Beyond the Institute of Medicine Health Literacy Report

Are the Recommendations Being Taken Seriously?

Ruth M. Parker, MD,¹ David A. Kindig, MD, PhD²

¹Department of Medicine, Emory University School of Medicine, Atlanta, GA, USA; ²Wisconsin Public Health & Health Policy Institute, University of Wisconsin at Madison, Madison, WI, USA.

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This issue indicates that a substantial amount of work is underway by serious investigators on a variety of health literacy topics. Our purpose in this editorial is to place this work in the context of the Institute of Medicine (IOM) 2004 Health Literacy report, which we were privileged to help create. We will conclude that while progress is being made, the scope is not broad enough and the pace not fast enough to make the progress that is necessary. In the words of the report, “efforts to improve quality, reduce costs, and reduce disparities cannot succeed without simultaneous improvements in health literacy.”¹

The charge to the IOM committee had 4 elements: define the scope of the problem of health literacy, identify the obstacles to creating a health-literate public, assess the approaches that have been attempted, and identify goals for health literacy efforts and suggest effective approaches. The report defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,” and found that 90 million American adults “may lack the needed literacy skills to effectively use the U.S. health care system.”¹ While these sentences seem to focus on the individual, the first consensus finding of the committee was that health literacy is “based on the interaction of the individual’s skills with health contexts . . . the health care system, the education system, and broad social and cultural factors at home, at work, and in the community.”¹ Figure 1 displays these contexts and multiple intervention points.

Based on this model, the committee argued that the responsibility for health literacy improvement must be shared by these various sectors and that the health care system carries “significant but not sole responsibility for health literacy improvement.”¹ Based on this broad view, the report issued a set of recommendations including the following:

- Increased federal and nonfederal funds for health literacy research are urgently needed;
- New measures of health literacy must be developed and evaluated;
- Accreditation requirements for schools should require the implementation of National Health Education Standards and demonstration programs should be funded to support state efforts to achieve such standards;
- Professional schools should incorporate health literacy into their curricula and areas of competence;

- Public and private health care systems should develop and support demonstrations to identify the most effective ways the health care system can reduce the negative effects of limited health literacy; and
- NCQA, JCAHO, CMS, and other accreditation bodies should incorporate health literacy into their standards: health literacy assessment should be a part of health care information systems and quality data collection.

Many of the IOM report recommendations called for much-needed health literacy research. Thirteen Institutes and Centers of the National Institutes of Health and AHRQ issued a Program Announcement with Review (PAR) focusing on “Understanding and Promoting Health Literacy” in June 2004.² The program’s goal includes increasing understanding of the nature of health literacy and its relationships with health outcomes. The PAR encouraged research in 6 areas, which included the following: measurement, variation over the life course, mediators and moderators of low health literacy, outcomes, interventions, and new technologies. The NIH expects the research to assist them in their mission of communicating scientific health information to the public and to health providers. In addition, the research will hopefully be useful in strengthening health information knowledge and communication skills of the public, thereby advancing one of the national goals of *Healthy People 2010*. For the 2004 deadline, there were 59 applications submitted for RO1 funding and 69 applications for RO3 funding. Eight of the sponsoring organizations awarded \$9.1 million to fund 19 research projects from 2005 to 2009. Over 100 RO1 and RO3 applications were reviewed for the 2006 cycle.²

This is a good start on the research agenda, but more than research is needed. There are things we know enough about already to move forward on. One of these is measurement,

FIGURE 1. Potential intervention points.

Address correspondence and requests for reprints to Dr. Parker: Emory University School of Medicine, 49 Jesse Hill Dr., Atlanta, GA 30303 (e-mail: Rpark01@emory.edu).

covered in this special issue with pieces that address the continued need to advance measuring individual skills. Efforts to advance population-level measurement and indicators are also greatly needed. After release of the IOM report on health literacy, preliminary data from the Department of Education 2003 National Assessment of Adult Literacy (NAAL) became available in December 2005.³ This survey of individuals' print literacy skills was performed as a follow-up to the National Adult Literacy Survey (NALS) of 1992, which had provided the most accurate portrait to date of American's literacy skills.⁴ The IOM report finding regarding the magnitude of the problem of health literacy was based on NALS data. The results of the 2005 NAAL survey show that the literacy skills of American adults have not changed dramatically over the last decade.³ The average skills of U.S. adults are not adequate for understanding and using our health care system, and the population with the greatest health literacy demands, the elderly, has the poorest literacy skills. The Department of Education collaborated with the Department of Health and Human Services (HHS) to create a Health Literacy Component for the NAAL survey. Data from this analysis, scheduled for release in 2006, will allow a comparison of overall literacy skills with specific literacy skills in the health context. Data from the survey will provide a baseline for the *Healthy People 2010* objective. Importantly, although HHS is involved with the Health Literacy Component analysis, the survey instrument and data are owned by the Department of Education. Although there is public access to presorted data in this population survey, there is no ability to access the raw data or survey questions. There is no on-going population-based survey of health literacy within the health sector, and the only population-based effort to measure health literacy captures only individuals' skills of print materials. There remains a pressing need to advance population-based measures and indicators of a health-literate public.

The IOM report included a commissioned survey of systematic approaches to health literacy that are in use but may not be reflected in the peer-reviewed literature.¹ Most of the examples cited fell into the category of "simplifying materials," but there were also technology-based communication techniques and meaningful multisectoral partnerships. Respondents noted 3 fairly consistent themes regarding lessons learned, including: the lack of organizational support and policies, the need for quality standards, and the need for multiple modalities for improving health literacy. Health literacy efforts were often the work of a committed few within large agencies and organizations. There appears to be growing support within various federal health agencies to incorporate health literacy into the mission of their work. The Health Resources Service Administration (HRSA) Bureau of Health Professionals now has institutional policy for health literacy, and in January 2006 health literacy was included in the HRSA Performance Plan Measure under Quality.⁵ The HHS Health Literacy Workgroup, now in its third year, allows for interagency collaboration, communication, and coordination of efforts to further health literacy.

Building a health-literate America requires both incremental and systemic change. Incremental change should target future generations; efforts to improve the literacy and health literacy of all Americans through education are essential. Numerous IOM recommendations relate to the need for educational improvements to advance health literacy. We see a critical need to find partners in primary and secondary education to work collaboratively on how to introduce essential

health curricular components when time and curricula are already constrained. Attaining the National Health Education Standards and meeting the basic literacy requirements as they apply to health literacy are mutual goals of those in the worlds of health and education.¹

Numerous professional schools and societies are working to educate health professionals in their schools and through continued medical education. The Joint Commission on Accreditation of Health Care Organizations plans to release a public policy report devoted to health literacy, and members of industry and professional societies continue to advance the issue with national meetings and publications. Specific IOM recommendations related to the need to engage consumers in the process of health communications development. Recent experience with Medicare Part D enrollment highlights the mass confusion, misinformation, and misunderstandings that result when complicated, essential health information is not clearly communicated. Engaging consumers in the process of developing meaningful health communication regarding complicated information is essential, yet so often not done.

Similarly, the IOM report called for involving patients in the informed consent process to ensure truly "informed" consent in research. Institutional and sponsor protection, rather than patient (or consumer) protection, continue to dominate the informed consent process.

The IOM Roundtable on Health Literacy held its first session in January 2006. This forum enables dialogue and discussion among key leaders and representatives to exchange information and address cutting-edge issues. This effort holds promise for further engaging stakeholders in articulating and participating in creating solutions that advance a health-literate America.⁶ An early effort of the Roundtable includes compiling a status report of responses to the report's 15 recommendations posed as part of a comprehensive strategy for improving health literacy and offering the benefit of optimal health to all Americans.

The challenges posed by the IOM report were daunting and will clearly require sustained efforts over several decades. We believe that the report was a wakeup call to action, which resonated with many in both the public and private sectors. While the progress noted here in just 2 years is substantial, maintaining the efforts over the long haul will require significant commitment of time and resources. It would not be unprecedented for this commitment to diminish. Efforts such as those reported here must be continued and increased if the IOM committee's vision for a health-literate America, and the improved health and lowered expenditures that will come from it, is to be realized

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