by Anthony Tassi

THE EMERGENCE OF HEALTH LITERACY AS A PUBLIC POLICY PRIORITY

From Research to Consensus to Action

AFTER YEARS OF RESEARCH AND ADVOCACY ON the part of literacy and public health professionals, medical researchers, and physicians, the concept of "health literacy" has begun to emerge as a significant national issue. In April 2004, the Institute of Medicine (IOM) issued *Health Literacy: A Prescription to End Confusion*, a definitive report that should serve as a wake-up call to policymakers and private sector decision-makers alike. "The public's ability to understand and make informed decisions about their health is a frequently ignored problem that can have a profound impact on individuals' health and the health care system," said Dr. David Kindig, professor emeritus at the University of Wisconsin and the report's lead author (as cited in The National Academies, 2004).

The emergence of health literacy as a public policy priority has significant implications for the adult education community. Adult education and English for speakers of other languages (ESOL) programs will no doubt be called upon to integrate health literacy skills instruction into existing curricula, a call many programs have already answered in a variety of ways. In addition, heightened awareness of health literacy throughout the health care system may present a new opportunity for adult educators to collaborate with health care professionals. Pedagogical insights honed through years of adult literacy and ESOL practice could inform new partnerships across health and education sectors to meet the challenge of enhancing health literacy among all Americans.

Before addressing the nature of these opportunities, it may be helpful to review some of the key issues in the health literacy research to date and the points of agreement in the emerging consensus. By its very nature, the summary below will omit important issues and perhaps overly simplify others. The IOM report offers what may be the definitive statement on what is known about health literacy and what gaps still exist in the knowledge base. It should be required reading for all those interested in a more thorough review.

Overview of the Research on Literacy and Health

Health literacy is not a new issue. Researchers and practitioners have been examining the connection between literacy and health for decades. The key findings of this body of work—that inadequate literacy skills have negative consequences for people's health—should come as no surprise to the adult literacy community. However, the sheer volume of research documenting the problem and the breadth of topics covered may surprise many

literacy and health care professionals. For example, in a recent review of medical research issued in conjunction with the IOM report, the U.S. Agency for Healthcare Research and Quality identified more than 3,000 articles published since 1980 that examine some aspect of the effects of low literacy on health (Berkman et al., 2004).

While research methods, study populations, and the strength of results vary from study to study, there is a remarkable consistency of findings across the literature. Many of these key findings can be grouped into the following major themes:

- **Worse overall health status.** Individuals with lower levels of literacy report worse health status and have higher incidence of chronic disease than individuals with higher levels of literacy (Parker, Williams, Clark, & Nurss, 1997; Rudd, Moeykens, & Colton, 1999). While inadequate literacy is closely related to poverty and other factors known to be linked to lower health status, research suggests that the association of low literacy and poor health holds true even after adjusting for such socioeconomic factors (Weiss, Hart, McGee, & D'Estelle, 1992).
- **Presentation for treatment at later stages of disease.** Adults with low literacy levels appear not to seek preventive and primary care as often or as early as their counterparts with more advanced literacy skills (Rudd et al., 1999). Men with low literacy skills who have prostate cancer have been found to be more likely to present for initial treatment at a later stage of disease, thereby reducing their chances of survival. Literacy levels have been found in several studies to be a better predictor of metastatic disease at presentation than the age or race of the patient (Bennett et al., 1998; Kim et al., 1999).
- **Higher rates of hospitalization.** Individuals with lower levels of literacy, as a group, are likely to be hospitalized more often than individuals with higher levels of literacy (Baker, Parker, Williams, & Clark, 1998; Weiss & Palmer, 2004). The cost associated with this higher rate of hospital admissions adds many billions of dollars to national health expenditures (National Academy on an Aging Society, 1998).
- **Less knowledge of health and disease.** Individuals with lower literacy skills have less knowledge of basic information needed to maintain health (Rudd et al., 1999). Extensive research among individuals with AIDS, asthma, cancer, diabetes, and other conditions has documented the association between patients' literacy levels, their understanding of their disease, and their ability to manage their condition (Davis et al., 1996; Kalichman & Rompa, 2000; Williams, Baker, Honig, Lee, & Nowlan, 1998).
- **Difficulty understanding and using health information.** The 1992 National Adult Literacy Survey found that nearly half of the American public read at the 8th grade level or below and that 40 percent of Americans with chronic medical conditions read at the 5th grade level or below (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Over 300 studies conducted in almost every imaginable health care setting have documented that health care information is routinely written above these reading levels (IOM, 2004).

An Emerging Consensus on Health Literacy

There is an emerging consensus among health and education experts that the concept of "health literacy" goes well beyond the ability to read (which remains the most common measure for health literacy in the literature) and encompasses listening, speaking, writing, and arithmetic skills as well. These skills are needed to fill out patient registration forms, health insurance forms, and other documents; to understand and participate in communications with physicians, nurses, and other health care workers; to accurately assess and communicate the severity or duration of symptoms; to administer medications correctly and prevent drug errors; and for many other health-related tasks, large and small. In its report, the IOM adopted the definition of health literacy developed by the National Library of Medicine and used in Healthy People 2010 (U.S. Department of Health and Human Services, 2000): "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (IOM, 2004, p. 4).

Within the growing field of health literacy, this definition represents a middle ground of sorts. It goes further than concepts that relate strictly to patients' ability to read and understand without taking into consideration issues of access and context. However, it stops short of definitions that also include functional aspects of health literacy, such as "the competence to use such information and services in ways which are health-enhancing" (Bennett, 2003, citing 1995 National Health Education Standards).

While the IOM definition of health literacy may not go as far as some literacy and health practitioners would find useful, it does establish important conceptual clarity. The IOM's definition roots health literacy in the concept of "capacity." Efforts to enhance health literacy should enhance, strengthen, and build the capacity of individuals and communities. Health literacy is therefore positive in nature and focused on skills development rather than remediation of patient deficits or transmission of specific knowledge or information. Health literacy is not about health education. It is not about making information more accessible. It is not about making health materials available in

appropriate languages or reading levels. These are all important activities that should be undertaken in light of, in response to, and informed by, an individual's or a community's relative level of health literacy.

Another important implication of the IOM definition is that health literacy is dependent on factors outside the control or domain of the individual. Some of these factors may be cultural and societal; others may be related to household composition. The resources and skills made available to an individual in the health promotion, disease prevention, and medical care contexts are perhaps the most important among these identifiable factors. For example, even an individual with a 12th grade reading level or beyond will not learn anything about his or her medical condition while waiting for a doctor if the clinic where he or she is waiting has no patient education materials available.

While literacy and health professionals and scholars may debate the merits of one definition of health literacy over another, consensus has started to emerge around these key points: The problems associated with limited health literacy and interventions to ameliorate them do not start and end with patients, and efforts to enhance health literacy skills among individuals and families must be matched by interventions on the part of the health care sector to improve communications and systems (IOM, 2004).

Framework for Action

Finding the Levers of Change in the Health Sector

From this emerging consensus and the increasing priority being placed on health literacy, a framework for action can be established. Within the health care sector, the IOM argues for a mission-critical perspective: "Health literacy is fundamental to quality care," according to Dr. Kindig (as cited in The National Academies, 2004). The challenge will be to make this mandate operational by understanding how the concepts surrounding health literacy relate to other systemic efforts to improve quality of care. There are three such systemic efforts that come to mind:

- Reducing racial and ethnic disparities in care
- Improving patient safety and reducing medical errors
- Improving health outcomes for people with chronic medical conditions

Alarming disparities in health status, access to care, and health outcomes along racial and ethnic lines have long plagued the nation's health care system (IOM, 2003). In the past ten years, the health care sector has become increasingly serious about and committed to finding better ways to address these critical shortcomings of the system. Viewing the issues of disparity through the lens of health literacy may offer a powerful complement to existing efforts. Literacy and language skills are not evenly distributed across the population: The National Adult Literacy Survey of 1992 found African-American and immigrant populations were disadvantaged with respect to literacy levels (Kirsch et al., 1993). It is safe to assume that the distribution of health literacy skills is likewise skewed across the population. Therefore, interventions that seek to enhance low health literacy skills among a patient population will likely address racial and ethnic disparities as well.

A second large-scale challenge currently being tackled throughout the health care system is the imperative to improve patient safety and reduce medical errors. More actively involving patients in their care decisions and communicating more frequently about these decisions can also play a significant role in meeting this challenge. Perhaps the most common medical error is the incorrect administration of prescription medications (Kohn, Corrigan, & Donaldson, 2000). Health literacy could play a central role in implementing successful error-reduction programs. Enhancing patients' ability to accurately communicate their symptoms, allergies, medical history, and other vital information could prevent physician errors in prescribing the wrong drug at the wrong dose. Enhancing patients' reading ability and self-advocacy skills—such as the importance of asking questions and the right to informed consent—could help reduce dispensing errors at the bedside. Such interventions may prove to be more cost-effective than information technology solutions or changes in staffing patterns. Likewise, enhancing patient health literacy skills could markedly improve medication management skills outside the clinical setting, improving adherence to therapies and reducing drug errors.

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A third system-wide challenge that could benefit from the integration of a health literacy perspective is chronic disease management, which has become a growing priority as the rates of chronic disease increase and the population ages. On the level of rhetoric, the chronic disease management field has already adopted a number of the key principles of health literacy. In fact, many initiatives now employ the term "chronic care management," and health care providers are no longer "educating" patients, but rather helping them develop self-efficacy skills and supporting them in the self-management process. Whether the

reality of the field has met this rhetoric is not always apparent. Often, the acknowledged low literacy levels of a patient population appear to be addressed by adopting plain language in patient education materials or reducing the reading level of the text. Both are important steps, but neither helps the patient to become a better reader. To their credit, many health care providers have developed non-written materials, such as videos, but the technology has not been leveraged to maximize efficacy in providing interactivity and assistance to individuals with low literacy skills. Some programs may help their patients learn how to tell time and manage the timing requirements of medication therapies (for example, two hours before a meal, three times a day), two threshold-level skills needed to manage a chronic condition. Fewer programs, however, appear to be rethinking the timing of appointments, diagnostic procedures, and medication administration in light of the needs and relative health literacy skill level of their patient population. The ambulatory care "advanced access" movement—which allows patients to call for same-day or next-day clinic appointments and attempts to provide all necessary services during one visit—is one promising exception to this rule.

Implications for Adult Education

Health literacy is likely to grow in importance within the field of adult education. Devising ways to integrate health literacy into the classroom may, in some ways, be easier to accomplish than convincing the health care sector to embrace the concept and its implications. Recent experience with implementing family literacy programs—and, before that, workforce development programs—indicates that the field of adult literacy is adept at responding to new mandates and opportunities. However, the call to implement health literacy instruction does present a number of unique challenges: Developing resolutions will require thoughtful deliberation.

Health is intensely personal, highly subjective, and imbued with significant cultural and religious meaning. This combination of attributes can make for fruitful and stimulating classroom learning; however, it can also be a Pandora's box, waiting to be opened by an unsuspecting instructor. Health literacy instructors will need to be guided and trained on how to handle sensitive topics that may come up in the classroom and how to respect the reality that individuals have vastly different health care models that inform many of their daily choices. Programs should have relationships with social service agencies so they can refer learners to trusted resources with appropriate expertise.

Health care is incredibly complex and given to frequent new developments that are often sensationalized and inaccurately portrayed on the evening news. The so-called best medical advice—on topics such as cholesterol and dietary guidelines—seems to change every few years, and direct-to-consumer pharmaceutical advertising is a multi-billion dollar business. Adult education and ESOL instructors have neither the time nor the training to keep up with this ever-changing body of knowledge and opinion or to sort through the cacophony of conflicting voices. Basing a health literacy program on specific instructions with respect to specific medical conditions—even if the conditions are relevant to all learners in the class—is unlikely to succeed except under the best of circumstances.

In addition to these obstacles, the fiscal climate within adult education remains painstakingly tight. Cutbacks have forced many programs to do more with less and have prevented even more from acquiring new materials and learning technologies. Some programs have also found that the heightened attention to "accountability" and the push for standardized assessment have increased administrative burdens and decreased pedagogical freedom and creativity.

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By focusing health literacy programs on enhancing skills and capacities that are relevant for multiple domains of adult learners' lives, adult educators may be able to meet the challenges and avoid some of the identified pitfalls—even within this climate. Working with the strengths of instructors, it should be possible to identify and reasonably enhance "transferable" functional literacy skills, which are critical to maintaining health and accessing care. Program managers may find it useful to establish partnerships with health care providers in order to develop these competencies and create linkages that will enable their learners to access care more readily.

The Potential for Collaboration

The adult education sector has a significant contribution to make in the effort to enhance the health literacy of the American public. In addition to expanding health literacy into more classrooms, adult literacy and ESOL programs can partner with health care providers and public health agencies to help fill critical gaps in skills and resources, thereby supporting systematic efforts on the part of the health care system to enhance health literacy skills.

Health care providers—doctors, nurses, case managers, health educators, and administrators—need better insight into how adults learn and into how to communicate effectively with individuals from other cultures who speak minimal or no

English. They need to learn strategies for rapidly assessing whether patients have understood, and can make appropriate use of, written and oral communication. Adult educators can provide these insights.

The adult education system can teach the health care system how to break down complicated tasks and ambitious learning objectives into smaller, more realistic learning goals and then how to help adults recognize and build upon their incremental progress. One need think no farther than the ubiquitous newsprint that adorns the walls of adult education classrooms throughout the country: Someone obtained a driver's license; someone else filled out a job application; a third person got a library card. These are all small steps in developing and using functional literacy skills.

Adult educators can help health care providers deepen their understanding of the principles of patient-centered care systems. By learning how adult education programs have developed and implemented learner-centered instructional models—with authentic assessment, individualized goal setting, skills-based curricula, participatory classroom strategies, availability of progressively more advanced instruction, linkages to important non-literacy resources, and so on—health care providers can reflect on their own practices. These methodologies are particularly relevant to the growing trend of provider-based chronic disease management efforts.

In addition to pedagogical and program development insights, the adult education system has two other related strengths that would complement the work of many health care providers: trust and access to adult learners and their families. Teachers and tutors often serve as lifelines for new immigrants: helping them with the most basic tasks of survival in a new country, familiarizing them with local customs, and guiding them to appropriate resources. For native-born citizens, literacy instructors serve as guides through a long, difficult, and often highly emotional process. To help them reach vulnerable populations and to work in communities with low health status and high levels of mistrust of the formal health care system, health care providers and public health workers need allies outside of their profession who are trusted by these populations and communities.

The thousands of adult education classrooms throughout the country also offer an impressive platform for reaching a broad cohort of adults with significant health problems and poor access to services. This group of adults—highly motivated and already embarking on a process of self-improvement—is precisely the population that our health care system is adept at dealing with, if they can be reached and connected to care and other appropriate resources. Indeed, it would be hard to imagine a better scenario for health promotion and disease prevention: Adults routinely make time in their schedule to come together in small groups once or twice a week over the course of many months, if not years, in a supportive community-based environment. Health care providers should be beating down the doors of adult education programs to gain access to these programs.

While the exact synergies described above may not be available to all programs, the potential for collaboration across the health and adult education sectors is significant. Such partnerships will mobilize the creative thinking that is needed to put health literacy into action.

References

American Medical Association. (1999). Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. *Journal of the American Medical Association, 281*, 552–557.

Baker, D. W., Parker, R. M., Williams, M. V., Clark, W. S., & Nurss, J. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health. 87*(6), 1027–1030.

Baker, D. W., Parker, R. M., Williams, M. V., & Clark, W.S. (1998). Health literacy and the risk of hospital admission. *Journal of General Internal Medicine. 13*(12), 791–798.

Baker, D. W. (2002). "Past Successes and Future Challenges." Presented at the Health Literacy: Leading Edge Practices 5th Annual Conference. Washington, DC. Retrieved May 15, 2004, from http://www.pfizerhealthliteracy.org

Bennett, C. L., Ferreira, M. R., Davis, T. C., Kaplan, J., Weinberger, M., Kuzel, T., Seday, M. A., & Sartor, O. (1998). Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *Journal of Clinical Oncology. 16*(9), 3101–3104.

Bennett, D. (2003, October). *Low literacy, high risk: The hidden challenge facing health care in California.* Pasadena, CA: California Literacy, Inc.

Berkman, N. D., Bonito, A. J., DeWalt, D. A., Pignone, M. P., Sheridan, S. L., Lohr, K., Lux, L., Sutton, S.F., & Swinson, T. (2004, January). Literacy and health outcomes. *AHQR Publication No. 04-E007-2.* Rockville, MD: Agency for Healthcare Research and Quality.

Davis, T. C., Arnold, C., Berkel, H. J., Nandy, I., Jackson, R. H., & Glass, J. (1996). Knowledge and attitude on screening mammography among low-literate, low-income women. *Cancer. 78*(9), 1912–1920.

Ebeling S. (2003). *Lessons and tips for addressing health literacy issues in a medical setting.* Harvard School of Public Health: Health Literacy Website. Retrieved May 15, 2004, from http://www.hsph.harvard.edu/healthliteracy/insights.html

Institute of Medicine. (2000). *To err is human: Building a safer health system.* Washington, DC: The National Academy Press.

Institute of Medicine. (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care.* Washington, DC: The National Academy Press.

Institute of Medicine. (2004). *Health literacy: A prescription to end confusion.* Washington, DC: The National Academy Press.

Kalichman, S.C., & Rompa, D. (2000). Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology. 25*(4), 337–344.

Kim, S. P., Bennett, C. L., Chan, C., Chmiel, J., Falcone, D., Knight, S. J., Kuzel, T., Davis, T. C., Elstein, A. S., Moran, E., Robertson, C. N., & Smith, J. S. (1999). QOL and outcomes research in prostate cancer patients with low socioeconomic status. *Oncology*. *33*(4), 163–165, 169–170.

Kirsch, I. S., Jungeblut, A., Jenkins, L., & Kolstad, A. (1993). *Adult literacy in America: A first look at the results of the National Adult Literacy Survey* (NALS). Washington, DC: National Center for Education Statistics, U.S. Department of Education.

The National Academies. (2004, April 8). *90 million Americans are burdened with inadequate health literacy.* Washington, DC: The National Academy Press. Retrieved October 1, 2004, from http://www4.nas.edu/news.nsf/6a3520dc2dbfc2ad85256ca8005c1381/a582ebfc554e736685256e70005e27d1?OpenDocument

National Academy on an Aging Society. (1998). *Understanding health literacy: New estimates of the costs of inadequate health literacy.* Paper presented at Pfizer conference, Promoting Health Literacy: A Call to Action, Washington, DC.

Rudd, R. E., Moeykens, B. A., & Colton, T. C. (1999). Health and literacy: A review of medical and public health literature. In J. Comings, B. Garners, & C. Smith (Eds.), *Annual Review of Adult Learning and Literacy*, *1*, 158–199.

U.S. Department of Health and Human Services. (2000). *Healthy People 2010: Understanding and improving health.* Washington, DC: U.S. Government Printing Office.

Williams, M. V., Baker, D. W., Honig, E. G., Lee, T. M., & Nowlan, A. (1998). Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest*. *114*(4), 1008–1015.

Weiss, B. D., Hart, G., McGee, D. L., & D'Estelle, S. (1992). Health status of illiterate adults: Relation between literacy and health status among persons with low literacy skills. *Journal of the American Board of Family Practice*, *5*, 257–264.

Weiss B. D., & Palmer, R. (2004). Relationship between health care costs and very low literacy in a medically needy and indigent Medicaid population. *The Journal of the American Board of Family Practice, 17*, 44–47.

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