

Brownsville, Texas

In 1994, an outbreak of ancephalis in Brownsville led private foundations to fund the “One Border Foundation,” which provided support to the community. The main technique developed to educate community members of Brownsville was the use of “promotoras,” women ages 40 to 67 who go door-to-door in the community to assist people with understanding health-care issues. The use of promotoras is now a permanent technique used by Brownsville Community Health Center to help people with health-care and insurance needs. Promotoras link people to services and follow-up with them on a continuous basis. They help determine eligibility for various forms of health insurance coverage and help enroll those who are eligible.

Pharmacists at the clinic also interact with community members on a one-on-one basis. They first ask patients to bring their pill bottles and ensure that the number of remaining pills matches the renewal date on the prescription bottle. If the pharmacist finds that the patient is not taking medications properly, he or she contacts the doctor, who then speaks with the patient or family. The doctor then determines whether a promotora should visit the home to assist the patient with medications. Booths are also available at the health center for patients to speak one-on-one with a pharmacist.

Southside Area Health Education Center

Hopewell Senior Health Literacy Project

Hopewell, Virginia

Concerned about access to health care in rural environments, the Southside Area Health Education Center (SAHEC) sought and received a grant from a local foundation in 1998 to implement the Hopewell Senior Health Literacy Project. This project had three main elements:

- 1) To survey seniors to obtain more reliable data on health literacy among seniors in this community.
- 2) To provide group programs for the older adults to improve their health literacy.

- 3) To work with the community to bring about a better understanding of health literacy issues among health and human services professionals.

Screenings were conducted in various community setting to gauge the literacy levels of seniors age 55 and older. Staff from SAHEC went into these settings and determined how seniors wanted to learn and the health topics in which they were interested. Southside also provided in-services at local hospitals to make staff aware of the problem of health literacy and to help them recognize those who may have low health literacy skills.

RESEARCH SETTING

**Johns Hopkins University
Oncology Center**

Pictograph Research Project
Baltimore, Maryland

In 1999, Dr. Peter Houts received a one-year grant to develop and study pictographs and how they can help people with low functional literacy skills remember spoken medical instructions. As a result, 193 pictographs representing 236 actions that patients and family caregivers should take to manage seven problems stemming from cancer and HIV/AIDS were developed. Adults with limited literacy skills were recruited from an inner city job-training program to test the effectiveness of these pictographs. Subjects were first shown the pictographs and told what they meant. Immediately after this instruction, as well as one month later, subjects were shown the pictographs again and asked their meanings. The relatively high recall rates suggest that pictographs could be an effective way to increase information available to people with low health literacy for managing symptoms and problems related to complex illnesses.

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APPENDIX C—Pictographs



Take medicines on a schedule as directed by the doctor



Don't eat fried foods

APPENDIX D—Health Literacy Bibliography

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APPENDIX E—Health Literacy Web Sites

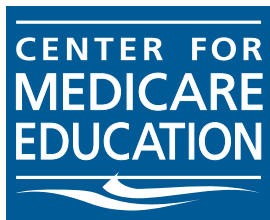
Libertynet. www.libertynet.org. Health Promotion Council.

Sisters Together. www.hsph.harvard.edu/sisters-together. About Sisters Together.

World Education. www.worlded.org. Health and Literacy Compendium, New England Literacy Resource Center, Project Web sites.

Health Care Financing Administration. www.hcfa.gov.

National Medicare Education Program. www.nmep.org.



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