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A REPORT ON HEALTH LITERACY

Adult Basic and Literacy Education

*Interagency Coordinating Council*

JULY 2002

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AS DIRECTED

## *Health Literacy Skills:*

A list of basic skills commonly needed for health literacy.

- reading
- writing
- numeracy
- speaking
- listening
- problem solving
- information gathering
- decision making
- critical thinking



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# *Adult Basic and Literacy Education Interagency Coordinating Council*

The Adult Basic and Literacy Education Interagency Coordinating Council (ABLE ICC) is charged with the tasks of providing recommendations for the coordination of adult basic and literacy education services across state departments and developing strategies to communicate the need for and benefits of adult literacy services.

The ABLE ICC is composed of representatives from the First Lady's Office and the Departments of Education, Labor and Industry, Public Welfare, Community and Economic Development, Health, and Aging. In addition, there are Governor-appointed members who represent adult literacy providers; business, industry, and labor; the media; adult education coalitions and associations; adult learners; and other adult literacy stakeholders.

In 1999, the ABLE ICC published its first report, **Blueprint for Change: Adult Basic and Literacy Education Services in Pennsylvania**, which contains eight recommendations. A second report will be released in late fall 2002. **A Report on Health Literacy** is a special topic report, intended to accompany the Blueprint for Change reports.

On July 11, 2001, the ABLE ICC conducted a health literacy forum to bring together a diverse group of health care and adult literacy stakeholders to explore an equally wide range of perspectives to health literacy issues.

Following presentations by a panel of health care and adult literacy experts, participants divided into five focus groups, each group examined one of the following aspects of health literacy.

- Health education and low literacy.
- Health literacy issues in the workplace.
- Navigating the health care system.
- Health literacy and older adults.
- Health literacy as it relates to English language skills and cultural issues.

ADULT BASIC AND LITERACY EDUCATION INTERAGENCY

R E P O R T o n



*health*  
*literacy*

## COORDINATING COUNCIL

This report is a follow-up to the ABLE ICC's health literacy forum and is intended to serve as the beginning of a statewide, interdepartmental health literacy initiative. The health literacy topics discussed during the forum are presented in this document, each with priority issues and a brief review of current research findings.

One of the challenges is the development of a definition of health literacy that incorporates different perspectives, while identifying the role literacy plays in health care and healthy living — at home, in the community, and in the workplace. Most experts agree that health literacy is critical to accessing health care and knowing how to navigate the health-care system, and that it involves the ability to read, understand, and act on health information.

The National Adult Literacy Survey (1992) found that 40 to 44 million Americans are functionally illiterate, meaning they lack the basic skills to function successfully as family members, workers, and citizens — another 50 million have marginal literacy skills. Pennsylvania's State Adult Literacy Survey (1994) found that more than four million adults in the Commonwealth are in need of adult basic and literacy education to function adequately (*Kirsch et al. 1993, 1994*). Overall, research findings indicate that low literacy correlates statistically with poor health and is a barrier to health care access.

“Jan Burns is a 66-year-old woman with a peculiar habit: Whenever she visits her doctor's office, she tells the staff she forgot her glasses — or claims her hand is too sore to write — simply, so she doesn't have to read or fill out forms. It's not that she's trying to avoid her bill, or afraid of giving out personal information. Mrs. Burns is one of the 90 million Americans

struggling with low health literacy.”  
(*Source: AMA Foundation, Tackling the Problem of Health Illiteracy.*)

Research reveals that:

- Patients with the greatest health-care needs may have the least ability to read and comprehend information needed to function successfully as patients.
- Patients with limited literacy skills face incredible barriers in today's health-care system.
- Physicians need to become aware of literacy-related health issues and play a much greater role to address the problems.

“When it comes to healthy living, people face many choices and challenges, such as choosing whether to eat a balanced diet, engage in physical activity, or avoid tobacco,” says Pennsylvania's Physician General, Dr. Rob Muscalus. “But making the right choice can often be tough and very confusing. It can be especially difficult for persons who lack the knowledge and skills they need to do some very basic things, such as interpreting food package labels, reading health education materials, completing health questionnaires and insurance forms, or trying to understand directions on prescriptions and other medicines.”

Dr. Muscalus adds, “As a result, low health literacy can have a profound effect on a person's health; raising awareness about this issue is of major importance. The challenge exists for all of us to look around in our communities and organizations to identify what the needs are and then to work toward one common goal — literacy for all Pennsylvanians.”



In 1998, the House of Delegates of the American Medical Association acknowledged that approximately twenty-five percent of the adult population have difficulty understanding both oral and written health-care information and adopted a policy that recognizes illiteracy as a barrier to the access and delivery of health care (Osborne, 1999).

Research indicates that patients with the greatest health-care needs may have the least ability to read and understand information needed to function successfully as patients.

In addition, adults with low literacy levels and their families tend to have more health problems than individuals with higher-level skills. This is often due to one or more of the following factors:

- They are less likely to make regular doctor visits and have preventive medical tests.
- They are unable to read medication labels and written instructions for follow-up medical care.
- They are less likely to have smoke detectors, fire extinguishers, or first aid kits in their homes.
- They smoke more and drink more coffee.
- They exercise less.
- They tend to live in substandard housing located in dangerous neighborhoods.
- They have jobs that tend to be more hazardous and tend to get hurt on the job more frequently (*Perrin, 1989*).

In 1995, Mark Williams, M.D.; Ruth Parker, M.D.; David Baker, M.D.; and others from Emory University in Atlanta conducted a study of more than 2,600 adults who sought emergency care at Grady Memorial-Atlanta and Harbor-UCLA Medical Center. They found that:

- Twenty percent of low-income outpatients did not understand when their next appointment was scheduled.
- Twenty-five to 58 percent did not understand the instructions to “take medicine on an empty stomach.”
- Forty-nine percent could not determine if they were eligible for free care from reading a hospital financial form.
- Forty-one to 75 percent could not understand a standard consent form.
- Thirty-three percent could not read and understand basic health-related materials.

Moreover, with only print-based materials available, low-literate adults often lack information about where to go and when to seek health care (*Weiss, 1992; Williams, 1995*). A number of studies have revealed that informed consent forms and medicine package information inserts are among the most difficult and complex reading materials patients encounter in health-care settings. Most often these are written at the 8th grade to college level (*Smith, 1994*).

## THE ISSUES

1. One of the major barriers to health literacy is the heavy reliance on print materials written at the 10th+ grade level. Consequently, individuals with low literacy skills are at risk of not being able to understand information distributed by health-care providers.
2. Adults with inadequate basic skills have a complex array of communication difficulties, which may interact to have a negative influence on health-care outcomes. Consequently, they often have worse health status and less understanding of their medical conditions and treatments.
3. Patients who ask questions about their health and engage doctors in conversation about their health care tend to have fewer ailments than those who do not communicate well with their doctors. In general, patients ask less than one percent of the questions during doctor-patient conversations; low-literate patients are even more reluctant to ask questions.
4. There are questions regarding the role of health-care providers, namely physicians, in terms of responsibility for educating patients.
5. There is a need for the pharmaceutical industry to become more aware of literacy problems.

Low health literacy can affect the overall productivity and economic success of workers and the workplace — often causing poor job performance, high rates of absenteeism, and increased employer/employee health insurance costs. For many workers, low literacy results in feelings of shame and a fear of being discovered as “work illiterate.”

When low literacy affects the workplace, it can be dangerous — to be safe and healthy, employees need to understand basic safety procedures and disclosures on safety data sheets for hazardous materials. Low health literacy can also affect the economic well-being of employees — employees need to be healthy in order to be a productive team member in the workplace, and must be able to understand health plan options. A lack of basic skills can be a barrier to understanding a medical treatment plan, to reading prescriptions, or even knowing when to call a doctor and, in turn, can exacerbate workplace issues such as absenteeism and work-related accidents — ultimately affecting workplace performance and overall productivity.

From the perspective of labor, the health literacy of union membership is critical to the effective functioning of negotiated health benefits. In addition, promoting health literacy through the union contributes to the improved health of union members and their families and more informed use of workplace health benefit plans. Health literacy promotions may include employee training on the union’s health benefit package and how benefits are accessed, education on health issues

that commonly affect union members (e.g. diabetes, hypertension, nutrition, exercise, stress), and, for health-care workers, an understanding of the health-care industry and the health-care delivery system.

## THE ISSUES

1. Employees need basic skills to understand workplace safety instructions, including the appropriate use of potentially dangerous equipment and hazardous materials.
2. Employees need literacy skills to understand workplace medical insurance plans and policies regarding sick time and pay.
3. Without a strong foundation of English language and basic literacy skills, health-care workers are limited to low-skill jobs that offer low wages and often provide no medical benefits.
4. Because adults with low literacy levels and their families tend to have more health problems than individuals with higher level skills, low-literate workers also tend to have higher absenteeism rates due to frequent sickness and doctor visits, and more frequent and longer hospitalization.
5. Health literacy professionals need to know how to work with the CareerLink System in workforce education referrals.
6. Research needs to be conducted to determine if reduced insurance payments can work as incentives to encourage employees to use opportunities to increase their health literacy.



**L**ow-literate adults tend to use substantially more health-care services than those with higher-level skills. Research findings indicate that inadequate health literacy may increase the risk of hospitalization and low-literate patients are less likely to have health insurance.

The health-care provider-patient relationship is critical to the success of health-care outcomes, but health-care professionals often fail to understand that some of their patients may have basic skills deficiencies. They assume their patients understand the information they have given them, both orally and in writing, and will ask questions if they don't understand. Dr. Ruth Parker, Associate Professor of Medicine at the Emory School of Medicine in Atlanta, is concerned about the possibility of misinformation, miscommunication, and mistakes when providing low-literate patients with health care. She points out that many patients with basic skills deficiencies rely on their memory to recall medical instructions (*QI/TQM, 2001*).

Dr. Mack Lipkin, Director of the Division of Primary Care and Professor of Clinical Medicine at New York University, believes that true understanding of health information involves a form of action related to health outcomes, and that this includes the patient's reading ability, as well as motivation and decision making — comprehension of health-care information is about decision making either by the physician or by the physician and patient (*Pfizer, 1998*).

Dr. Eugene Smith, Pharmacy Officer, Navajo Area, Indian Health Service, warns that the odds are not good of reaching the right specialist the first time you enter a medical system, and that the complexity of medical systems is a health literacy issue. Moreover, low-literate adults do not know where to go to get answers to their questions.

Dr. Dennis Fortenberry, Associate Director of Adolescent Medicine at James Whitcomb Riley Hospital for Children, Indiana University School of Medicine, further supports the need for literacy to navigate medical systems and suggests that functional literacy involves competency in information gathering to evaluate a situation — and that literacy is fundamental to information-gathering and decision-making competencies (*Pfizer, 1998*).

Research indicates that:

- Only about 50 percent of all patients take medication as directed.
- Patients who have trouble reading have difficulty following prescribed treatments.
- Patients with low literacy are five times more likely to misinterpret their prescriptions than those with adequate reading skills.
- More than 80 percent of low-literate adults could not read the rights and responsibilities of a Medicaid application.
- Approximately 74 percent did not know if they were eligible for free care.
- Low-literate adults are often unable to understand medical plans and fear financial consequences (*Williams, 1995*).

There are health literacy legal ramifications for health-care professionals. Recent court decisions suggest that merely handing a patient a consent form to sign does not satisfy a provider's legal obligation to get informed consent. A low-literate patient has a legal right to receive verbal information about the risks, benefits, and alternatives to a proposed medical procedure.

The National Academy on an Aging Society reports that a lack of basic skills contributes to the cost of health-care services — it is estimated that low literacy increases annual health-care expenditures by more than \$73 billion. Literacy-related costs break down into the following:

1. Between three and eight percent of personal health-care expenditures may be wasted because of low levels of basic skills. Out-of-pocket expenditures by patients total more than \$11 billion, or 16 percent of the literacy-related costs.
2. Medicare pays 39 percent of the literacy-related costs. Medicaid pays more than \$10 billion, or 14 percent of literacy-related costs.
3. Employers may pay as much as 17 percent of literacy-related health-care costs.
4. Most of the literacy-related cost is passed on to the taxpayer.

#### THE ISSUES

1. Complicated health-care systems cause great confusion on the part of consumers with inadequate basic skills.
2. Information-gathering and decision-making competencies are critical to healthy living and health care.
3. Health-care providers need to become aware of and sensitive to literacy problems.
4. The bureaucracy of health-care benefit plans and complexity of insurance policies and coverage make most hard to read and interpret.
5. Low literacy increases the cost of health care.

## TWO HEALTH LITERACY ASSESSMENTS:

The Rapid Estimate of Adult Literacy in Medicine (REALM) is a screening instrument used to assess an adult learner's ability to read a list of 125 common medical words and lay terms for body parts and illnesses — words are arranged in columns by the number of syllables they contain. It is designed to assist health-care professionals in determining a patient's literacy level. The assessment takes about five minutes to administer and score. (Terry Davis, Ph.D., Michael Crouch, Ph.D., & Sandy Long, Ph.D., 1991, Louisiana State University Medical Center.)

The Test of Functional Health Literacy in Adults (TOFHLA) is a 50-item reading comprehension and 17-item numerical ability test that was developed using actual hospital materials. The assessment takes about 22 minutes to administer and there is a Spanish version available. (Joanne R. Nurss, Ph.D., 1995, Director, Center for the Study of Adult Literacy, Georgia State University.)

## HEALTH LITERACY AND OLDER ADULTS

Low health literacy is particularly common among older adults for two primary reasons. First, older adults have more frequent doctor visits, hospital admissions, chronic illnesses, multiple problems requiring several medications taken on varied schedules, and failing eyesight, as well as reduced memory and hearing loss. Compounding the effects of aging on health, there is a second factor — the least educated older adults tend to be the most ill. Advanced age, in combination with low literacy levels, has a negative impact on the health of older adults and leads to increased spending on health care. Research findings report:

- More than 66 percent of U.S. adults, over age 59, have either inadequate or marginal literacy skills (*Kirsch et al., 1993*).
- Approximately 80 percent of patients over 60 years of age have inadequate levels of health literacy.

- Seventy-five percent of community clinic patients over 60 read at a level below fourth grade.
- Approximately 20 percent of older adults have difficulty reading written information from health-care providers.
- The mean reading level of U.S. adults is at grade 8 and the mean reading level of Medicaid enrollees is at grade 5.3.

Research also indicates that health literacy declines dramatically with age. As such, elderly managed-care enrollees may not have the literacy skills necessary to function adequately in the health-care environment. In addition, low health literacy may impair elderly patients' understanding of health materials and messages, and may limit their ability to care for their medical problems. In fact, one out of three senior citizens does not have the literacy skills needed to understand instructions for prescriptions, medical forms, and doctors' directions (*Gramarian et al., 1999*).

Older adults often have problems learning new health-care information due to inadequate reading, math, and problem-solving skills. This is often due to limited schooling, never acquiring strong basic skills, or losing skills due to lack of use — many older adults rarely read and get most of their information from television or listening to the radio. Research also indicates that there are aging factors that may affect learning, and certain medications may impair cognitive processing and problem-solving skills (*Osborne, 1999*).



## THE ISSUES

1. Older adults lacking adequate literacy skills are more likely to have more serious illnesses due to their inability to make informed decisions about healthy living and preventive health care.
2. Many elderly patients have limited ability to read and comprehend medical information pertinent to their health and are at high risk because of their need to take various medications and follow complex health-care procedures.
3. Seniors with inadequate literacy skills are seriously disadvantaged when required to take a more active and independent approach to their own health care.
4. Many older adults don't know where to go for different types of health-care information.
5. Many older adults have difficulty understanding health-care costs, options, and systems.
  - Lower-cost health-care options often depend on the ability of patients to coordinate their own care and communicate with the professionals who provide support; however, elderly patients may not have the literacy skills necessary to function adequately in the health-care environment.
6. Informational health-care brochures can present problems—more than one version of a brochure is too expensive for some organizations, but easy-to-read brochures insult some highly educated older adults.
7. Many health-care groups think older adults can/will use the Internet for health-care information, but many older adults lack access to technology and may also lack the basic literacy skills needed to use computers or the Internet.

- Information and communication technologies may help reduce health disparities through their potential for promoting health, preventing disease, and supporting clinical care. Unfortunately, those who have preventable health problems and lack health insurance coverage are the least likely to have access to such technologies. Barriers to technology access include cost, geographic location, illiteracy, disability, and factors related to the capacity of people to use these technologies appropriately and effectively (*Eng et al., 1998*).
8. More research is needed to better serve the complex learning needs of older adults.



## HEALTH LITERACY AS IT RELATES TO ENGLISH LANGUAGE SKILLS AND CULTURAL ISSUES

Health literacy includes both language and cultural issues. One issue has to do with disparities in disease and death rates among different populations — disease does not affect all segments of society equally. These disparities result from the interplay of socio-economic conditions, cultural and language factors, and a lack of education and low literacy levels — this includes inadequate English literacy skills that can be an obstacle to both healthy living and obtaining primary health care in the United States.

In 2000, 28.4 million foreign-born people resided in the U.S.; of those, 90 percent were 18 years of age and older. The 2000 Census reported that 17.6 percent of the U.S. population were speaking a language other than English; in Pennsylvania, 7.7 percent of the Commonwealth's population were speaking a language other than English.

English as a Second Language (ESL) programs are the fastest growing component of state-administered adult education programs. Nationwide, ESL participants maintained a narrow lead in enrollments in 2000, accounting for 38 percent of adult education participants. ESL was followed closely by adult basic education (ABE) enrollments at 37 percent and adult secondary education (ASE) enrollments at 25 percent.

There are numerous challenges associated with improving the health literacy of adults with minimal English language skills. In addition to the challenge of improving English language skills of adults who may have limited literacy in their native language, cultural beliefs related to health issues can affect the appropriateness of literacy education — including the selection of appropriate health-care materials to be used in instruction. These challenges reveal the need for training of both literacy education and health-care professionals.

### THE ISSUES

1. Language and cultural barriers can impede access to safe and informed health care.
  - In some urban hospitals, up to 80 different languages are being spoken by patients on a regular basis.
2. Limited English speaking patients often have difficulty understanding and navigating American health-care systems.
  - A lack of understanding of information, an inability and fear to ask questions, and many other barriers commonly prevent ESL patients from understanding exactly where to go or what to do, and also prevent an understanding of what their physicians or other health-care providers are saying. Clearly, the consequences of not being able to understand or speak English can have a negative impact on both healthy living and health care.
3. Translation services can help only to a limited degree because exact translations are very difficult. Moreover, it is hard to establish trust between physician and patient, or provide the highest quality care when they don't speak the same language. For example, when the patient cannot answer diagnostic questions, physicians may have to resort to ordering more tests to reach the diagnosis.
4. There are questions regarding the role of health-care providers, namely physicians, and what their role should be in terms of treating ESL patients.
5. The pharmaceutical industry must become more aware of language and cultural barriers.



## HEALTH LITERACY RECOMMENDATIONS

The ABLE ICC Health Literacy Forum panelists and participants suggested the following:

- Develop a new paradigm and a different approach to health literacy — the current health-care system does not acknowledge low literacy as a health issue. As such, many patients have great difficulty obtaining and using health-care services because of the reliance on the written word to communicate information and medical instructions, complete forms, and navigate the health-care system. Moreover, patients with inadequate health literacy use preventive health-care services less than those with higher health literacy.
- Encourage health-care providers to review patients' levels of understanding of key health points and, to ensure understanding, to ask patients to “show or teach” them the specific instructions for health-care information they've been given. Be sure health-care professionals are trained in order to minimize the risk of losing patients due to insensitive literacy testing in health-care settings.
- Place greater emphasis on effective health communication, which is necessary for consumers to successfully understand and navigate an increasingly complex health-care system. Without that ability, patients are less likely to know the diagnosis, the name and purpose of medications, the correct management of illness, and how to improve their health behaviors.
- Conduct more targeted research to assess the health literacy skills of specific populations and evaluate the literacy demands of health-related information and materials.
- Take a close look at the training of health-care professionals to ensure health literacy is addressed as a critical issue. Include information on health literacy in schools, media, and the workplace.
- Conduct an examination of the health literacy challenges for health-care insurers.
- Develop health awareness activities in schools, at the workplace, and in the community.
- Identify core health literacy competencies in education.
- Link communication on public health to health literacy.
- Increase professional awareness and expertise in health literacy and cross-cultural communications.
- Identify and/or develop health literacy communication resources.
- Explore technology possibilities for health care.
- Review policies and procedures to circumvent barriers to health care.
- Develop baseline measurements to review health literacy programs. Identify key partners for health literacy programs. Offer incentives for demonstrating models of success — and, once identified as successful, implement and showcase models that work.

## SUGGESTED STRATEGIES

The following are strategies identified by forum participants to address a variety of health literacy issues.

1. Change the overall perception of health literacy, both in terminology and in awareness — get rid of the word “health illiterate” and replace with “health awareness or health management skills.”
2. Increase awareness of the need for health literacy.
3. Increase awareness levels of physicians and other health-care providers — most are not aware that many of their patients do not know what they are saying, often taking for granted that their patients understand.
4. Create comprehensive literacy materials at different reading levels and in different languages.
  - Consider the Plain Language Approach, which emphasizes the use of short, simple sentences with common words in the communication of medical information.
5. Train health-care service providers in the writing of appropriate health-care materials, including health-care program guidelines and insurance regulations.
6. Consider visual aids for adults with low literacy levels.
  - Create educational video programs for patients to view in their doctors’ offices.
7. Make greater use of technology and the Internet.
  - Use computers to produce different levels of health-care information.
8. Establish a clearinghouse for health materials for different groups.
  - For physicians, for dissemination to patients.
  - For literacy agencies, for adult learners.
  - For pharmacies that do not have extensive and appropriate drug-education materials.
9. Create/develop effective communication strategies for health-care providers and patients.
  - Include a comprehensive list of questions that patients can use to obtain information from their physicians — customized by situation and condition.
10. Encourage patients to take a time-out after a doctor visit to see a video, hear an audiotape, or do something else to ensure they understand what their physician told them.
11. Create recommendations for health-care professionals, addressing:
  - Pharmacists: how can we make it readable?
  - Physicians: how do you ask questions to ensure patients understand information?
12. Enlist greater involvement — involve literacy experts as the first line of action.
13. Encourage every literacy agency that gets state funding to look at these issues — involve state and local agencies.
14. Seek greater involvement of national organizations, such as the American Medical Association (AMA).
15. Identify models that work.
16. Encourage medical associations to address the issue of low health literacy in medical school and residency programs to help physicians understand the issues during their training.
17. Include health literacy in the continuing professional development of health-care providers.
18. Change health insurance incentives — focus on prevention versus intervention — encourage patients to take responsibility for their own health care.
19. Incorporate health literacy into health counseling.
20. Reach out to other potential partners (such as the Pennsylvania Business Roundtable, State Chamber of Business and Industry). Tap into experience, rather than time, and include small businesses.
21. Take advantage of existing workplace literacy resources that use mentors, checklists, skills building, and communication strategies to encourage employees to take responsibility for their own health.

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A health literacy resource:  
The Health Literacy  
Introductory Kit

To order a copy of the Health Literacy Introductory Kit, please call the AMA Customer Service Center at 1-800-621-8335 or visit the AMA Press web site. The kit is located under “communications and patient relations” products and includes the following. Cost to AMA members is \$15.00, cost to non-members is \$25.00. The item stock code number is OP221001.

- Low Health Literacy: You Can't Tell By Looking - A video presenting a series of vignettes of individuals affected by this problem.
- Health Literacy: Report of the AMA Council on Scientific Affairs
- Suggestions for using the kit
- Fact sheets on health literacy
- Local literacy resources
- Speakers bureau
- Slides/overheads
- Physician/patient educational resources
- Discussion guide with a physician feedback survey

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*inform*  
*think*  
*solve*