



Implications of Health Literacy for Public Health: Workshop Summary

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Maria Hewitt and Lyla M. Hernandez, Rapporteurs; Roundtable on Health Literacy; Board on Population Health and Public Health Practice; Institute of Medicine

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IMPLICATIONS OF HEALTH LITERACY FOR PUBLIC HEALTH

W O R K S H O P S U M M A R Y

Maria Hewitt and Lyla M. Hernandez, *Rapporteurs*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

INSTITUTE OF MEDICINE
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Willing is not enough; we must do.”*

—Goethe



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This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

Helen Osborne, Health Literacy Consulting

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Steven Rush, UnitedHealth Group

Carol Teutsch, Health Care Institute

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Hugh Tilson**, University of North Carolina School of Public Health. Appointed by the Institute of Medicine, he was responsible for

making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteurs and the institution.

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1

Introduction

Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. Nearly half of all American adults—90 million people—have inadequate health literacy to navigate the health care system (IOM, 2004).

The Institute of Medicine convened the Roundtable on Health Literacy to address issues raised in the report, *Health Literacy: A Prescription to End Confusion* (IOM, 2004). The roundtable brings together leaders from the federal government, foundations, health plans, associations, and private companies to discuss challenges facing health literacy practice and research and to identify approaches to promote health literacy in both the public and private sectors. The roundtable also serves to educate the public, press, and policy makers regarding issues related to health literacy. The roundtable sponsors workshops for members and the public to discuss approaches to resolve key challenges.

An area of interest for the roundtable is the implications of health literacy for public health. As a result, the roundtable sponsored a workshop in Irvine, California, on November 21, 2013, that focused on the implications of health literacy for the mission and essential services of public health. The workshop featured the presentation of a commissioned paper on health literacy activities under way in public health organizations. Other presentations examined the implications of health literacy for the mission and essential services of public health, for example, community health and safety, disease prevention, disaster management, or health communication.

The workshop was organized by an independent planning committee

in accordance with the procedures of the National Academy of Sciences.¹ The planning group included Olivia Carter-Pokras, Jennifer Dillaha, Patrick McGarry, Andrew Pleasant, Lindsey Robinson, Rima Rudd, and Steven Rush. The role of the workshop planning committee was limited to planning the workshop. Planning committee members developed the agenda topics, and selected and invited expert speakers and discussants to address identified topics. Unlike a consensus committee report, a workshop summary may not contain conclusions and recommendations. Therefore, this summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. All views presented in the report are those of workshop participants. The report does not contain any findings or recommendations by the planning committee or the roundtable.

The workshop was moderated by Roundtable Chair George Isham. Chapter 2 frames health literacy in the context of public health. Chapter 3 describes public health literacy efforts in three states. In Chapter 4, how health literacy facilitates public health activity is further explored. Chapter 5 covers public health literacy implementation and research. Chapter 6 follows with a general discussion of the day's proceedings.

REFERENCE

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

¹ The planning committee's role was limited to planning the workshop. The workshop summary has been prepared by the rapporteurs as a factual account of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the Institute of Medicine. They should not be construed as reflecting any group consensus.

2

Background and Overview

PUBLIC HEALTH LITERACY

*Rima Rudd, Sc.D.
Harvard School of Public Health*

Roundtable member Rima Rudd outlined several of the actions needed to perform the 10 essential services of public health (see Table 2-1). She highlighted the diversity and varied nature of these services and the very broad public health agenda at the local, state, and national levels. Rudd acknowledged the challenges ahead, especially in addressing the needs of vulnerable and high-risk populations and communities. She believes it is imperative that researchers offer public health practitioners insights into how health literacy can promote their ongoing work. Health literacy researchers can broaden their research focus to examine public health activities and to consider how existing research findings in the medical encounter can inform public health communication needs. In so doing, researchers can partner with public health professionals to help them integrate health literate approaches into their ongoing work.

Rudd provided four insights from health literacy research that could be adopted (or adapted) by the public health community to influence their work. First, there is the established link between patients' literacy skills and health outcomes. For example, literacy levels have been shown to have an effect on knowledge, behaviors, risk factors, morbidity, and mortality. Second, well-established barriers to access to health information include not just health educational materials, but also applications, surveys, documents,

TABLE 2-1 Actions Needed in the Provision of Public Health’s Essential Services

Essential Services of Public Health	Actions
1. Health promotion	Monitor
2. Health protection	Diagnose
3. Environmental health	Inform
4. Occupational health	Mobilize
5. Disease prevention and screening	Develop
6. Disaster preparedness	Enforce
7. Mobilization	Link
8. Health policy	Assure
9. Data collection and dissemination	Evaluate
10. Workforce training and development	Research

SOURCE: Rudd, 2013.

and displays. Third, the actions of health professionals, how they write, speak, and engage with people, can erect unnecessary barriers. Finally, Rudd emphasized the importance of the health environment, noting that it can contain barriers to understanding and navigation of systems. She added that health-literate attributes of health care organizations have been defined by Brach et al. (2012b) in a paper published by the Institute of Medicine (IOM).

In the realm of public health, Rudd described how attention to health literacy can contribute to participation in programs aimed at health promotion, disease prevention, and screening. She noted that health literacy affects an individual’s ability to benefit from community-based public health efforts targeted to improve chronic disease management. Rudd said health literacy contributes to disparities in morbidity and mortality. The consequences of having a mismatch between health system demands and population literacy skills include limited access to information, barriers to services and care, and difficulties navigating health and social service institutions—all of which can contribute to profound disparities in health, she said.

Rudd suggested that not all relationships between health literacy and outcomes have been clearly documented yet, but that the field is advancing. Health literacy studies are now starting to focus on the listening and speaking skills of patients as well as the professionals with whom they interact. Indeed, she noted, professionals’ communication skills may dictate the success of the transfer of information, the ease of dialogue, and the quality of discussion. In the past 5 years, health literacy researchers have also started to investigate math computational skills and concepts. An understanding of math is often critical to decision making. This is of particular concern

to public health because public health communications often rely on mathematical concepts such as “normal,” “range,” and “risk.” She pointed out that *risk* is an especially complex mathematical concept that the public as well as many professionals need help in understanding (Goodman et al., 2013; Sheridan and Pignone, 2002).

Organizations such as the American Medical Association (AMA Foundation, 2009) and The Joint Commission (2007) are recognizing the need to remove barriers from health care institutions to create “shame-free” environments and support literacy friendly exchanges, Rudd said. She added that these organizational issues are relevant to both social service and public health institutions.

Rudd described some of health literacy’s tested approaches that can be of interest. For example, tools are now available that aid in the development and assessment of information in print and online. Formative research and pilot testing have long been among the recommended procedures and can be used to examine the language, organization, and structure of materials. Recommended pretesting procedures depend on collaboration with, and feedback from, members of the intended audience. Techniques have also been developed to improve interpersonal exchanges. Three techniques have been well documented and tested: (1) encouraging the asking of questions; (2) applying teach-back (having the patient repeat back key information); and (3) using decision aids. Rudd pointed out that decision making and positive actions are facilitated through participation and engagement on the part of individuals in both clinical settings and communities.

Rudd then discussed the role of health literacy in reducing health disparities. Health information language, content, organization, structure, and format can be examined and altered to lower the cognitive demand on the end user. A focus on professional education and training can enhance skills and bring health literacy issues to the fore. Reformulating institutional norms is another important intervention to foster health literacy. In addition, she said, while assessment tools for examination of materials have come a long way, further development is needed for certain media, for example, labels, data-gathering instruments, and media messaging content.

Action to enhance health literacy must focus on improving individual skills and making health service, education, and information systems more health literacy friendly, Rudd said. Health literacy friendly systems and settings are ones that actively measure, monitor, evaluate, and adjust their communications to meet the needs (and skills) of their users. In short, the focus has to be on both improving individual skills and changing systems. The components of a friendly health literacy environment have been documented and their effects on ease of navigation established, Rudd said.

How applicable are the lessons from health literacy to public health? Rudd said that health literacy has a very strong fit with public health, in

part, due to the theoretical foundation of public health with its concern for the interaction between the environment and society. She added that epidemiology is founded on the notion of the reciprocal relationship between persons and the environment. Furthermore, the social ecological model in public health is consistent with the underpinnings of health literacy. According to this model, individuals and families are considered in the context of a very complex social, physical, economic, and political environment. Individuals are, in effect, embedded within multiple levels of structures and environments. Consequently, health literacy issues cannot be addressed without attention to the broader context.

Rudd pointed out that public health addresses the needs of vulnerable populations. According to adult literacy surveys conducted in 1992 (Murray et al., 1997), 2003 (Murray et al., 2005), and 2012 (Goodman et al., 2013), people with limited literacy:

- Have limited access to information;
- Have difficulty navigating complex systems;
- Are unlikely to be engaged in civic activities; and
- Have limited employment opportunities.

Research has shown that these translate into having limited income, diminished social status, and a sense of being marginalized, Rudd said. The association with poverty means that low literacy families are at further risk as they may also live in poor housing stock and areas of environmental degradation. Furthermore, they are also more likely to be employed in institutions and companies where there are hazardous work environments. Rudd concluded her remarks about multiple layers of risk with the social science finding that those with limited resources and limited social capital may also have diminished collective efficacy.¹

To reduce disparities, Rudd outlined four areas where health literacy insights could be applied to public health services

1. Enhance the awareness and skills of the workforce.
2. Reduce barriers to information.
3. Improve data collection and dissemination.
4. Enhance partnership developments.

Figure 2-1 illustrates how health literacy studies and applications can be expanded outside of the health care setting to play a role in each of the

¹ Collective efficacy is “the willingness of individuals to work together towards a common goal.” <http://www.ask.com/question/definition-of-collective-efficacy> (accessed April 1, 2014).

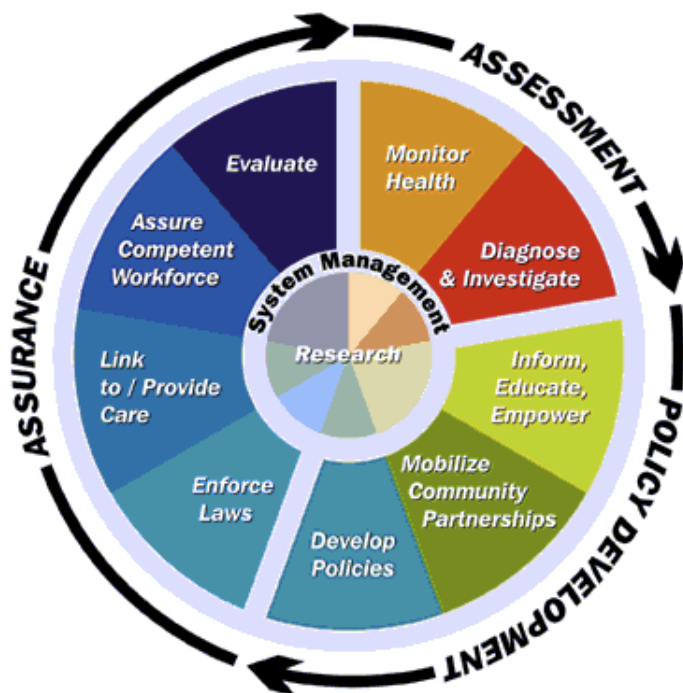


FIGURE 2-1 Essential public health services.
SOURCE: ODPHP, 2008.

essential public health services of assessment, policy development, assurance, and research.

The field of health literacy studies has included examinations of self-care and follow-up, management of chronic disease, and prescription drug labeling, Rudd said. Other studies that have been done relate to health activities at home, at work, in the community, and in the policy arena. However, most of the work has focused on health care rather than on public health contexts.

Rudd used a “connect the dots” exercise (see Figure 2-2) to illustrate the importance of thinking “outside the box.” She first displayed nine dots in the configuration below. She then asked the members of the audience to connect all the dots using only four straight lines. The solution to the problem is shown in the figure.

Rudd said that the *conceptual box* constraining health literacy thus far has been the focus on the health care context. Moving outside the box into

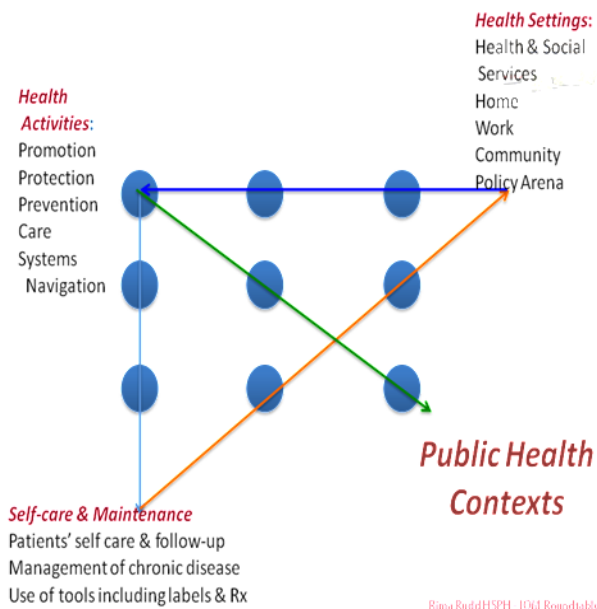


FIGURE 2-2 Thinking outside the box.
SOURCE: Rudd, 2013.

public health contexts would more readily support a strong partnership between those currently working in health literacy and public health policy makers and practitioners.

Thus, Rudd noted, additional health literacy work is needed in the areas of health promotion, protection, prevention, and systems navigation. Rudd suggested that partnerships between those working in health literacy be formed with public health practitioners so that a public health perspective to health literacy can be brought to bear on a diverse set of topics, such as water quality, emergency response, food safety, air quality, civic engagement, and policy decisions.

Rudd, referencing Dubos (1959), stated that public health is an interdisciplinary field concerned with social organization and the culture that promotes and supports the survival of the group. She indicated that the challenge ahead is the removal of literacy-related barriers from the various public health environments in order to support and encourage the capacity of communities. Building on Nutbeam's notion of health literacy as an evolving concept, Rudd and her colleagues suggested that attention be given to the capacity and capability of health systems and the ability of health professionals to support and actively encourage effective social, political, and individual action for health (Rudd, 2010; Rudd et al., 2012).

Rudd outlined several public health literacy challenges and suggested that these challenges could be met through partnerships between those focused on health literacy and those focused on public health practice and communication. Actions that could be taken, she said, include

- implementing and evaluating professional continuing education and training programs that increase health literacy awareness and skills;
- integrating applicable health literacy lessons learned in policy efforts and programs design;
- enhancing communication efforts with health literacy in mind;
- developing, monitoring, and evaluating health literacy components of community programs; and
- testing efficacious action and developing gold standards for practice.

Rudd said action is needed to overcome the well-documented high prevalence of limited health literacy, its relationship to health outcomes, and the mismatch between the literacy demands of the health care system and the skill level of U.S. adults. She reiterated the potential for health literacy to play an important role in supporting public health goals and outlined several health literacy actions that could support the 10 essential public health services:

1. Monitor health status to identify community health problems.
2. Diagnose and investigate health problems and health hazards in the community.
3. Inform, educate, and empower people about health issues.
4. Mobilize community partnerships to identify and solve health problems.
5. Develop policies and plans that support individual and community health efforts.
6. Enforce laws and regulations that protect health and ensure safety.
7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable.
8. Assure a competent public health and personal health care workforce.
9. Evaluate the effectiveness, accessibility, and quality of personal and population-based health services.–
10. Research to identify new insights and innovative solutions to health problems.

Dr. Rudd concluded her remarks by recommending a resource from the Centers for Disease Control and Prevention: an online health literacy course for health professionals (<http://www.cdc.gov/healthliteracy/gettrainingce.html> [accessed July 25, 2014]).

REFRAMING HEALTH LITERACY AS A PUBLIC HEALTH ISSUE

Chloe E. Bird, Ph.D.
The RAND Corporation

Everyone is potentially affected by a mismatch between their literacy skills and the materials that are available to them, Bird asserted. Certain groups are, however, disproportionately affected, such as the elderly, racial and ethnic minorities, immigrants, and those with limited education. The potential population of individuals adversely affected by health literacy is very large because each person is just one diagnosis, one accident, or one event from being in a situation where the information needed to function is more than can be absorbed. At such a juncture individuals need to develop some critical skills.

Bird pointed out that although most people usually think of reading ability when they think about health literacy, it is important to recognize the importance of numeracy skills in this context. One's ability to solve complex problems is one aspect, for example, when someone needs to take a medication three times per day either 1 hour before eating or 2 hours after eating. Individuals need to be able to problem solve and find the assistance or tools available if they cannot adequately perform the necessary task.

Bird described health literacy as a critical pathway through which education, income, and other resources, including community capital resources, affect health care quality, disparities, and outcomes. Identifying people with low health literacy is challenging and potentially very stigmatizing. It remains a hidden epidemic. Yet, she said, identifying individuals who are unable to use the information they have been given, whether it is about prevention, treatment, or other aspects of health, enhances the ability to deliver care and address or prevent a particular health problem.

Identifying individuals with low health literacy is critical, Bird said, yet there are challenges to doing so. For example, screening for low health literacy is very expensive, time consuming, and not well suited to a health care setting. In addition, there is a lack of consensus on how best to screen. Furthermore, Bird said the interventions available to address health literacy issues are difficult to target at the individual level.

Health decisions tend to be made in a social context, not in isolation, Bird said. As people inform themselves and begin to deal with their health

and health care, they rely somewhat on the health literacy of those around them, their social network: friends, family, neighbors, and coworkers. From a constrained-choice perspective, the individual is shaped by this array of opportunities, and these opportunities end up affecting their ability to pursue a healthy life. As a result, an individual living in an area with relatively high health literacy may benefit from the knowledge and abilities of friends and neighbors.

As an example, Bird described how her neighbor and babysitter, a Greek immigrant with a moderate education, lives in an area of high health literacy and therefore can turn to neighbors to obtain good information that augments what she may have received from the health care system. This additional input has helped her deal with different health crises around aging and other concerns. Bird said this same person, were she living in an area with very low health literacy, would be more likely to receive information that is dated, incorrect, or aimed at solving other kinds of problems, such as how to balance the expense of medication with paying rent. In such an environment, her neighbors may not have the information she needs to help her determine whether she is experiencing a serious symptom and how to deal with it. Bird said the concept of constrained choice² has been an area of investigation that she has pursued with her colleague Pat Rieker.

Focusing on communities rather than individuals is very beneficial, Bird said, because that focus provides additional opportunities for action. She described communities as key stakeholders. Mapping can be used effectively to identify communities characterized by low health literacy. Providing informative maps helps communities take ownership of the identified problem. The community that is mapped and takes on shared responsibility could represent the service area of a medical group, a health plan, or the municipality in which the individual lives. Bird said a focus on communities can lead to more efficient resource use and a positive return on investment for the organizations that are attempting to reach out with interventions to improve health and health care. In the context of scarce resources, Bird said, this benefit of efficiency is critical.

At RAND, a project to map health literacy to small geographic areas was led by Laurie Martin with colleagues Bird and Nicole Lurie. A predictive model was developed using data from the National Survey on Health Literacy. The model incorporates attributes found on the Census (and on the American Community Survey), for example, age, gender, race/ethnicity, education, income, and marital status. The output of the model has been

² Constrained choice includes the opportunities and choices with which one is confronted when making decisions and the constraints that are imposed on that decision-making process.

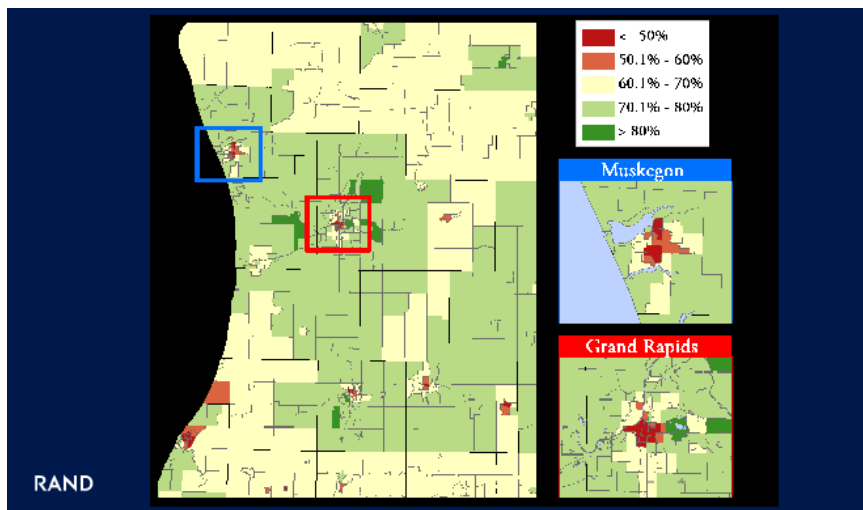


FIGURE 2-3 Percentage of population with “above basic” health literacy.
SOURCE: Martin, 2011.

applied to Census data to identify “hot spots” that represent areas with predictably high levels of low health literacy.³

Figure 2-3 is a map showing the region surrounding Grand Rapids, Michigan, and the percentage of the population with “above basic” health literacy (i.e., intermediate or proficient across an area). The highlighted dark red areas have particularly low levels of above basic health literacy. Bird said having this type and level of geographic information is particularly helpful for those planning public health interventions.

Bird described how hot spots can be categorized and prioritized. One type of hot spot illustrates areas where a particular problem is especially prevalent, for example, asthma or diabetes. The other type of hotspot identifies areas predicted to have low health literacy. Overlaying these maps is instructive, she said. In Cleveland, for example, high prevalence asthma hotspots were identified in low-income African American communities. When the health literacy map was overlaid with the prevalence map, low health literacy hotspots were identified with a relatively high prevalence. These areas could be targeted for public health interventions. Maps allow planners to assess the density of the population, the location where most cases reside, and where to intervene to have the greatest impact. Another advantage of maps is that they are relatively easy to understand. Maps can

³ Information on the RAND mapping project can be found at <http://www.rand.org/health/projects/missouri-health-literacy.html> (accessed July 25, 2014).

display a lot of complex information in an understandable format to illustrate the location and size of a particular problem.

Bird said she has used maps to communicate with decision makers who often have their own hypotheses on the source of a problem within their community. The maps can be used to investigate the merits of these hypotheses. She has been able to show a series of maps to decision makers and answer questions such as “Did the map show a relationship to poverty?” “Did it map onto linguistic isolation?” The maps can provide visual clues as to what is occurring.

It is important to understand, Bird said, that interventions may be ineffective in the absence of information on the size and geographic distribution of a problem and where in a community there are health literacy deficits. Without such information, interventions can fail, perform only marginally, or even exacerbate disparities. This could occur if the intervention is not targeted appropriately and the most advantaged groups in a community benefit from the intervention, but the intended audience is missed. Figure 2-4 illustrates an example of this mismatch of intervention to target popu-

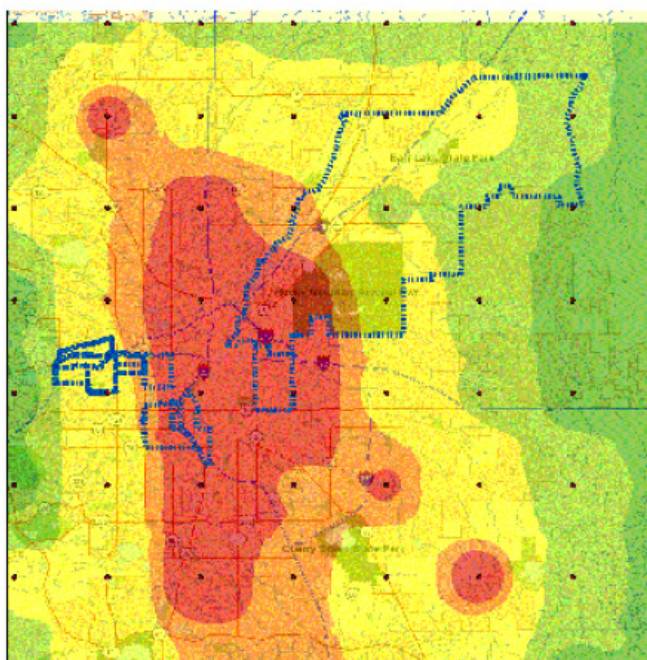


FIGURE 2-4 Missing information can lead you in the wrong direction.
SOURCE: Bird, 2013.

lation. Here, the targeted areas for the intervention are outlined in blue. In fact, the condition of HbA1c adherence among diabetics was most problematic in the darkly shaded areas. Bird described how, in this example, well-intentioned individuals went in with an evidence-based intervention known to have a reasonable return on investment, but failed to show a sizable benefit and serve the disadvantaged communities as intended because they did not focus on the areas with greatest adherence problems.

Bird concluded by saying that maps are powerful tools that can be used to target research activities and interventions to optimize the effects of programs. Mapping can help identify the areas and topics that are a priority for an intervention. It can also bring partners to the table for collaboration and effective communication. These aspects of mapping increase the return on investments. Moreover, mapping can aid in the selection of appropriate interventions and ensure they are targeted effectively, Bird said.

PRESENTATION OF COMMISSIONED PAPER

*Andrew Pleasant, Ph.D.
Canyon Ranch Institute*

Pleasant first thanked the Institute of Medicine (IOM) for the opportunity to develop the commissioned paper, “A Prescription Is Not Enough: Improving Public Health with Health Literacy,” with his coauthors Jennifer Cabe, Laurie Martin, and R. V. Rikard. (The complete paper can be found later in this report.) The paper includes three case studies that describe health literacy in the context of state public health departments in Arkansas, Louisiana, and Nebraska. These states could be considered to have developed or adopted best practices that currently exist within the field of health literacy. Their programs could be adapted to meet the needs of other jurisdictions, he said, and were selected because they serve as examples for other states to emulate.

The focus of the commissioned paper is on local, state, tribal, and territorial public health organizations. To gauge the status of health literacy within state public health departments, the investigators used two main methods. First, they directly contacted every state’s public health department (and that of the District of Columbia) using the main e-mail address, telephone contact information, or online contact form and asked one question, “Who is responsible for health literacy within your organization?” They then conducted an online survey of public health department employees using a wide variety of electronic listservs and mass communication tools as well as direct contacts to selected individuals, for example, members of the American Public Health Association listed as working at a

public health department. These multiple direct inquiries reached thousands of potential participants.

In response to the question about responsibility for health literacy within each state health department, only one state, Arkansas reported having a staff member within the department of public health whose explicit title included the phrase “health literacy.” Pleasant said this level of response does not mean that other departments are not addressing health literacy, but that it is an indicator of the importance of the issue within the department. Results of the survey are shown in Figure 2-5. Despite contacting each health department at least three times, only 24 of 51 health departments responded to the survey. Among the participants from state health departments:

- Seven reported having a designated point of contact or someone whose responsibilities include health literacy (Arkansas, Delaware, Florida, Georgia, Kentucky, Oklahoma, Texas).
- Seven reported that while they did not have a staff person in particular who was a point of contact or who worked primarily in health literacy, they made the point that health literacy is a part of their work (Arizona, Colorado, Connecticut, Montana, New York, Ohio, Oregon).
- Ten reported that they did not have any formal efforts to address health literacy (Alabama, Alaska, California, Iowa, Maryland, Michigan, New Hampshire, Pennsylvania, South Dakota, Wyoming).

The investigators received 63 responses to the online survey, representing 61 organizations. Pleasant said that this is a low response rate given the extensive outreach efforts made. Although the response rate was low, the participants were from local, state, tribal, and territorial public health organizations responsible for large populations, on average more than 3 million people. When the populations represented by the 61 participants are totaled, they represent a population of more than 95 million residents, about one-third of the U.S. population. According to Pleasant, the participants had, on average, a little more than 16 years of experience within the field and generally held middle and upper management positions. So participants, while small in number, were perfectly placed within the field of public health to offer important insights.

When asked how they defined health literacy, seven participants said they used the definition from the IOM publication on health literacy commonly used by the U.S. Department of Health and Human Services. More than half said they used one of several other definitions. Twelve said they did not have a preferred definition and a few said they were in the process of creating their own.

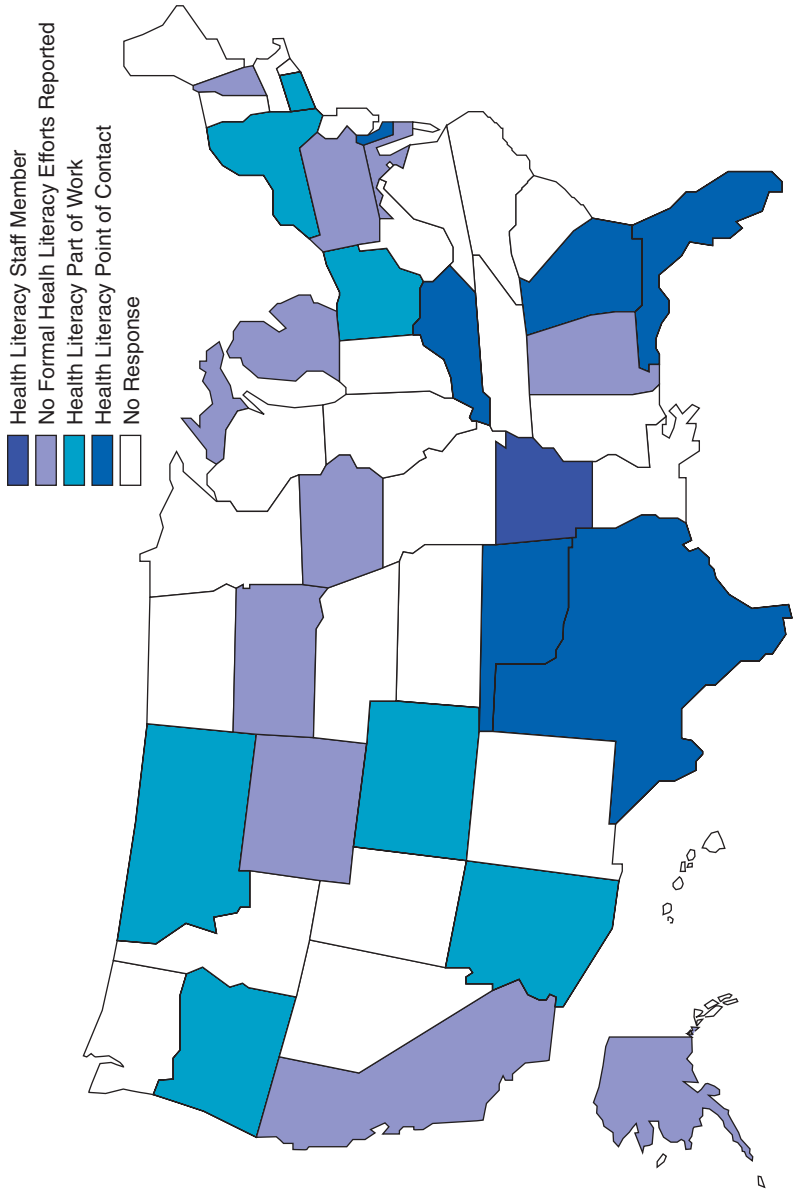


FIGURE 2-5 Health literacy within state departments of public health.
SOURCE: Pleasant, 2013.

When asked whether health literacy is an issue for the public only, public health organizations only, or both equally, 38 of 53 participants (72 percent) indicated that it is an issue for both. In response to questions about attributes of a health-literate organization (Brach et al., 2012a), most participants agreed that the attributes were part of their mission (see Table 2-2). Pleasant said the survey results indicate that most attributes are generally appropriate to a public health context as well as the clinical and medical contexts for which they were originally designed.

Pleasant reported that, in responses to questions about particular health literacy activities, more than half the participants said they were (see Table 2-3):

- rewriting materials to make them easier to read and understand (70.8 percent);
- developing an awareness of cultural competencies (70.2 percent); and
- training staff to communicate with clients in simple, clear language (55.3 percent).

Pleasant shared illustrative quotes from two survey participants:

1. I have been frustrated with the approaches and discussion of health literacy in my agency and in general. There seems to be a lot of misconceptions about how it impacts what we do—like we should be doing separate initiatives to address health literacy and then continuing to also do what we usually do rather than incorporating (health literacy) as an ongoing consideration as we work day to day.
2. Much of the research done is contradictory and far removed from public health practice and often uses approaches that are not realistic for the practice world. I think there needs to be work done to frame health literacy as the usual way of doing business, a core public health skill and not an addition or an exception for certain groups.

Dr. Pleasant made the following recommendations:

- Develop and implement a locally relevant, specific, measurable, actionable, realistic, and time-bound plan to increase the capacity to address health literacy across each public health organization.
- Require public health agencies to report on the health literacy status of the populations they serve on an annual basis.
- Create incentives through policy, funding, and regulations for public health organizations at all levels to engage with and demonstrate

TABLE 2-2 Perceived Relevance of the 10 Attributes of a Health-Literate Organization

10 Attributes of Health Literate Organization			
Likert Scale with Labels of Strongly Disagree (1), Disagree, Agree, and Strongly Agree (4) - Higher Than 2.5 Indicates More Agreement Than Disagreement	n	Average Response	Number of Participants Indicating Not Relevant to the Organization's Mission
Has leadership that makes health literacy integral to its mission, structure, and operations	61	2.9	0
Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement	61	3.0	0
Prepares the workforce to be health literate and monitors progress	61	3.0	2
Includes populations served in the design, implementation, and evaluation of health information and services	61	2.9	0
Meets the needs of populations with a range of health literacy skills while avoiding stigmatization	60	2.9	0
Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact	59	2.7	2
Provides easy access to health information and services and navigation assistance	59	3.0	0
Designs and distributes print, audiovisual, and social media content that is easy to act on and understand	58	3.1	1
Addresses health literacy in high-risk situations, including care transitions and communications about medicines	59	2.9	7
Communicates clearly what health plans cover and what individuals will have to pay for services	59	2.8	19

SOURCE: Pleasant, 2013.

TABLE 2-3 Health Literacy Activities Within Public Health Departments

Which Health Literacy Activities Has Your Public Health Organization Considered or Initiated?					
Three-Point Scale - Mean Higher Than 2 Indicates More Participants Reported Initiating Each Health Literacy Activity Than Have Not	Number of Participants Selecting (percentage of total)				
	N	Mean of Responses	Currently Conducting	Considered, But Not Conducting	Not Considered
Rewriting materials to make them easier to read and understand	48	2.6	34 (70.8%)	8 (16.7%)	6 (12.5%)
Developing an awareness of cultural competencies	47	2.6	33 (70.2%)	9 (19.1%)	5 (10.6%)
Training staff to communicate with clients in simple, clear language	47	2.4	26 (55.3%)	16 (34.0%)	5 (10.6%)
Training translators to communicate with clients in simple, clear language	46	2.2	20 (43.5%)	14 (30.4%)	12 (26.1%)
Rewriting signage so that it is visible and easy to understand	46	2.2	20 (43.5%)	14 (30.4%)	12 (26.1%)
Piloting new materials with members of intended audience	48	2.0	16 (33.3%)	18 (37.5%)	14 (29.2%)
Using health topics to teach literacy skills	46	1.9	13 (28.3%)	15 (32.6%)	18 (39.1%)
Adopting an organization-wide plain-language policy that promotes clear communication between provider and health care consumer	45	1.8	11 (24.4%)	15 (33.3%)	19 (42.2%)

SOURCE: Pleasant, 2013.

gains in public health through the explicit incorporation of health literacy into the entire spectrum of efforts to improve public health.

- Mandate that health literacy be included in curricula for all public health and allied health professions.
- Engage with public health organizations such as the American Public Health Association, Association of State and Territorial Health Officers, National Association of County and City Health Officials, National Association of Local Boards of Health, and Society of Public Health Educators to mandate training and evaluation of the health literacy awareness and skills of all public health professionals.
- Build and actively promote an open-access and evidence-based repository of the best practices of health literacy that have been proven to improve public health.
- Ensure that all future legislation addressing the organization and funding of public health efforts in the United States explicitly addresses the opportunities that health literacy presents to public health organizations.
- Launch and fund significant and nationwide efforts to explicitly improve the health literacy and literacy skills of all U.S. residents.
- Draft and adopt health literacy policies within all public health organizations.

Pleasant said that while the United States has conducted national assessments of literacy that sometimes include health literacy, there has never been a national literacy campaign. He noted that other nations have adopted health literacy policies within all public health organizations.

Pleasant noted that the 10th anniversary of the 2004 IOM report *Health Literacy: A Prescription to End Confusion* is this year (IOM, 2004). The main focus of that report is on clinical and medical applications of health literacy and does not adequately cover health literacy in public health, he said. He concluded his presentation by saying that the IOM report needs to be updated to help clarify the definition of health literacy, report on the research that has been completed in the past decade, and incorporate relevant materials to the field of public health.

DISCUSSION

Roundtable member Patrick McGarry from the American Academy of Family Physicians discussed an initiative under way to accredit public health agencies. The Public Health Accreditation Board has created standards and measures, one related to the need to document the provision of information regarding health risks, health behaviors, prevention, and

wellness. He noted that health literacy is mentioned once in this measure and, throughout the entire set of standards, there are only 14 references to literacy. McGarry asked the panel to comment on this situation and indicated that substantive advances could not be expected if public health practitioners and organizations are not held to health literacy standards.

Panelist and roundtable member Rima Rudd commented that the process of diffusion of innovation is slow and that similar lags in adopting evidence-based practices can be seen in medicine, dentistry, and any of the social service fields. She said that patience is needed and that the message has to be repeated. In addition, Rudd indicated that new partnerships had to be formed and that those in the health literacy field have to make themselves available to provide briefings and services. Furthermore, in Rudd's opinion, training programs should be made available at low or no cost. She continued by stating that those in the health literacy field must remain very active and continue to work to get the message out.

In response, Pleasant added that the diffusion of innovation model requires information leaders and champions. According to this model developed by Everett Rogers, Pleasant noted that such champions kick off the diffusion process. Pleasant added that in the 10 years since the release of the IOM report *Health Literacy: A Prescription to End Confusion* many information leaders and champions have emerged. These individuals can continue to work to reach a broader audience.

Panel member Chloe Bird suggested that standards are needed to evaluate health education materials. In her view, such standards could improve both materials intended for the general population, but also those designed to reach specific population groups. Bird observed that materials are often not evaluated and are therefore ineffective communication tools. Bird mentioned the work of a graduate student who evaluated the reports sent to women following mammograms. The student graded the reports, for example, on how well they communicated information that was actionable. The student determined that only about 5 percent of the reports came anywhere near being intelligible in terms of communicating what the result meant and what next steps were needed. The results were unexpected because this was an area where few thought there would be a problem. Bird said that in her experience, this example represents the tip of the iceberg.

Standards are needed, Bird said, but in addition it would be helpful to have a free, publicly available, centralized service where departments could report that their validated instruments and educational materials have met the standards. Unfortunately many people think developing materials for low literacy individuals is easy. She noted that it is actually complicated, so sharing information about validation and effective communication would be very helpful.

Torrie Harris from the Louisiana Public Health Institute said that one

of the Public Health Accreditation Board's standards focuses on culture and linguistic competency, an area that is closely aligned with health literacy.

Dean Schillinger from the University of California, San Francisco, and San Francisco General Hospital (part of the San Francisco Department of Public Health) said that public health departments operate under severe constraints, including the public's lack of understanding of public health and its role in health promotion and disease prevention. He suggested that reframing how the public thinks about public health is an important health literacy challenge. Schillinger reported that when he asks his patients about the role of the health department, they often say "that it is where you go to get your gonorrhea and Chlamydia checked out." To improve public support of public health institutions, Schillinger proposed that the image of public health needs to be reframed. There is a fundamental health literacy problem in translating the meaning and value of public health to the general public.

Pleasant agreed with Schillinger, but added that the public's misunderstanding of public health can be traced in part to the public health community. It is, in effect, a two-sided problem. He said the adoption of health literacy within public health is needed to change this fundamental lack of understanding of the role and mission of public health. He suggested that public health departments redirect their limited resources to health literacy. This investment would change public perceptions and allow them to realize greater public health gains.

Rudd added that the public's lack of understanding of the role of public health can also be traced to a lack of emphasis on the dissemination of findings. Public health departments and the Centers for Disease Control and Prevention (CDC) do an excellent job of tracking, monitoring, and gathering data. However, in her opinion, these organizations do not do as good a job translating the findings to the public. Bringing relevant findings to the public in understandable ways would highlight the efforts of public health. She added that such a strategy would highlight not only the identification of significant public health issues, but it would also communicate the important role of the public health community in addressing them. In Rudd's view, this is a perspective that the public is missing.

Rudd went on to discuss the need for community engagement and to act on the lessons learned from research in this area. Community members can be involved in the investigative process by simply asking, "What does this mean to you?" "What are the possible interpretations?" "Did we leave out any information?" "Does this resonate with you?" and "What are the possible solutions that occur to you?" In her experience, this type of dialogue engages populations and communities and fosters diffusion of innovation. In Rudd's view, the emphasis needs to shift away from the collection of data to the dissemination of data and to dialogue.

Bird discussed the importance of incorporating public health content into the educational curriculum in schools, as early as elementary school. In her view, children should receive instruction in both individual health and population health. There is science underlying both areas. Basic information about how vaccines work is an example of a topic that has both individual and public health dimensions. Some individuals are skeptical about the value of vaccines, but do not necessarily know enough to sort through the literature in a way that matches their own concerns about risks. Bird added that early education on how to access reliable information and then process that information to make informed personal decisions would greatly further health literacy. This lack of understanding on the part of the public has, in Bird's opinion, greatly undermined public health.

Roundtable member Winston Wong commented on the map Pleasant presented that illustrated the results of the survey of health literacy activities in public health departments. The map suggests that at least half of state public health departments lack a focus on health literacy. This, he said, indicates that health literacy is not a priority in terms of their ability to survive in the 21st century. Linda Neuhauser from the Health Research for Action Center at the School of Public Health at the University of California, Berkeley, in commenting on the results of the survey conducted by Pleasant, said that although there is usually no one person in most state health departments who can be identified as the health literacy champion or most knowledgeable person, she believes there are likely many health literacy-related activities going on in states, but it is very hard to get that information using a survey approach.

Alice Horowitz from the University of Maryland School of Public Health agreed, saying that although Maryland shows up on that map as not reporting any formal efforts to address health literacy, in fact there is a lot of activity at the State Health Department. For example, the state has a CDC grant to launch an oral health literacy campaign. Maryland has an oral health plan with one of the three focus areas being health literacy.

Torrie Harris from Louisiana said that many state health literacy activities take place in offices of health equity or minority health. She added that nearly all states receive federal funds to focus on the needs of underserved populations. These efforts may not have been represented in the survey. Pleasant agreed, saying the health literacy activities appear to be hidden, or at least not ascertained in the survey. Isham also agreed that information on health literacy activities appears to be hidden, but attributed this, in part, to poor communication on the part of the health department. He noted that more than half of the states did not reply to a request for information that was made through their listed public e-mail address or website portal. Pleasant added that there may be ongoing health literacy activities within public health departments, but if their activity does not have an identifiable

person who is responsible, then further progress, especially establishing partnerships, would likely be inhibited.

Wong asked the panel to comment on the recent controversy that was headlined in major newspapers, that is, guidelines on the use of statin drugs. Wong recounted how the guidelines relied on a risk calculator that, when applied to the American population, would put a large percentage of the American public on these medications to lower the risk of heart disease. Wong asked the panel to reflect on how a public health department could help in communicating the complex issues that underlie this controversy.

Rudd commented on the lack of rigor underpinning some public communication efforts. Critical to the success of such efforts is working with members of the intended audience. Pretesting messages can help determine if the appropriate language is being used and if the intended messages are comprehended and usable. Rudd described how in her work she has gained the most insights from the people who are going to be using the information. Neuhauser agreed with Rudd on her views regarding translational research. In her experience, she has found that what works is engaging the end users and stakeholders in the design, implementation, and interpretation of the research from the very beginning. She emphasized the need for such action-oriented research to effectively impact public health. Isham remarked that the controversy and confusion surrounding the cardiovascular guidelines indicates there was insufficient public health participation in their development and release.

Bird reiterated Wong's concern about the misunderstanding of the guidelines on statin use. In her experience, many are assuming that the problem of heart disease in the population will go away with the change in guidelines. What is not appreciated is that if people do not understand why they need to be on statins and why there has been a shift in concern about cardiovascular disease, there could be unintended consequences of the guidelines. One factor that led to the change in the guideline recommendations is the growing awareness that as longevity increases, individuals will eventually develop heart disease, Bird said. The challenge is how to communicate both short-term and long-term risk. If the public does not understand these concepts, there is the potential to greatly further increase racial, ethnic, and gender disparities in health outcomes. Bird pointed out that more men take statins and benefit from them than women. This issue has not been well researched.

Bird added that one area that has received attention is informed consent. In her view, there has been little progress in obtaining well-informed research consent from potential subjects. She shared an example of a potential research subject who Bird had taken through the consent process and then was asked to explain to Bird what consent meant to her. This subject said to Bird, "Well, apparently if you pick my one arm, I get surgery, and if you pick my other arm, I get something else, but I don't know why you're

using arms.” This example illustrated for Bird the need to ask, “What does it mean for you?” to ensure that communication has succeeded. Pleasant added that the research conducted within the intended audience is relatively inexpensive and has tremendous benefit. Bird observed that the consent process is too often not focused on communication, but is instead completed to meet legal obligations. She added that consent may have to be completed on an emergent basis, which limits the ability to effectively communicate.

Shanpin Fanchiang from Rancho Los Amigos National Rehabilitation Center (one of the four public hospitals in the County of Los Angeles) suggested that health literacy has come a long way. She mentioned the consideration of health literacy in the County of Los Angeles Patient Safety Committee’s efforts to improve medication safety. She also cited an example of the incorporation of health literacy into public health communications, a webinar, and print materials developed by AARP in collaboration with the American Occupational Therapy Association. The topic related to the need for adult children to talk to their parents about safe driving. In her view, these materials were very effective and incorporated principles of health literacy. She reiterated the need to focus on action-based information because there is a mindset of “we will lead you to the water, but we are not going to force you to drink.” Some members of the public hear public health messages and say, “yeah, yeah, yeah . . . just tell me what I need to do.” Messages can be constructed to provide actions that individuals can take.

Fanchiang went on to describe an important opportunity to further health literacy. The National Committee for Quality Assurance has developed a Patient-Centered Medical Home standard. According to the standard, health care providers need to present information about resources to patients and to document the patient’s response and their intended course of action. Such standards and a focus on professional training and public education will contribute to patients being able to navigate their own health care.

Rudd identified a need for new innovative communication strategies. The assumption that putting a query in writing will elicit the needed response or that health educational materials given to people will produce the intended behavioral change is naïve, she said. The circumstances under which the messages are delivered and the financial implications of the desired action may inhibit compliance. Rudd suggested that some barriers to communication could be overcome if communication experts were involved. She described an experience in 2004 of mailing a guide on hosting health literacy forums to state and local departments of public health. The use of the mail as a dissemination strategy was not successful. The need for communication experts is especially needed with the newer means of communication such as Twitter.

Isam commented that Bird presented informative examples of mapping that illustrated how people are affected whether they reside in a high or low health literacy area. He asked if there was an example of an intervention that has changed the level of health literacy in an area. Bird replied that the mapping work at RAND has focused on informing health plans or other organizations on how to target and customize health-related messages. For example, health plans may need to communicate information on health risks and prevention, how to get information from the pharmacist about prescriptions, and how to come prepared for a health appointment. Bird said health plans cannot ignore health literacy given the consequences. She cited the example of parents misunderstanding the directions for using prescription lice shampoo and administering it to their child orally, something that can lead to seizures.

Bird added that in addition to health consequences, there are financial consequences of poor communication, for example, those related to missed appointments. Patients may miss appointments unintentionally because they do not understand the scheduling information or directions mailed to them. Likewise, valuable health care resources are lost when patients do not understand how they were supposed to prepare for an expensive test or procedure. When providers experience these consequences of low health literacy and problematic areas can be mapped, then health plans can see the value of investing in resources to, for example, target follow-up phone calls to these areas to go over orally with a patient how they plan on getting to the appointment and what it means to come to the appointment prepared.

Rudd mentioned work completed in the 1990s for the Department of Education by Steve Reder, an adult educator and linguist from Portland State University. He used the 1992 statistics on adult literacy in the United States to develop computer models and identify pockets of low literacy. He did this for every state and for regions within states. He also provided an analysis of literacy skills within every municipality in every state. According to Rudd, Reder hoped this information would inform policy and funding for adult education. Rudd observed that adult education is an area that is less developed and receives less public support than public health. Rudd said that collaborations between those engaged in health literacy and those working in the area of education could be very fruitful.

Isam noted that some of the respondents to the health department survey were using different definitions of health literacy. He asked Pleasant if it was time to reconsider and redefine health literacy. Pleasant said that from both a research and policy perspective, it would be helpful to further develop the definition of health literacy. For example, he mentioned the disconnect between existing health literacy screeners and the current definitions as a barrier to measurement. He stated that good measures are necessary when evaluating the adoption of new policies and programs and good

evidence of the success of interventions is needed to shift decision making at all levels of government.

Isham observed that there are differences of opinion on how to intervene to improve health literacy. On the one hand, there is the skill level of the individual. On the other hand, there is the complex interface between the individual and a public health system or professional. Isham raised the recent example of the difficulties individuals faced when trying to navigate the website to sign up for health insurance under the Patient Protection and Affordable Care Act (ACA). The system had technical shortcomings and some of the concepts underlying the purchase of insurance are complex. Isham said that only the most persistent and well-educated individuals were likely going to be able to navigate the system until these issues are resolved. He asked the panel if enough emphasis is being given to simplifying the design of systems, their interfaces, and the language that is used within these systems.

Both Bird and Pleasant stated that not enough attention is being paid to these issues. Rudd also agreed, but stated that the tools available to address these issues are not being used. She highlighted the tool developed by the Agency for Healthcare Research and Quality for assessing websites from the perspective of health literacy. The problem again is lack of diffusion. She indicated that more efforts are needed to discuss, convince, and promote these opportunities. Pleasant added that given the success of the IOM 2004 report *Health Literacy: A Prescription to End Confusion* that a revised and updated report could further impact both clinical and public health systems. Isham added that some members of the Roundtable might want to revise the Brach et al. (2012b) document on the attributes of health-literate health care organizations to give further emphasis to this issue.

In response to Rudd's comment on the need to use available tools, Schillinger described his experience completing his medical training during the peak of the AIDS epidemic. He witnessed how a health department effectively partnered with an empowered citizenry. At this time, the gay community was extremely active in driving the research agenda and in shaping how the health department created messages to reach affected communities. This collaboration was instrumental in achieving much success within a decade. Schillinger added that it was an incredible example of how an affected population and an open-minded health department can create dialogue. He added that this collaboration was not without tension and conflict, but in his view, it led to a miraculous outcome in less than a generation. Schillinger suggested that there are lessons to be learned from other models, such as in the areas of tuberculosis control and improving perinatal outcomes in the developing world.

In response to Schillinger's description of the successes attained in HIV/AIDS, Bird said the achievements were due, in part, to the efforts

of a highly educated, literate, well-insured population familiar with ways to affect policy. Rudd added that these lessons of engagement have been passed down from one movement to another. For example, she mentioned that the HIV/AIDS activists learned strategies from the civil rights movement. Women organizing around breast cancer issues went to San Francisco to learn from the HIV/AIDS activists. The environmental justice movement has also benefitted from, and provided guidance to, others. Rudd noted that these movements are not necessarily dependent on highly educated individuals. Pleasant agreed and said that his organization, the Canyon Ranch Institute, is working with partners in the South Bronx to change the way products, such as sodas, are displayed and sold across the community. The goal is to have healthy choice products given the same shelf space as less healthy choices, for example, products with high fat and sugar content. Such efforts can emerge from within the public health community and from within clinical institutions. He said, “We don’t have to wait for an empowered community.”

Kathryn Atchison from the University of California, Los Angeles, discussed the need to involve youth in the development of health literacy tools. Their expertise and facility with new technology can be harnessed. She cited the example of engineering students gathering to develop tools for individuals with disabilities. In addition, a group in Northern California, called Health Sherpas, developed in 3 days a free Web-based tool to help individuals find and sign up for health insurance under the ACA (<http://www.thehealthsherpa.com>). Atchison stated that young people are well suited for developing appropriate tools for the variety of informational platforms now available.

Marie Fongwa from the Azusa Pacific University School of Nursing suggested that individuals be educated and trained to take the results of translational research and put it into practice.

Isham referenced a series of IOM reports on public health (IOM, 2011a,b, 2012). The reports conclude that public health is underfunded and make several recommendations, including that

- an additional \$12 billion be spent on public health incrementally;
- a mechanism for raising that revenue be devised; and
- a minimum set of essential services available through public health agencies be established.

Isham said it would be helpful to consider the role that health literacy might play in such a minimum set of essential public health services. He concluded by acknowledging the difficulties facing public health, but said that most of these difficulties could be traced to their diminishing financial support.

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3

Current Health Department Efforts in Health Literacy

LOUISIANA

*Torrie T. Harris, Dr.P.H., M.P.H.
Louisiana Public Health Institute*

The Louisiana Public Health Institute (LPHI) provides support to governmental public health through technical assistance and additional support with staff, sharing data, and stakeholder meetings, according to Torrie T. Harris. The LPHI was founded in 1997 as a 501(c)(3) nonprofit organization and is based in New Orleans. The LPHI's mission is to promote and improve health and quality of life through diverse public-private partnerships with government, health care delivery systems, foundations, academia, community groups, the media, and private businesses at the community, parish, and state levels. Through these partnerships, LPHI fosters innovation and leverages resources to address current and emerging health issues by providing expertise in the following areas:

- Fiscal and administrative management
- Population-based health program delivery
- Community health
- Mental health
- School health and wellness
- Health policy development, implementation, and evaluation
- Training and technical assistance
- Research and evaluation

- Health information services
- Health communications and social marketing
- Convening/partnering

One of the advantages of being in a small, nonprofit organization such as the LPHI, Harris said, is the lack of bureaucracy and the ability to save time when processing grants and contracts.

There are 37 public health institutes (PHIs) across the United States (25 operating PHIs, 6 provisional and developmental PHIs, and 6 affiliate members). These organizations make up the National Network of Public Health Institutes (NNPHI). NNPHI was established in 2001 with funding from the Centers for Disease Control and Prevention (CDC) and the Robert Wood Johnson Foundation. The NNPHI provides a forum for learning for PHIs across the country and fosters the development of emerging institutes nationwide.

The Louisiana PHI has two main divisions, health systems and community health. The health systems division, which is responsible for the primary care and behavioral health programs, has several ongoing areas of activity, Harris said. For example, a health information exchange was created in New Orleans using a grant from the Centers for Medicare & Medicaid Services (CMS). With support from Johnson & Johnson, a program was launched to integrate mental health services into primary care clinics across New Orleans. The Kellogg Foundation is supporting School Health Connections, a program that allows schools to hire a school health coordinator and maintain the staff person for 3 years. A school-based health coalition addresses health issues throughout the community. A “4 Real Health Teen Pregnancy Prevention Project” trains youth on sexual health topics. Harris said that although teaching reproductive or sexual health is not permitted in Louisiana schools, the program aimed at reproductive health training is allowed because it is offered in the summer as part of a summer enrichment program. She added that Louisiana has the second highest rate of HIV infection in the nation. Another PHI program is the Louisiana Positive Charge initiative, which links newly diagnosed individuals and persons living with HIV infection who are not in care to HIV primary care. Patient-centered approaches used within this program include assessing clients for basic health literacy and for their knowledge of HIV/AIDS, medication management, and other aspects of care.

One project in the community health division is Fit NOLA, an initiative to tackle obesity and the lack of physical activity in New Orleans. The city government is promoting this program as a way to improve Louisiana’s health ranking from 50th in the nation in 2013 to 18th, Harris said. The LPHI is working with government partners to try to meet this ambitious goal. The Fit NOLA project has a steering committee that is focused

on physical activity and obesity and the mayor and health commissioner engage nontraditional partners (e.g., the business community) as partners in this effort. Harris said New Orleans is well known for its food and celebratory atmosphere, aspects of the culture that have negative consequences in terms of obesity. Other barriers to healthy behaviors in New Orleans include natural disasters and a rainy hurricane season that discourages outdoor exercise. Blue Cross Blue Shield has provided a challenge grant to support communities across the state to enact similar projects focusing on physical activity and obesity.

Harris said another effort of Fit NOLA is the collaboration among a community health clinic, Tulane University, a farmers' market, the police department, and a number of other organizations. This effort offers diabetic patients and their support groups doctor-prescribed prescriptions for fruits and vegetables. This approach gives patients a voucher that is redeemable at the local farmers' market and is worth double its value.

Harris said the New Orleans Recreation and Development Commission is working, with community input, to enhance the infrastructure of parks in low-income neighborhoods. A technical assistance effort to increase the number of bike paths in cities and to improve pedestrian safety by enhancing infrastructure of streets and roads is run by the Center for Community Capacity.

Another project in the healthy communities portfolio is a mapping project, Harris said. A website, HealthyNOLA.org, provides information on health outcomes in the 72 neighborhoods in New Orleans. Neighborhood liaisons help people navigate the website to ensure that the information is correct. Harris said the website is intended as an empowerment tool to assist individuals in making a difference in their own neighborhoods.

The Gulf Region Health Outreach Project, Primary Care Capacity Program is supported with funds from the Gulf Coast oil spill British Petroleum medical settlement. To enhance primary care capacity, Harris said that the LPHI is focusing on improving health information systems, hiring mental health specialists, and increasing the capacity of federally qualified health centers and similar clinics across the Gulf Coast to provide patient-centered medical homes for their patients. Health literacy and community asset mapping is included to help the health departments with their public health improvement plans, community health assessments, and obtaining accreditation from the Public Health Accreditation Board.

Another program is the Louisiana Campaign for Tobacco-Free Living, which is a statewide tobacco control program funded by the cigarette excise tax. This program implements and evaluates comprehensive initiatives that prevent and reduce tobacco use and exposure to secondhand smoke. Harris said that efforts are under way to reach several target audiences, including communities of color, colleges and universities, youth ages 11 to 17, musi-

cians, and service industry employees. In Louisiana the *Smoke Free Air Act* covers restaurants that only serve food. If there is a bar in the restaurant, smoking is allowed in outdoor areas. In bars that do not serve food, smoking is permitted. Harris said many restaurant workers and musicians are inhaling secondhand smoke. A component of the program's multimedia campaign is a website that targets musicians and service industry employees (<http://www.letsbetotallyclear.org>). The Louisiana Cultural Economy Foundation, an organization that supports Louisiana cultural workers, is involved in this initiative. These are examples of how the PHI's Media and Communication Division and the Research and Evaluation Division complement programmatic activities.

Harris concluded her presentations by saying that PHIs can complement and support the work of public health departments because they are able to advocate for health policies. PHIs are also able to meet with decision makers to educate and inform them on community health issues that may affect their constituents.

NEBRASKA

*Susan Bockrath, M.P.H., CHES
Nebraska Association of Local Health Directors
Outreach Partnership to Improve Health Literacy*

Bockrath said that Nebraska is large—about half the size of California with one-tenth of California's population density; about 14 percent of the population is elderly (a somewhat higher percentage than the national average) and the state lacks ethnic and racial diversity relative to many other states (i.e., 90 percent of the population identified as white in the most recent Census). There is a growing Hispanic population and estimates predict that Hispanics will make up about a quarter of Nebraska's population by 2050. There is also a sizable refugee community, with Omaha having the largest population of Sudanese individuals outside of Sudan. Omaha is home to a large African American community. There are also four native tribes in Nebraska.

Health Literacy Nebraska was founded in May 2011. A statewide summit was held in January 2012. Since then two working groups have been formed. The first has focused on training and developed the "Plain Language on the Plains" quarterly webinar. The second working group has identified health literacy questions to be incorporated into the CDC Behavioral Risk Factor Surveillance System (BRFSS) survey for Nebraska (see Box 3-1). The results of the survey will be used to create a map of

BOX 3-1^a
Behavioral Risk Factor Surveillance Survey
Health Literacy Items

1. How confident are you filling out medical forms yourself? For example, insurance forms, questionnaires, and doctor's office forms?
 - a. Not at all
 - b. A little bit
 - c. Somewhat
 - d. Quite a bit
 - e. Extremely

2. How often do you have problems learning about your health condition because of difficulty understanding written information?
 - a. Always
 - b. Often
 - c. Sometimes
 - d. Rarely
 - e. Never

3. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
 - a. Always
 - b. Often
 - c. Sometimes
 - d. Rarely
 - e. Never

^a Following the workshop the questions were pilot tested. After consultation with content experts on the pilot test results, Health Literacy Nebraska revised the questions. The revised questions may be found in Appendix D.

SOURCES: Adapted from Chew et al., 2008, and Morris et al., 2006.

health literacy and to analyze the relationship between health literacy and negative health outcomes.

Bockrath said the overriding goal of Nebraska's Outreach Partnership to Improve Health Literacy (funded through the Health Resources and Services Administration [HRSA] Office of Rural Health Policy) is to improve literacy at the local level in all of Nebraska's 93 counties. These counties are served by 21 local health departments. Many of the local health departments are responsible for large geographic areas, some as large as the state of Maryland. Nebraska's public health system is decentralized in the sense that all of them are stand-alone agencies. Sixteen rural health departments

are participating in the project and are responsible for 83 of the 89 designated rural or frontier counties in the state. Nebraska's three urban districts are currently not able to receive direct services from the project because the funds are exclusively for rural jurisdictions.

Bockrath said the project began with a needs assessment conducted through a survey and site visits. Results of the assessment led to a focus on the following objectives for the 3-year project:

1. All written communication and materials are health literate and at an appropriate reading level for the intended audience.
2. Regularly use a functional, user-friendly system of sharing and collaboration related to all focus areas, across all rural local health departments and tribal health departments.
3. Address language access for all audiences using health-literate strategies.
4. Health-literate practice is implemented throughout the public health system.

Bockrath said that site visits and technical assistance have been offered to 19 sites. One hundred forty-four local health department staff and directors participated in onsite training and qualitative data gathering. One of the project's most successful activities, Bockrath said, has been the conduct of five health-literate writers' workshops. A total of 77 local health department staff participated in these all-day events held in various locations across the state. During the workshops, staff work on their own health information materials. The workshops include a didactic session, where an overview of health literacy is provided, but the emphasis is on the local level and review of local materials. Bockrath said these workshops have been well received.

The project also sent eight people to the Institute for Healthcare Advancement's Health Literacy Conference in May 2013. In addition, software licenses for Health Literacy AdvisorTM and hard copy "Starter Kits" have been distributed to all of the local health departments.

To improve communication and collaboration, Bockrath said the project's infrastructure has been strengthened in several ways. Improvements have been made to the Nebraska Association of Local Health Departments website and an internal listserv was created to facilitate direct communication with staff, directors, and partners. The project also purchased GoToWebinarTM software that is being used to enable web-based collaborative document review. According to feedback obtained from the writers' workshops, staff want to be able to continue to work across the state with their partners and with counterparts in other health departments. In

response, Bockrath said regular collaboration opportunities will be set up using this software.

Bockrath said the project is also applying health literacy to the task of addressing language access. The project will cosponsor a conference highlighting health literacy and cultural competency during the summer of 2014. In other areas, training is planned to better prepare the local health department staff to spread the word about health literacy. The goal is to have local health department personnel talking to their partners about health literacy as it pertains to their local clinics, hospitals, and other service sites. During the third year of the project, all of the project health departments will be developing their own pilot projects.

Bockrath discussed the applicability of the attributes of health-literate health care organizations¹ to her work with local public health organizations. The first three attributes, that among other things address leadership, planning, and workforce development, are directly applicable to Nebraska's public health departments, she said, especially as these issues are at the heart of their grant project. Leadership within Nebraska's local health departments has embraced health literacy because it is viewed as providing great returns on investment for clients, Bockrath said. Efforts continue at the local level to connect health literacy to ongoing work in the area of quality improvement and to create policies on health literacy.

Some of the attributes are not being met, Bockrath said. For example, the attribute related to the inclusion of "populations served in the design, implementation, and evaluation of information and services" is not being addressed systematically by Nebraska's local health departments. Results from the survey conducted before the initiation of the grant-funded interventions found that less than one third of staff had been testing or developing materials with target populations. At the time of the survey, respondents tended to rate their health department's health literacy capabilities fairly high. When asked whether they were meeting the needs of populations of various literacy skills, 43 percent reported that they were. Bockrath hypothesized that if the survey were conducted again, the health departments would likely rate themselves less favorably because they have since learned, through workshops and training, some of the better approaches used to achieve improved outcomes.

Nebraska's local health departments have not always included the populations served when designing and implementing programs, Bockrath said. This deficit is, in her view, explained by a lack of resources and the fact that involving target audiences in this work is time consuming and resource intensive. The need to travel vast distances to reach target populations in

¹ The 10 attributes can be found in the discussion paper *Attributes of Health Literate Health Care Organizations* at <http://www.iom.edu/health-lit-attributes> (accessed July 25, 2014).

many parts of the state is also a barrier. Sometimes, a coalition partner who represents a group of interest serves as a proxy for the intended audience. This individual is asked if a particular communication is effective. Bockrath suggested that these coalition partners need to be asked to take the next step and involve the members of their community.

Through the survey and site visits conducted early in the grant cycle, Bockrath found inconsistent use of health literacy techniques such as the “Teach-Back” method. She said that “usability testing” could be a proxy for teach-back at the population level. She added that the survey found deficits in terms of having written materials available to meet the needs of individuals with limited English proficiency.

Many of Nebraska’s local health departments do not provide direct clinical services. The organizational attributes that have been developed that emphasize clinical services are less applicable to those public health departments.

Bockrath concluded her presentation by saying that many aspects of the attributes of health-literate health care organizations are relevant to public health departments. In her view, language access issues need to be further highlighted. It is a topic that is central to both health literacy and cultural competency. She added that it would be helpful to integrate initiatives aimed at furthering health literacy and cultural competency and to identify language access as a good place for public health departments to start.

ARKANSAS

*Jennifer Dillaha, M.D.
Arkansas Department of Health*

Dillaha described the Arkansas Department of Health as a unified health department, with its main office in Little Rock overseeing 94 local health units in Arkansas’ 75 counties. All staff in local health departments are employees of the state of Arkansas Department of Health. The department is divided into centers. The Center for Health Advancement is responsible for most of the state’s health promotion programs. The Center for Local Public Health operates all the local health units in the state’s five regions.

Arkansas has a population of nearly 3 million and a relatively high poverty rate (fifth in the nation), but about the highest in terms of child poverty. The state is also characterized by a high rate of disability; poor health status; low levels of educational attainment; and low rates of Internet usage. Dillaha said that it is estimated (using the RAND predictive model)

that 37 percent of adults in Arkansas have low health literacy (defined as basic and below basic health literacy).²

Dillaha reviewed the origins of the health literacy movement in Arkansas. In 2007, Dillaha, as director of the Center for Health Advancement, became aware that people could not access, understand, and use available health information. After reading the Institute of Medicine report *Health Literacy: A Prescription to End Confusion* (IOM, 2004), she partnered with a local pediatrician, Chad Rodgers, who had received health literacy training through the American Medical Association, to disseminate information on health literacy. They gave a presentation at a 2007 public health grand rounds on health literacy, which ignited interest and caused a ripple effect. Over the next year and a half, Dillaha identified people and organizations interested in health literacy.

In 2008 health literacy was integrated into the strategic plan for the Arkansas Department of Health, Dillaha said. The current version of this plan, shown in Figure 3-1, has health literacy identified as a crosscutting strategy.

Dillaha highlighted two important events that occurred in 2009. First, the Partnership for Health Literacy in Arkansas (PHLA) was formed at a meeting sponsored by the Arkansas Department of Health, Arkansas Literacy Councils, University of Arkansas Division of Agriculture Cooperative Extension Service, and Arkansas Children's Hospital. Second, the Partnership became the official Health Literacy Section of the Arkansas Public Health Association. This organization provides interested partners with a fiduciary umbrella and access to other important resources. Since 2009, Dillaha has given a number of talks to interested parties, including the Governor's Roundtable on Healthcare, health care providers through the HRSA-funded Arkansas Geriatric Education Center, staff of the University of Arkansas for Medical Sciences Area Health Education Centers, Federally Qualified Community Health Centers, geriatric clinics that are part of the Arkansas Aging Initiative, and additional talks at public health grand rounds.

Dillaha said PHLA has implemented health literacy interventions aimed at improving health outcomes in three domains: culture and society; the health system; and the education system. In 2013 the Partnership sponsored an all-day conference on adult education that benefitted from the participation of Winston Lawrence from the Literacy Assistance Center in New York and Greg Smith from the Florida Literacy Coalition. In 2014 the conference will focus on health literacy for older adults with the assistance of Michael Villaire from the Institute for Healthcare Advancement.

² See presentation by Chloe Bird on page 10 for a description of RAND's predictive model for health literacy and its mapping project.

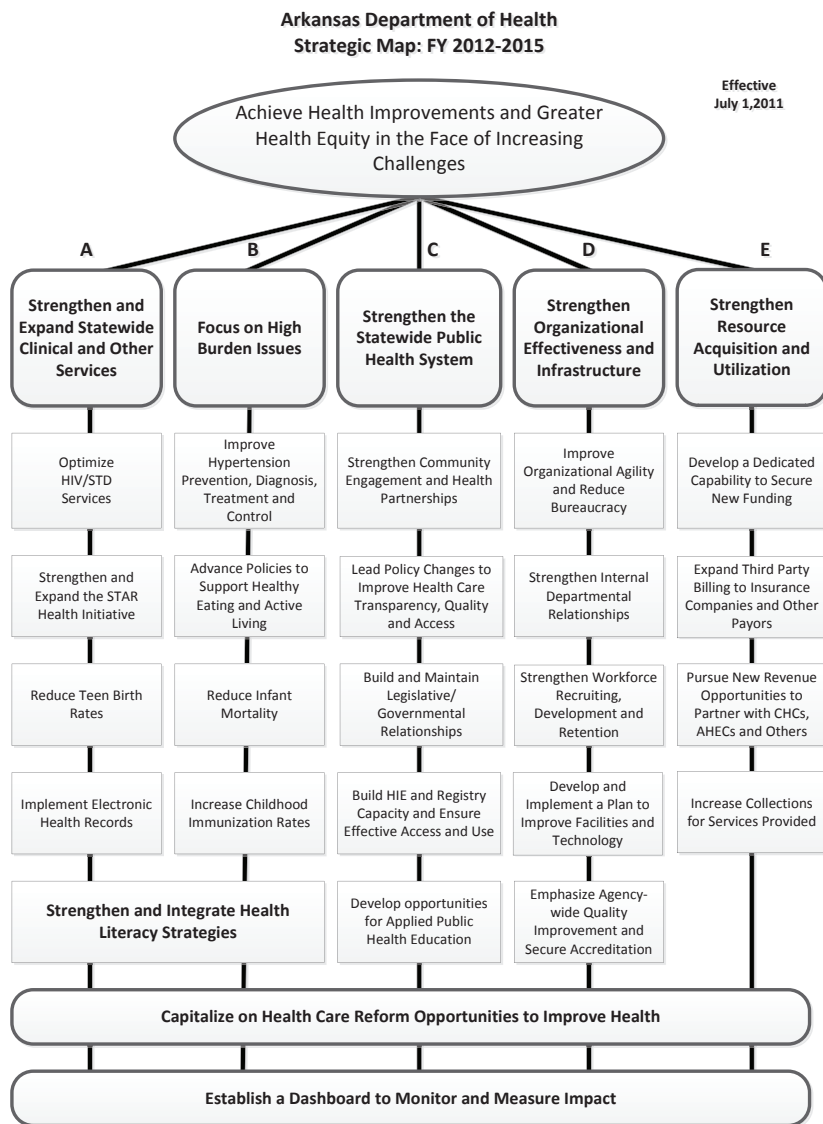


FIGURE 3-1 Arkansas Department of Health strategic map.
SOURCE: Arkansas Department of Health, 2013.

Various programs within the Arkansas Department of Health have integrated health literacy into their planning and programs, Dillaha said. For example, the Chronic Disease Branch has used CDC funds to expand the ability of the Arkansas Literacy Councils to empower patients, especially in the area of health promotion and prevention with the use of the Staying Healthy Curriculum from Florida, which teaches health vocabulary and concepts to new readers and to English language learners.

The Family Health Branch of the health department has implemented home visiting as a strategy that supports health literacy, Dillaha said. With funding available through the Patient Protection and Affordable Care Act, a Nurse-Family Partnership program was initiated following the David Olds model,³ which Dillaha described as being primarily a health literacy intervention. Arkansas Children's Hospital, in partnership with the Department of Health Family Health Branch, also received funding to establish the Arkansas Home Visiting Network, which includes a focus on health literacy. Also, the Arkansas Women's Health Program worked with Health and Human Services Region VI on the Health Equity Partnership, which integrated health literacy into family planning materials.

Another health literacy effort is the Coordinated School Health initiative, which Dillaha described as a partnership that includes the Arkansas Department of Health, the Department of Education, and many other organizations focused on education. This initiative aims to bring school-based health promotion efforts under one coordinating umbrella. Through this initiative, Arkansas Children's Hospital is making HealthTeacher available to all of the public health schools in the state by the end of 2014. HealthTeacher is a K through 12 health education curriculum specifically designed to advance health literacy. The HealthTeacher curriculum is already available to all of the state's Catholic schools through Arkansas Children's Hospital's partnership with Mercy Health.

As part of CDC's National Public Health Improvement Initiative, Dillaha said that three initiatives are under way in Arkansas: a Plain Language Quality Improvement Project; a Health Literacy Research Conference; and an effort to work on the state's public health accreditation. The Plain Language Learning Community, a group of Health Department staff facilitated by the Health Department's Office of Health Communications and Marketing, advocates for improving communication through the use of plain language. Their recommendations are being implemented across the department, Dillaha said. Health literacy research conferences were held in 2011 and 2012

³ "The Nurse-Family Partnership (NFP) is a program of prenatal and infancy home visiting by nurses for low-income first-time mothers." http://www.brookings.edu/~media/research/files/reports/2010/10/13%20investing%20in%20young%20children%20haskins/1013_investing_in_young_children_haskins_ch6.pdf (accessed February 20, 2012).

and featured Andrew Pleasant and R. V. Rikard as speakers. The CDC grant also provided funds to obtain estimates of health literacy levels using the RAND methodology so that county level and Census-tract level data would be available to researchers. The research conference has been transferred to the University of Arkansas for Medical Sciences Translational Research Institute. This institute now holds quarterly health literacy research grand rounds that have featured presentations from health literacy experts such as Terry Davis and Michael Wolf.

Dillaha said the health literacy community is working to provide training for health care providers to implement the Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit throughout Arkansas. Providers trained in implementing the toolkit include the University of Arkansas for Medical Sciences Regional Centers (Area Health Education Centers); clinics participating in the Arkansas Chronic Illness Collaborative; 69 primary care clinics participating in CMS' Comprehensive Primary Care Initiative; and some clinics and staff at the University of Arkansas for Medical Sciences. Plans call for training to be made available to the Arkansas Department of Health's local health units, as well as to the state's Federally Qualified Community Health Centers.

Dillaha said the State Health Assessment and State Health Improvement Plan, a document that was completed as part of the public health accreditation process, focuses on three areas: life expectancy, infant mortality, and health literacy. This document is available at the health department's website (<http://www.healthy.arkansas.gov>).

Creation of the Arkansas Action Plan to Improve Health Literacy is a dynamic process, Dillaha said. The goals of the National Action Plan to Improve Health Literacy (http://www.health.gov/communication/hlactionplan/pdf/Health_Literacy_Action_Plan.pdf) were adapted to meet the unique needs of Arkansas. The partners throughout the state are setting their own objectives, which will be tracked. This work in progress can be found at the Partnership for Health Literacy in Arkansas' website (PHLA.net). The Action Plan's seven goals are as follows:

1. Make health and safety information easy to understand so that people who need it can get it and use it to take action.
2. Make changes that improve the health literacy of the health care system.
3. Include health literacy in the lesson plans for all children in Arkansas, from infants through college students.
4. Work with the adult education system and other organizations in Arkansas to improve the health literacy of the people in the communities they serve.
5. Build a network of health literacy partners committed to making

changes at their organizations that will improve health literacy in Arkansas.

6. Do research to better understand and measure what works to improve health literacy of the public and the health care system.
7. Share and promote the use of health literacy practices that are based on the best science available.

Dillaha shared some of the lessons learned from her experiences in Arkansas. She emphasized the importance of establishing an understanding of health literacy that is widely accepted. The Arkansas partnership has not developed a single definition, but rather describes what health literacy is. In her experience, many individuals have a health literacy story to share. In an era of constrained resources, efforts to improve health literacy need to be implemented using resources currently available, which may mean using current resources differently and following health literacy principles. The experience in Arkansas has also reinforced the importance of supporting health literacy partners and helping them reach their goals, Dillaha said.

Merely increasing awareness of the problem of low health literacy is insufficient to improve it, Dillaha said. She pointed out that greater capacity is needed within health departments to address health literacy. An important strategy for improvement, she said, is the identification and support of change agents. These are people who can operate in their own spheres of influence and are key to developing partnerships, promoting systems change, and stimulating new thinking.

DISCUSSION

Pleasant began the discussion of the panel's presentations by thanking the representatives from Arkansas, Louisiana, and Nebraska for sharing their experiences and serving as case studies for the commissioned paper (at the end of this report). In his view, the work within these three states represents stellar examples of how health literacy can be integrated into public health departments across the country.

Roundtable member Patrick McGarry asked Bockrath about the state-specific health literacy questions that will be added to the BRFSS. How were the questions formulated and how will they be used? Bockrath replied that the questions were adapted from those developed through the research of Chu and Wallace. She pointed out that Health Literacy Nebraska, and not the State Health Department, is paying for the addition of the three questions. These same three questions were included in Kansas' BRFSS survey in 2012. This will allow some cross-border, Nebraska-to-Kansas comparisons. Bockrath stated that the usefulness of the information will be assessed and, if deemed of value, the hope is that the state will want to pay for the inclu-

sion of these survey items on a regular basis. In her view, the BRFSS data will be useful in raising awareness of the problem of low health literacy. She still finds areas where decision makers are in denial in terms of the existence of the problem. Second, she stated that the data will be useful in demonstrating the value of low health literacy in predicting negative health outcomes. Bockrath said the BRFSS survey could also provide important information on whether public health communications are improving.

Rudd observed that the term “case study” gives the false impression that a unique experience is being described. In fact, the three cases offer a lesson in how to integrate health literacy throughout a state. She asked the panel whether there was a way to identify the steps along this pathway to integration that other states could take. She specifically asked the panel to respond to two potential actions that could theoretically be taken. First, could a requirement be put in place for all employees of public health departments, whether state or local, to take a short online course in health literacy, such as the one developed by CDC? Such a course could be required of all existing staff and part of the orientation for all incoming staff. Second, would it be possible to have a regulation that all contractors with departments of public health who are responsible for the design of websites and health education materials show evidence of meeting certain criteria, for example, that they pilot test materials with the intended audience?

Harris shared her experiences as the director for Health Equity in Kentucky. While there, she worked with the commissioner and the Workforce Development Division on staff training. A webinar about cultural and linguistic competency as related to health equity was designed, called Train. Staff were required to take the webinar and brown bag lunches were offered to complement the webinar. Most public health departments have access to this webinar. Harris added that to implement such a policy, it is important to encourage decision makers and work with human resources entities. She added that the implementation of such policies takes time.

In terms of contractors, Harris stated that it would be necessary to work with staff who develop health system contracts. When Harris was involved in the state’s Tobacco-Free Living Program, she created a standard that required the input from the diverse populations targeted by the messages on panels set up to develop plans and messaging. There was a history of issuing messages that did not reflect the needs of high-risk populations. The new policy helps to ensure that vendors and contractors have a diversity perspective.

Dillaha questioned whether a mandate such as those proposed by Rudd would be workable. She has found that it is most helpful to make training accessible and then to encourage participation. Arkansas is a relatively poor state with serious information technology infrastructure issues. For

example, she said the state purchased 10 licenses for the Health Literacy AdvisorTM software and made sure that at least one person in each region had access to the program. However, the software could not be used because of computer systems incompatibility.

Dillaha said a state agency outside of the health department is responsible for the development of websites. Given the volume of their work, it is difficult for them to adequately address the needs of the health department. As a result, a staff member at the Office of Health Communications and Marketing taught herself HTML so that the website-based needs of the department could be met. Dillaha added that this individual is part of the plain-language learning community and receives requests to perform readability analyses for online content. Dillaha concluded that some health departments would not be able to implement a mandated training requirement, given their lack of staff and expertise. In her view, developing the infrastructure and growing the expertise are priorities. Bockrath added that having such infrastructure and expertise could be adopted by health departments as a best practice goal.

Dogan Eroglu from the CDC's Office of the Associate Director for Communication commented that after hearing Pleasant's summary of the health department survey he was worried and asked himself, "Is it that bad?" When he learned through the discussion that health literacy activities were ongoing, but hidden, he was relieved. When Eroglu heard from the representatives from Arkansas, Louisiana, and Nebraska, he stated that he was encouraged. In his view, there appear to be great practices and tools available that need to be taken to scale.

Deb Scholten, health director at the Northeast Nebraska Public Health Department, is a colleague of Bockrath and involved in both the Nebraska Association of Local Health Directors and Health Literacy Nebraska. Scholten observed that although the Nebraska health department started its health literacy project in 2008, the case study illustrates how Nebraska remains in an early stage of public health development in terms of its local health departments. She noted that only 22 of the state's 96 counties had health departments prior to 2001. Scholten said that in the four counties where she works, there is a notion that public health is something new that the government thought up. Many of the health directors had never heard of public health. This lack of a basic understanding of public health is itself a barrier that needs to be overcome. She added that new employees are required to take online courses on three topics: public health 101; health literacy; and public health emergency response preparedness.

Roundtable member Cindy Brach from AHRQ asked Bockrath whether having templates would help her organization implement the attributes of a health-literate health care organization. Bockrath replied that templates are needed for health literacy policies for local health departments in general,

and not specific to the attributes. She added that many templates are available for states to use, but she was not aware of one that characterizes health literacy policy requirements of local health departments. Bockrath stated that such a template would be useful because although health department directors are committed to integrating health literacy into training opportunities and programs, they do not have time to develop policies from scratch.

Harris said such a template would not necessarily be helpful. Instead, she thinks agencies need to have clear objectives that address cultural and linguistic competency and to have processes in place to ensure that the target audience is included as part of the planning process. In the end, the health department should be able to answer these questions in the affirmative: “Did we include the intended audience at the outset of planning?” “Did we market this intervention to the appropriate population?” and “Did the intervention work?”

Dillaha said that model policies could be helpful and be considered a template. She added that states with limited resources can gain from the experiences of others. A template could facilitate sharing of successful policies and processes. Models can stimulate thinking and discussion. Bockrath agreed and said the term “model” seemed more appropriate in this context than “template.”

Brach asked Dillaha why the Arkansas Department of Health decided to prioritize training in universal precautions. Dillaha replied that the focus on universal precautions came about because the department needed to overcome the perspective held by many public health professionals and health care providers that health literacy is a deficit of the person rather than the system in which they operate. The toolkit allows providers, whether they are in a primary care clinic or a local health unit, to assess their practices and then look for evidence of ways to improve them. She noted that a particularly useful section of the toolkit teaches the “plan, do, study” cycle, a much-needed concept to incorporate into both the public health and health care systems. Dillaha added that the toolkit provides simple exercises that clinic staff can do on their own and it allows them to, in effect, “own the process.” Dillaha observed that many providers are frustrated with the current system and acknowledged that there is room for improvement. Some improvements, especially in the area of communications, are not costly and not difficult to implement. She added that the use of the toolkit is a relatively easy way to engage individuals new to the area and to address the so-called low-hanging fruit.

Rudd said the planning committee for the workshop articulated a strategic long-term plan of building relationships with people in public health and then examining the 10 attributes of a health-literate health care organization and their applicability to public health. She added that the

presentations and discussion have greatly added to an understanding of what a health-literate public health organization would look like. Isham invited the panel to make additional comments on the 10 attributes and how they might be adapted to public health organizations. Bockrath reiterated her concern that the attributes that are related to communications with health plans and health insurance coverage issues are often not directly relevant to public health departments. In Nebraska, for example, she noted that there is no reimbursement for public health services. She added that attribute 7, which addresses navigational issues, is more relevant to clinical services within the health care system than to public health. Bockrath said these attributes do not need to be eliminated. Instead, the attributes can be written so that public health interests are reflected. It is important that health department personnel understand that the attributes apply to them as well as to others.

Bockrath stated that issues related to language access could be further accentuated in the attributes because it is something essential to public health, especially for those serving rural areas. Bockrath said that having CLAS (Culturally and Linguistically Appropriate Services) standards as part of the attributes would be useful because health departments are key access points for community interaction. This level of engagement would be enhanced by the practices that are called for in the CLAS standards.

Dillaha added that some of the attributes may relate more closely to clinical areas, while others could apply more directly to public health. For example, issues related to septic systems are under the purview of public health, and attributes related to these functions would likely not be applicable to clinical settings. In short, Dillaha suggested that some of the attributes could be generally applicable while others could target either health care or public health entities.

Harris concluded the discussion by noting that health literacy is about understanding our own biases, being aware of other people's cultural experiences, looking at the environment in which they live, and understanding some of their challenges. She added that it is important to meet individuals where they are, form trusting relationships, and find ways to sustain programs and efforts that will really help their communities.

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4

Health Literacy Facilitates Public Health Efforts

APPLYING HEALTH LITERACY PRINCIPLES TO PUBLIC HEALTH EFFORTS IN PREPAREDNESS AND NUTRITION

Linda Neuhauser, Dr.P.H., M.P.H.

University of California, Berkeley, School of Public Health

Early in her career as a public health nutritionist, Linda Neuhauser found that her science-based messages were not resonating with her clients. One of her colleagues, having similar disappointing interactions, concluded that “people don’t change, but it’s our job to tell them what to do.” Recognizing a serious problem, she began to explore how to better communicate, and this quest has turned into a lifelong career focused on using participatory processes to design, implement, and evaluate public health educational programs.

As a professor of public health and Principal Investigator of the Health Research for Action Center at the School of Public Health at the University of California, Berkeley, Neuhauser said she has the opportunity to work with researchers, students, communication experts, and policy analysts who study issues of health literacy. The group has a special focus on participatory design, which closely engages the intended end users in the development, implementation, and evaluation of communication approaches (Neuhauser et al., 2013a). This work has been ongoing for 20 years and has involved diverse populations across many public health topics throughout the world. Programs designed with such intensive participation work very well, she said, while programs that are not designed in such a fashion usually fail.

BOX 4-1
Seven Steps to Create Public Health “Clear Communication”

1. Define audiences and goals
2. Set up an advisory group that includes end users and stakeholders
3. Identify issues from formative research
4. Draft content using health literacy design principles
5. Conduct Usability testing—until it works
6. Codesign an implementation plan
7. Evaluate, revise, and scale up

SOURCES: Neuhauser, 2013; Neuhauser et al., 2013a.

Neuhauser described a seven-step model that focuses on health literacy and has proven to be very successful in developing good communications (see Box 4-1) (Neuhauser et al., 2013a).

The first step is to define the goals of the communication and to clearly identify the intended audiences. A special focus is needed on the diverse groups of end users, especially those who have communication barriers related to literacy, language, culture, and functional and access issues, previously referred to as disabilities, Neuhauser said.

The second step is to set up an advisory group. This group includes the end users and a range of stakeholders. Stakeholders may include researchers, policy makers, providers, community members, funders, the media, government representatives, and people from private industry. Neuhauser noted that an advisory group should represent a microcosm of stakeholders from many sectors that will facilitate the initiative. Its diversity improves the chances of having a successful program.

The third and fourth steps are to identify issues from formative research and then draft content according to health literacy design principles. The fifth step, usability testing, is critical, Neuhauser explained, because even the best known health literacy design principles cannot codify everything needed to make communication understandable, engaging, motivating, and actionable (Neuhauser et al., 2009). To achieve these attributes, strong input is needed from the intended audiences as the communication approach is developed (Neuhauser et al., 2013b). Usability testing involves one-on-one, in-person interviews with members of the focal audiences, especially people with limited health literacy skills and/or other communication barriers. Typically, several rounds of usability testing are required to adequately retest and revise the communication prototype adequately. Guidance from focus groups about prototypes can also be helpful.

The sixth step is to concurrently codesign the implementation. Neuhauser pointed out that even the greatest communication in the world will not be effective if the dissemination plan is not feasible in terms of implementation. This is another area where the input from the advisory committee is critical, she said. Finally, step 7 is to evaluate, revise, and scale up the program. This step also involves the principles of participatory design.

From her review of the literature on health literacy and public health nutrition programs, Neuhauser concluded that there is limited information on this topic in the peer-reviewed research literature and cited the value of the article by Carbone and Zoellner (2012). That article was a systemic review of 33 studies that were primarily related to measurement, development, readability, and assessing patients' individual health literacy skills. Neuhauser concluded that (1) the current literature does not generally cover broader issues in health literacy; (2) there are relatively few experimental studies on the effectiveness of interventions; and (3) research is needed not only on the individual level, but also pertaining to health systems and communities.

Although some research shows that nutritionists and dietitians are interested in health literacy and that they would like to have training to improve their communication skills, there is little evidence that they are receiving such training, Neuhauser said. If such training is not a requirement of licensing, she added, it will likely not be available in the near future. Therefore, integrating health literacy into licensing requirements is needed in the area of nutrition, as well as for all the other health professions.

Neuhauser described research she conducted to determine whether the government website related to the food pyramid adhered to health literacy principles (Neuhauser et al., 2007a). The website, MyPyramid.gov, was constructed to meet intended readability levels of seventh to eighth grade. However, when the site's readability was measured, it varied widely from seventh grade to above the college level. Furthermore, there was a lack of cultural relevance, which is very important from a public health perspective. The site also did not include information that pertained to families and communities. Neuhauser's research found that the website met only half of the U.S. Department of Health and Human Services Web usability criteria.

When Neuhauser contacted the U.S. Department of Agriculture to find out how the site was developed, she learned that the site content was written by professional nutritionists. The site had been tested with racially and ethnically diverse groups, but they did not specifically select people with low health literacy skills. Rather, the site designers involved a number of college students, which Neuhauser said is a common practice. She reiterated that a core problem in the design of communications is the lack of attention paid to end users, particularly those with health literacy challenges.

Neuhauser described an example of a very successful public health nutrition intervention, the First 5 California kit for new parents. Each year, this multimedia kit is given to 400,000 parents in California. It includes a parenting guide, a guide on what to do when your child gets sick, and a variety of other materials, including videos. Design of the intervention began in 2000 and included testing with diverse audiences and stakeholders. The kit is available in multiple languages with readability kept to the sixth to eighth grade level. According to the evaluation project led by Neuhauser, significant gains in knowledge and improvement in practices in such areas as nutrition and infant feeding were made within 6 weeks of receipt of the kit (Neuhauser et al., 2007b).

The impact of the program was remarkable, Neuhauser said. She added that there are numerous examples in the literature on health inequities where interventions widen knowledge gaps between different groups. Spanish speakers involved in this project had one third less knowledge about parenting practices than did English speakers at the outset of the study. Neuhauser's team found that 6 weeks after receiving a kit, the Spanish speakers completely erased this knowledge gap when compared to English speakers in the control group. She concluded that when programs are designed according to health literacy principles and intensively involve the end user, good results are achievable. This program has been adapted for use in four other states and overseas, including Australia.

Neuhauser highlighted four other examples of successful public health nutrition campaigns. The first is the California Network for Healthy California (<http://www.cdph.ca.gov/programs/CPNS>), which has a website that provides information on the value of increased fruit and vegetable consumption and daily physical activity. A second example is information from the U.S. Food and Drug Administration about food safety and nutrition. The third example is a project of the Eli Lilly Company and involves a booklet on healthy eating that was developed using health literacy principles and usability testing, and that was awarded the Institute for Healthcare Advancement's first place for published materials award in 2008. The final project included a picture of a plate that simply illustrated the size of healthy serving portions. Neuhauser also noted that pharmaceutical companies have invested in improving information they provide to people with nutrition-related diseases, for example, diabetes and hypertension.

On the topic of health literacy and emergency preparedness communication, Neuhauser said she has been working in this area during the past 5 years as part of a Centers for Disease Control and Prevention-funded project (Neuhauser et al., 2013c). A review of the literature revealed a general lack of evidence on this topic. One study by Friedman and colleagues (2008) analyzed 50 disaster or emergency preparedness websites and concluded that information was not consistently easy to read or visually

appropriate. Neuhauser said such information is needed because vulnerable populations are at extremely high risk for death and injury during disasters. In particular, she identified older adults and people who are deaf and hard-of-hearing (Deaf/HH) as groups for which better research and communication is needed.

Neuhauser reported on projects conducted within Deaf/HH communities. She mentioned that this community is large (estimated at 48 million people) and diverse. She pointed out that many members of the deaf community do not identify as “having a disability,” but instead consider themselves members of a minority linguistic group. They use American Sign Language (ASL) and other forms of communication. ASL is a gestural 3-D language that does not directly translate into a language such as English. Members of the deaf community generally have low literacy. Neuhauser said that any written materials should be at the third to fourth grade reading levels and that this group also needs information in ASL video formats. Neuhauser noted that health literacy standards for video formats are just emerging, and she and her colleagues are working on this area. Their team has conducted a national assessment of the state emergency operations plans in the United States and the U.S. territories to examine whether they included specific operational plans for people with disabilities, people who are Deaf/HH, and older adults (Ivey et al., in press). The research also included an assessment of emergency preparedness materials at community-based organizations for older adults and people who are Deaf/HH in one California county. The research team conducted interviews and focus groups to assess the availability and readability of materials (Neuhauser et al., 2013c). The advisory board for the project included researchers, policy makers, technology experts, community members, and representatives of different Deaf/HH subgroups. According to study findings:

- Only one-third of state plans mentioned the Deaf/HH population.
- Fewer than half of the community organizations serving the Deaf/HH population provided emergency preparedness materials.
- No materials met readability standards for the Deaf/HH community (the lowest was 7th grade and most were above the 10th grade level), and only one resource was at or below the recommended 6th grade level for older adult populations.

Neuhauser’s team found that the vast majority of service providers want plain-language materials. In addition, communication training on how to interact with people who are deaf and hard of hearing is critical for first responders (Engelman et al., 2013; Neuhauser et al., 2013c)

Neuhauser concluded her presentation by summarizing the study recommendations aimed at improving state emergency operations plans,

and policies of the Department of Homeland Security, the Federal Emergency Management Agency, and other national, state, and local emergency response organizations (Engelman et al., 2013):

- Provide national guidance to improve U.S. state emergency operations plans.
- Legislate standards for emergency alerts in the United States.
- Develop emergency preparedness materials with members of Deaf/HH populations.
- Adhere to health literacy principles.
- Define health literacy criteria for video formats.
- Use new technology: texts, mobile video, social media.
- Develop training for responders and service providers.

She emphasized that much needs to be done, but that using the seven-step, highly participatory process can greatly improve public health communications.

CHRONIC DISEASE PREVENTION

Jennifer Cabe, M.A.
Canyon Ranch Institute

Cabe said she was introduced to the importance of health literacy by Alice Horowitz and Cynthia Bauer when she served as a speechwriter to the 17th U.S. Surgeon General, Richard Carmona. She reiterated the point made earlier that there is clear evidence that individuals with lower health literacy are more likely to experience

- poorer overall health;
- misunderstanding of their health condition and its treatment;
- lack of adherence to medical regimens;
- low rates of screening and use of other preventive services;
- late stage of presentation for care of a chronic disease;
- increased health care costs;
- hospitalization; and
- death.

Cabe noted it is not yet clear if this relationship is causal or correlative. In preparation for the workshop, she investigated evidence of the converse of this relationship, that is, whether health literacy proficiency is protective in terms of health behaviors and outcomes. In her cursory review of the

literature, she was somewhat surprised to find little in the way of evidence for the potential benefits of such proficiency. For example, high health literacy would logically enable individuals to better retrieve and then process information about their health and then comfortably navigate the increasingly complex health care system. If health literacy proficiency could be directly linked to improved chronic disease outcomes, a strong social and economic argument could be made to promote health literacy. The financial costs of treating chronic diseases, many of which are preventable, are large and mounting, she said. Estimates are that they account for 18 or 19 percent of gross domestic product.¹ For every dollar spent on health care, 75 cents is spent on treating chronic disease,² and recent evidence suggests it is climbing up to 80 cents of every dollar.

Cabe said health literacy proficiency is increasingly important because the orientation toward prevention relies on the self-management of chronic disease, following care plans, making informed decisions and healthy behavior changes, and adhering to complex medication regimens while being alert for side effects and complications. Navigating the health insurance marketplace is challenging for many as well, she said. Millions of people newly eligible for publicly funded or subsidized health insurance in the United States must navigate the system to find, understand, evaluate, communicate, and use information. Gaining access to insurance coverage depends on one's ability to

- find reliable information;
- understand eligibility guidelines;
- complete forms and provide enrollment documentation;
- understand and apply concepts such as premiums, copayments, and benefits; and
- understand which services are and are not covered.

Cabe added that the ability to make one's way through the health care system, from primary care to specialist or from acute to long-term care, can itself be challenging and is likely much easier for those with high health literacy.

There is evidence that health literacy is at the core of the nation's poor international standing in terms of health, Cabe said, citing findings from a recent study by Kindig and Cheng (2013). In their analysis of female mortality by county from 1992 to 2006, they found several factors were

¹ World Bank (<http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS>) (accessed July 25, 2014).

² Centers for Disease Control and Prevention (<http://www.cdc.gov/chronicdisease/index.htm> [accessed July 25, 2014]).

associated with lower mortality rates, including higher education levels, not residing in the South or West, and low smoking rates. Medical care variables, such as the relative numbers of primary care providers, were not associated with lower rates. The authors concluded that improving health outcomes “will require increased public and private investment in the social and environmental determinants of health, beyond an exclusive focus on access to care or individual health behavior.”

In considering the findings of the Kindig and Cheng (2013) study, Cabe posed the question, “Does it then follow that health literacy can help public health systems to empower people to prevent chronic disease, regardless of socioeconomic status or other social determinants of health?” In her view, factors that are usually missing in public health approaches that impede progress in chronic disease prevention include

- involved and engaged users/audiences;
- linguistically and cultural appropriate messages;
- trust; and
- mutual respect.

Cabe endorsed fellow panelist Neuhauser’s “Seven Steps to Create Public Health Clear Communication” as a way to ensure interventions succeed and are cost effective. The seven steps approach results in involved and engaged users, messages that are understood, and trust and mutual respect. Cabe said these are all essential to sustained behavior change.

Cabe described four important targets for public health interventions: knowledge, beliefs, attitudes, and behaviors. She acknowledged the work of Cecilia Doak and her husband Len Doak, which led to the understanding that improving literacy leads to changing behavior. For example, to transition from learning to read to reading to learn is a significant behavior change. This behavior change is transformative, Cabe added. It allows individuals to understand information, put that information into the context of his or her life, communicate that information to others and, finally, use the information to affect his or her health and well-being.

The assumption that an individual with high health literacy will make healthy choices can be challenged, Cabe said. Some individuals with low health literacy exhibit excellent health behaviors while others with high health literacy have poor health behaviors. She cited the classic example of health care professionals who drink too much, do not manage their stress, or smoke cigarettes.

Cabe discussed the importance of forming partnerships, intervening early and often with individuals, and taking an integrative and team approach to public health interventions. To illustrate these concepts, she shared a testimonial of a Canyon Ranch client, Dean Rutland. Rutland participated in a health literacy wellness program designed by Canyon

Ranch Institute and offered to the Cleveland Clinic patient community. Her testimony, shared with permission, is summarized in Box 4-2.

Cabe said Rutland gives presentations in Cleveland churches to share her experiences. She is helping other people engage in healthy behaviors to

BOX 4-2

Testimony of Dean Rutland

I saw the flyer about the Canyon Ranch Institute Life Enhancement Program (LEP) in my Cleveland neighborhood at a time when I was feeling bad emotionally and spiritually. I knew I needed to do something, so I called to sign up.

I went in for my assessment and got a real shock. I couldn't do a single sit-up. I couldn't do jumping jacks or walk for 5 minutes on the treadmill. Then, I got the news that I had high blood pressure. It was so high that they told me to go see my doctor immediately.

I managed to hold my tears inside until I got out of the room, but I began to sob as the elevator doors closed. I was overwhelmed with the reality of what poor health I was in, and I was scared.

At that point, I had no intention of going ahead with the program. But Teresa Brown, the Core Team member who had done my initial assessment, called me at home. She talked to me about putting my embarrassment aside and taking the first step. She also assured me that I would meet others in the group who needed to make changes.

Teresa was right. Before long, I had made some new friends. We would even meet outside the program sessions to walk together. I could tell I was on the right track.

One of the hardest things I had to do was take the blood pressure medicine my doctor prescribed. I had a real "A-ha!" moment when he told me my blood pressure had gone down. With continued progress, I might not even need the medication. I knew I didn't want to take pills for the rest of my life, so it made me feel awesome to know I had done something so positive.

What I learned in the program helped me to change what I ate and motivated me to move every day. I completely restocked the food cabinet at home. My five children are encouraged to eat better and my daughter in North Carolina even walks with me. We use our phones to connect by voice and picture, and then we talk while we walk "together."

Since the CRI LEP, I've lost 40 pounds, and I finished my first 5K race. When I crossed the finish line, I wanted to keep on going, so now I'm training for a full marathon. I have to give a lot of credit to the CRI LEP, the Core Team members who supported me even after the program ended, my family, and the friends I've made.

Yes, I give myself some credit, too, because making changes took some courage. What I want others to know is that once you take that first step, you can't believe what you can accomplish!

SOURCE: Cabe, 2013.

prevent chronic disease, but is also assisting those living with chronic disease in reducing unhealthy behaviors. Rutland's story is a positive example of how health literacy can guide public health efforts, Cabe said, adding that health literacy is a powerful tool that can be used in addressing chronic disease. Health literacy can guide public health agencies and the people they serve in choices about where, when, why, and how to invest in chronic disease prevention.

Health literacy is often neglected in public health efforts to prevent chronic disease, Cabe said. When implementing public health interventions, she said the following issues should be addressed:

- engage people early and often;
- do not “dumb down” complex truths;
- explain complex issues carefully and check in often for understanding and action;
- prioritize prevention and wellness, not sick care;
- equally involve health professionals and the public;
- address the social determinants of health; and
- create multisector, effective partnerships.

The social, family, community, and economic costs of chronic disease can be addressed through these approaches, Cabe concluded.

THE BIGGER PICTURE: HARNESSING YOUTH VOICES TO IMPROVE PUBLIC HEALTH LITERACY IN DIABETES

*Dean Schillinger, M.D.
San Francisco General Hospital*

Schillinger introduced a California-based social marketing campaign titled “The Bigger Picture” that engages young people of color in diabetes prevention. The campaign focuses on painting a picture of the social and environmental conditions that are driving the diabetes epidemic, which is increasingly affecting younger people of color. Gabriel M. Cortez, a poet and campaign spokesperson of Panamanian descent, presented one of his poems that addresses the link between sugar-sweetened beverage consumption and diabetes among immigrant communities. A video of his presentation can be found at <http://iom.edu/Activities/PublicHealth/HealthLiteracy/2013-NOV-21/Videos/Panel3/Schillinger.aspx>.

To describe the purpose of this campaign, Schillinger reviewed the definition of public health literacy as articulated by Freedman and colleagues (2009). Public health literacy is “the degree to which individuals and groups

can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community.”

According to this definition, the purpose of public health literacy is to improve the health of the public by engaging stakeholders in public health efforts and addressing the determinants of health. Furthermore, public health literacy is viewed as a multidimensional construct, including conceptual foundations, critical skills, and a civic orientation.

To set the stage, Schillinger reviewed the distribution of diabetes types among U.S. children ages 10 to 19 by race/ethnicity (see Figure 4-1). Among non-Hispanic white children, 85 percent of diabetes cases are represented by Type 1 juvenile-onset diabetes. However, among all other race/ethnic

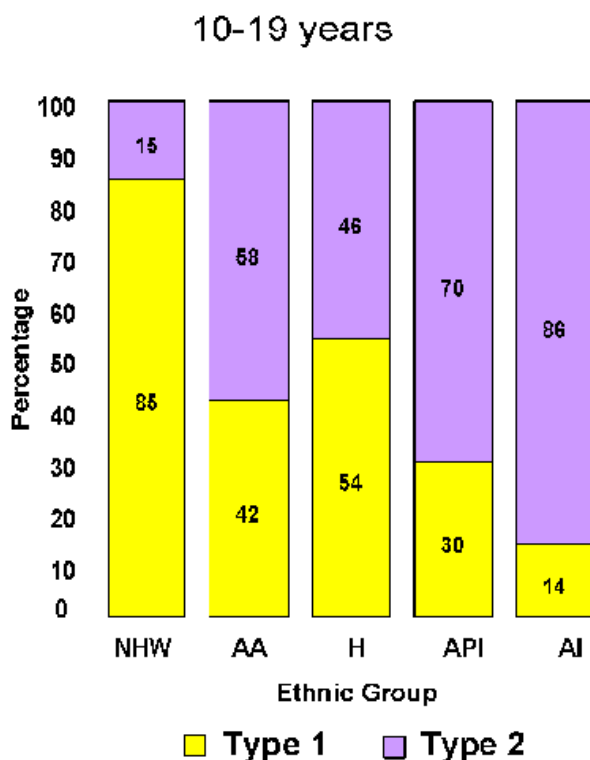


FIGURE 4-1 Distribution of diabetes types by race/ethnicity.

NOTE: AA = African American; AL = Alaskan Native; API = Asian and Pacific Islander; H = Hispanic; NHW = Non-Hispanic white.

SOURCE: Schillinger, 2013.

groups, about half of diabetes cases, and in some cases the overwhelming majority of diabetes cases, are Type 2, previously known as adult-onset diabetes. Schillinger noted that it is alarming that this so-called late-onset disease is occurring so frequently among children.

Schillinger reviewed the results of a recent national study (May et al., 2012) that found that in 1998, 1 in 11 children ages 12 to 19 had prediabetes or diabetes. In 2009, nearly one in four children in this age group had prediabetes or diabetes. These children have a 50 percent chance of developing frank diabetes³ within 5-10 years. It is important to note that in the intervening 10-year period, body mass index did not change. So although obesity is a strong predictor of Type 2 diabetes, Schillinger said it does not explain this explosion in cases of prediabetes among children.

Schillinger described some activities that have been undertaken as part of “The Bigger Picture” project. Four medically curated writing workshops have been held with participation from 30 poets affiliated with the group, “Youth Speaks” (<http://youthspeaks.org>). Poets, including Gabriel Cortez, have written 16 English poems that have been featured in public service announcements (PSAs) varying in length from 30 seconds to about 5 minutes. In addition, two Spanish-language PSAs have been produced and five more are in preproduction. Spanish and English websites have been developed (TheBiggerPicture.org) and the organization is active in social media. An educator toolkit has been created that can be used by teachers in high schools. English- and Spanish-language marketing materials and a Bigger Picture DVD have also been produced. The DVD includes many of the PSAs.

Schillinger reported that presentations at high school assemblies are the centerpiece of the project. To date, presentations have been made at 15 minority-serving public high schools. The 1-hour program is moderated by a Youth Speaks poet mentor and includes poet performances and viewing the video PSAs. The assemblies often include approximately 500 high school students who are from low-income neighborhoods.

Topics covered during the assembly program include (1) basic information about Type 2 diabetes; (2) statistics outlining the social and contextual determinants of this disease; and (3) resources and examples for community and policy action. Schillinger added that it is important to review aspects of the etiology of the disease because some students think diabetes is solely genetic because it is so prevalent within their families. Some schools have opted to participate in a supplementary one-hour writing program in which

³ Frank diabetes is stage 4 of the 5 stages of diabetes and “is characterized as stable decompensation with more severe β -cell dedifferentiation.” http://diabetes.diabetesjournals.org/content/53/suppl_3/S16.full (accessed February 20, 2014).

a subset of students write their own poems or stories in response to the assembly presentation.

Like many high school assemblies, the learning environment can be challenging because of rowdy behavior. Schillinger said that holding the attention of an auditorium filled with teenagers is a challenge, especially if the topic is about health. The project, however, has succeeded by featuring the talent of the Youth Speaks poets, who create a hush as soon as their performance begins. As an example, Schillinger asked Jose Vadi to present a poem for the Institute of Medicine (IOM) that is featured in one of the project's PSAs. The poem is called "Sole Mate" and can be viewed at the Bigger Picture website (<http://youthspeaks.org/thebiggerpicture/2013/02/01/sole-mate-3>). Diabetes can have harmful effects on feet (amputation), and Jose's poem explores how dependent we all are on our feet and asks, "What would we do if we lost all or part of one?" It ends with a shocking image of an amputation. The closing statement of the PSA attempts to put this problem in perspective, by reporting that "over 1,000 U.S. soldiers have lost a limb during the conflicts in Iraq and Afghanistan. During this same time period, over 70,000 Californians have lost a limb to diabetes."

Schillinger showed a second PSA that also features a poem by Jose Vadi, "The Corner," that is about the food environment in his Oakland, CA, neighborhood (<http://youthspeaks.org/thebiggerpicture/2013/02/01/the-corner-3>). In this poem, Vadi talks about the choices people make and questions whether we are actually making a choice about what to eat, or whether choices are made for us by forces beyond our control.

The campaign has thus far been focused on the San Francisco Bay Area, but expansion to other parts of California is under way. The project team hopes to make the campaign a national one. Through its presentations to date, the project has reached more than 2,500 high school students from 15 low-income public Bay Area schools. In addition, presentations have been made to more than 770 health, education, and community stakeholders. The campaign website has received more than 100,000 hits, and this has occurred with no advertising budget.

To help gauge the impact of the high school presentations, Schillinger enlisted a random sample of high school students who were given feedback clickers and asked to respond to a series of questions before and after the presentation (see Figure 4-2).

Schillinger reported that before the presentation, 70 percent of the students agreed that Type 2 diabetes is preventable. After the presentation, 92 percent believed it is preventable. Before the presentation, only 34 percent of high school students included environmental and social causes as influencing one's diabetes risk. After the presentation, 83 percent of the students acknowledged these risk factors. Schillinger said this improvement in knowledge signifies a gain in public health literacy.

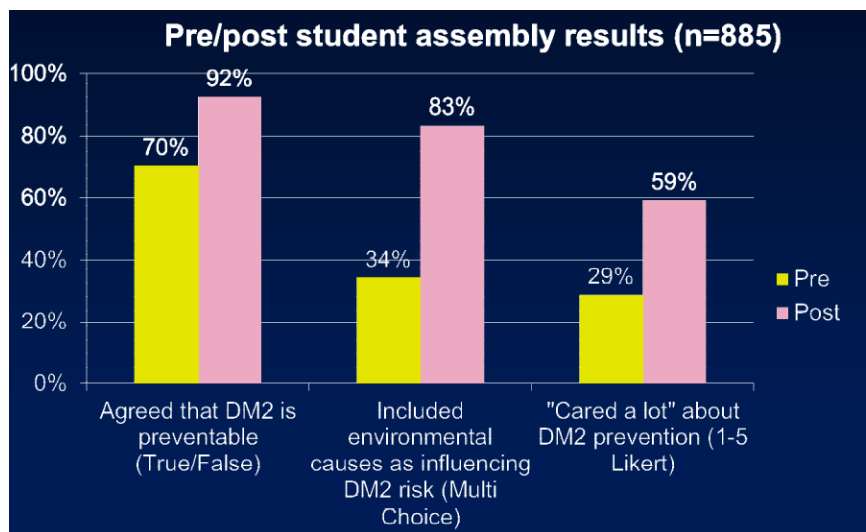


FIGURE 4-2 The Bigger Picture assembly improved outcomes.
SOURCE: Schillinger, 2013.

With respect to a call to action and a willingness to engage, Schillinger reported that only 29 percent cared a lot about diabetes prevention before the presentation. This rose to 59 percent of students answering five on a five-point Likert scale indicating “I care a lot about preventing diabetes.”

Evaluations among stakeholders found that before seeing the videos and hearing the poems, 67 percent believed that young people can serve as agents of social change. After seeing the videos, this response rose to 99 percent. Ninety-six percent of stakeholders reported that the strategies used in this project, that is, youth-generated, spoken-word pieces, were relevant to their organization.

Schillinger concluded by reviewing The Bigger Picture project’s next steps. Plans are to expand the Bay Area school visit program to other schools throughout the state, but initially to cities hard hit by the recent recession (e.g., Richmond, Stockton, and The Inland Empire in California). Eventually the program could be expanded nationally because Youth Speaks has sister programs throughout the United States. Schillinger added that he would like the project to extend to other chronic diseases because the social and environmental conditions causing diabetes are also causing hypertension, heart disease, and other conditions. In addition, there are plans to enhance and evaluate the Bigger Picture’s digital platform and to increase the campaign’s impact by developing and incorporating materials and content in other languages.

ORAL HEALTH

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Alice Horowitz pointed out that oral health is not generally viewed as an integral part of overall health. Yet oral diseases are often called a neglected epidemic. Among children ages 2 to 4, early childhood caries has increased 33 percent between 1988 and 2004 (Dye et al., 2007). It is now recognized as the most common disease of childhood.

Oral health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic oral health information and services needed to make appropriate health decisions” (National Center for Health Statistics, 2010). Horowitz said many people do not use appropriate preventive procedures, not by informed choice, but because they have never been taught about them, have no skills to seek information, or have no access to them. Increased oral health literacy provides people with the understanding and the means to exercise choice rather than suffering the consequences, she said.

Low levels of oral health literacy are associated with poor knowledge about oral health (Jones et al., 2007; Sabbahi et al., 2009), infrequent dental visits (White et al., 2008), greater severity of dental caries or tooth decay, higher rates of failed appointments (Holtzman et al., 2012), and lower oral health-related quality of life (Gong et al., 2007; Lee et al., 2007; Richman et al., 2007). Horowitz said these correlations between health literacy and oral health outcomes have only been documented in recent years and parallel findings regarding health literacy and medicine.

Horowitz reviewed the well-established interventions known to prevent or control tooth decay, especially when applied early for children. These interventions include fluoridation of public water supplies; appropriate use of fluoride toothpaste; application of pit and fissure sealants; reduction in sweets; and periodic visits to the dentist. Most people, if asked about how to prevent tooth decay, would likely reply, “brush your teeth twice a day.” According to Horowitz, relatively few would mention the use of fluoride and dental sealants. She noted that dental visits generally do not prevent oral health diseases because, as is the case in medicine, such visits are generally for diagnosis and treatment. She added that much of oral disease prevention is done at home, and what is needed are behavioral interventions.

The Maryland Dental Action Coalition, formed following the death of

Deamonte Driver,⁴ developed a state plan with three focus areas: access to oral health care; oral disease and injury prevention; and oral health literacy and education.

To address aspects of the oral health literacy and education focus area, the School of Public Health conducted a statewide needs assessment using focus groups and a telephone survey of a random sample of Maryland adults who had children ages 6 years and younger, Horowitz said. The survey asked respondents what they knew about preventing tooth decay, and how they rated the communication skills of their dental providers. The results of the survey indicated that low-income adults with young children do not understand how to prevent tooth decay (Horowitz et al., 2013a). They do not know what fluoride is, that fluoride is in their water, and that drinking tap water helps to prevent tooth decay. Horowitz said 98 percent of the central water supplies in Maryland are optimally fluoridated. However, adults in the survey who have Medicaid dental coverage did not know this. Most were drinking bottled water despite the cost and the impact on the environment. People with low incomes tend not to drink tap water for a variety of reasons: some complain of the taste or the color of the water, but a major factor is “keeping up appearances.” However, most bottled water does not include a sufficient amount of fluoride to prevent tooth decay, she said.

In addition to assessing adults with young children, surveys and focus groups of physicians, nurse practitioners, dentists, and dental hygienists also were conducted in Maryland (Horowitz et al. 2013a,b; Maybury et al., 2013). Providers were asked what they know and do about preventing tooth decay and whether recommended communication skills are used on a routine basis. According to survey results, providers do not use recommended communication techniques. Most respondents had never even heard of the teach-back method and certainly were not using it. This finding held across all provider groups. In addition, health care providers, including the dentists and dental hygienists, need to have training reinforced on how to prevent tooth decay, Horowitz said. For example, according to the survey, little or no attention was given to teaching mothers to clean their infant’s mouth and to check for early childhood tooth decay or white spots, early signs of decay. Similar disappointing findings emerged from the focus groups and surveys conducted of Head Start and Women, Infants, and Children (WIC) program coordinators and staff.

Another barrier to oral health is that many dental care providers do not accept Medicaid-eligible children or pregnant women, said Horowitz. A

⁴ Deamonte Driver was a 12-year-old boy from Prince George’s County, Maryland, who died from a brain infection that was the result of an abscessed tooth. His mother had been unable to get him adequate dental care.

pregnant woman age 21 and older is automatically dropped from Medicaid immediately after giving birth. Yet, Horowitz said, bacteria that cause tooth decay are generally transferred from the mother to the infant. The Maryland Dental Action Coalition is attempting to change this Medicaid coverage policy.

From a health literacy perspective, the findings from the information gathered represented “a perfect storm,” Horowitz said. The IOM report *Advancing Oral Health in America* recommended community-wide public education on the causes of oral diseases and the effectiveness of preventive interventions (IOM, 2011). The report also recommended professional education and best practices in preventing oral diseases and in improving communication skills.

A health literacy environmental scan also was conducted that included 26 out of the 32 public health dental clinics in Maryland that are located in Federally Qualified Health Centers, and city and county health departments. The methodology for the scan was consistent with that recommended by Rima Rudd and included in the Agency for Healthcare Research and Quality’s toolkit. The results of the scan indicated that thousands of dollars are being spent annually to treat early childhood caries. In some cases, very young children have to be treated for severe early childhood caries in operating rooms under general anesthesia.

Given the public’s lack of knowledge of prevention, the educational materials available through the dental clinics were assessed. Only one leaflet was found in some of the clinics that discussed water fluoridation, but it did not adhere to plain-language principles and included too much information. It is going to be rewritten, Horowitz said.

Based on the statewide oral health literacy assessment, a “Healthy Teeth, Healthy Kids” initiative was established by the Coalition in collaboration with the Department of Health and Mental Hygiene’s Office of Oral Health (<http://healthyteethhealthykids.org>). The purpose of this initiative, according to Horowitz, is “to help moms help themselves and their infants to have good oral health.” The initiative provides education to pregnant women through prenatal classes, WIC and Head Start programs, and high school programs for pregnant teens. Horowitz said that it is especially important to work in city and county health departments because programs are colocated and are under one umbrella. This means that the WIC program runs alongside the obstetrics and pediatric clinics. In these environments, it is difficult for staff to add dental issues to their already busy schedules because there is a tendency to address the client’s problem of the moment, she said.

Horowitz reiterated the importance of mothers needing to understand the importance of drinking fluoridated tap water and using fluoride toothpaste. She said that mothers need to clean their infants’ mouths as soon as

they begin to bathe their babies. She has observed that in prenatal classes, mothers are taught how to clean every orifice of the body except the mouth. The cleansing of the mouth needs to start early because by the age of 6 months, when the first baby tooth comes in, infants are likely to resist a new practice. If cleaning the baby's mouth starts early, it becomes an established habit over time. The initiative also teaches mothers to lift the baby's lip once a month to look for white spots or lines on the teeth. This is an early sign of decay and at this point the teeth can be remineralized or healed. Other components of the educational intervention focus on the need to limit sweets and to have a 1-year dental examination. Horowitz said that 45 states now encourage and reimburse physicians to use fluoride varnish on infants up to several times a year. Fluoride varnish is very effective, but most people, especially those with low incomes, do not know about it, Horowitz said.

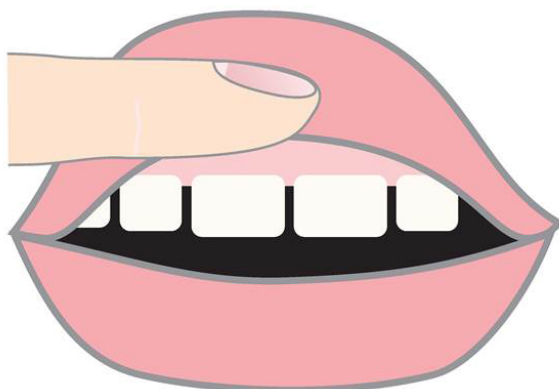
Several educational tools have been developed that are targeted to pregnant women and women with young children: a video, posters, leaflets, and magnets, all in both English and Spanish. The poster shown in Figure 4-3 provides guidance on cleaning a baby's mouth and checking for early signs of decay. The posters have been mounted in dental and WIC clinics and other clinical areas.

Although the ultimate indicator of the net effectiveness of a preventive regimen is its ability to actually prevent the targeted disease or condition, it is also necessary to measure knowledge and actual use of the recommended preventive regimen, Horowitz said. For example, if adults do not understand the value of community water fluoridation, they are not likely to get their drinking water from the tap. Horowitz described a major new focus area that is part of the state plan called "Get It from the Tap." The main message is that fluoride prevents cavities. This initiative and "Lift the Lip" have posters, magnets, and videos that are used to disseminate the messages.

In terms of next steps, Horowitz said the Maryland Dental Action Coalition will implement all of the education tools developed thus far in the settings serving pregnant women and women with young children. The educational tools were tested on that target audience, and the participating women told the design team what they wanted to see. The video features mothers because women said they wanted to hear from other moms, not doctors or dentists. Once the program is implemented, Horowitz said, the team will reevaluate knowledge and understanding of caries prevention among women, providers, and the public. In addition, the team will determine the percentage of infants who are free of caries. The goal is to reduce the number of children who are taken to the operating room for general anesthesia and treatment.

LIFT THE LIP

KEEP YOUR BABY CAVITY FREE



CLEAN BABY'S MOUTH

- Begin cleaning baby's gums and tongue the day after baby comes home from the hospital. Use a clean, damp washcloth.
- When baby is about one year, clean teeth with a soft toothbrush and a smear of fluoride toothpaste.

LIFT BABY'S LIP ONCE A MONTH

- Look for early cavities – white lines near the gum line.



Herschel S. Horowitz Center for Health Literacy
School of Public Health

FIGURE 4-3 Poster providing guidance on preventive dental care.

SOURCE: Herschel S. Horowitz Center for Health Literacy

DISCUSSION

Bockrath asked panel member Neuhauser about the language used for preparedness communications. In particular, she asked, “What kinds of tools are available pertaining to preparedness language? Is it possible to avoid creating a whole new language around the next major public health issue?” Bockrath said that until 9/11, there were about 10 preparedness-specific words. Since then an entire new public health vocabulary has emerged that requires translation for communication purposes. Neuhauser, in her work with deaf individuals, found that many words related to disasters were not available in American Sign Language. She found that developing glossaries of important words was very helpful.

Neuhauser said that medical students learn about 18,000 new words during their training. A whole new language of jargon is acquired and later used on the unsuspecting public. Health literacy has involved “dejargonizing” this vocabulary for the intended users. She added that in a high-risk situation such as a disaster, the associated emotional stress can diminish cognitive skills, making understanding communications difficult.

McGarry asked Cabe whether, when discussing prevention activities, confusion arises when distinctions are made in the context of public health among primary, secondary, and tertiary prevention. Cabe agreed that these aspects of public health do confuse people. In her experience some have a hard time understanding how a chronic disease can be prevented before there are any signs of it. Then, after a chronic disease such as diabetes is diagnosed, some of the communications shift to secondary and tertiary prevention, for example, avoiding an amputation. Schillinger said there is also confusion between prevention in terms of individual behavior change and the broader view of community change. He added that many of these distinctions depend on an understanding of human biology, disease, and health. These are areas where education is needed, especially in the era of the development of biomarkers and other risk factors.

Vadi, speaking from his experience of working with The Bigger Picture project, said it was important to distinguish the communications that put behavioral messages in a binary form: “if you do this, this will happen to you, and if you do that, bad things will happen.” The PSA that featured the egg on the frying pan to illustrate the effects of drugs on the brain was not nearly as effective as talking about a framework that describes individuals in the context of their community and the influences of the community on the individual. As an example, he pointed out that individuals have the ability to choose whether or not to buy a pack of junk food. However, some individuals live in “food deserts,” areas where their access to healthier options is extremely limited. Vadi concluded that individuals have to take responsibility for their health, but that individual responsibility is greatly

affected by the environments in which they live. He said that policies shape those environments; for example, the corn subsidies that were put in place in the 1970s have contributed to the Type 2 diabetes epidemic through the public's consumption of high-fructose corn syrup sugar-sweetened beverages. Many complex factors influence behavior on the individual, community, and policy levels. In Vadi's view, some public health messages used in the past have been oversimplified and too focused on individual choices without taking into account the complex influences of community- and policy-level factors.

Pleasant thanked the presenters from The Bigger Picture campaign and said they illustrated the vast range of approaches to addressing public health from a health literacy perspective. He pointed out that art, including the poetry from The Bigger Picture, is an important but sometimes neglected form of public health communication. Pleasant noted that artists can express opinions and create change by engaging people and defining what the ideal future should look like. He suggested that Vadi and Cortez read the work of Augusto Boal, who is from Brazil and writes about art and social change.

Vadi responded that although art can be extremely dogmatic, he has learned through the workshops that in order to be effective, the artist cannot become too hyperbolic. To communicate effectively and engage as many people as possible, he said it is important to let the audience know that the poem comes from a place of concern and not necessarily just rage. To identify solutions Vadi has found it useful to look at the current world, identify why things are flawed, and then turn to the past and analyze the change between past and present to discover the future. Vadi referred to a poem called the "Quantum Field" (<http://www.youtube.com/watch?v=zIL3kdE7mKk>). This poem was written by a young man named Tele'Jon Quinn, a graduate of Met-West High School in Oakland, who lives in a food desert. The poem is about a young man who tries to live a healthy lifestyle by working out and eating healthy food. However, he lives in a Twilight Zone world called the Quantum Field where his efforts are not appreciated. This poem is a reminder of the importance of cultural influences. He added that if you are a high school student going off campus at lunch to buy a kale salad while everyone else is seeking junk food, you are going to be ostracized.

Sarah Fine, the Bigger Picture project director, added that the workshops try to take a social justice perspective and shift the conversation from a "blame-the-victim scenario" to one that focuses on the environmental and systemic forces that affect chronic disease. She added that the messages need to go beyond "don't drink this soda or eat this food" and address issues such as why there are fewer resources allocated for outdoor spaces in poor neighborhoods than in wealthy neighborhoods. Again, it is important to

examine the driving forces behind why individual choices are made. Fine gave an example of a woman who participated in the sugar-sweetened beverage workshop. This woman came into the workshop with a liter of Coke, but when she learned about sugar industry tactics that target minorities, she left the workshop with the commitment not to drink any more soda. This woman's motivation to change came about because she realized that she was being exploited, Fine said. This type of message is much more motivating than one that tries to dictate "good" behavior.

Isham asked the panel to discuss ways to "scale up" effective public health communication programs. Horowitz said it is important to ensure that a pilot program makes a difference clinically before it is disseminated on a larger scale. The evaluation process can take a long time. The oral health intervention targeted to pregnant women will be implemented and evaluated in one Maryland county. Horowitz estimated it will take some time to demonstrate effectiveness because oral health will be tracked for several years. Once the program has been shown to improve oral health, it could go statewide and be adopted by other states. Isham asked about the process of transferring the knowledge gained in one state to another state. Horowitz said that if states realize they can benefit financially by preventing young children from being treated for severe tooth decay, they will eagerly adopt the program.

Schillinger stated that with respect to The Bigger Picture project, all that is needed is a major underwriter because platforms to launch the program and reach a wider audience are available through the national organization, Youth Speaks, which has a presence in most major urban areas. Social media and the program's Web presence are also useful mechanisms for dissemination. When approaching potential donors, Schillinger said it is important to have a sustainability plan. In response to questions about the feasibility of corporate sponsorship, Cabe discussed the value of developing partnerships with academic institutions, other nonprofits, and companies. Such partnerships allow program piloting, evaluation, replication, reevaluation, and then dissemination. Cabe said that in her experience at the Canyon Ranch Institute, public health agencies can work with corporations with the appropriate guidelines in place, for example, receiving unrestricted educational grant funding and adhering to strict evaluation protocols.

Neuhauser noted that there is a science and art to scaling up. She recommended exploring the World Health Organization *Expandnet* (WHO, 2008). Criteria include having a champion and participatory design. Neuhauser said sponsors are available who want to make a difference and Cabe added that corporations are interested in expressing their social responsibility.

Neuhauser expressed an interest in creative partnerships and asked representatives of The Bigger Picture project where they would go when seek-

ing a sponsor. She wondered about technology companies. Vadi responded by highlighting the power of social media. He mentioned that one of their videos, “The Product of His Environment,” was showcased on UpWorthy.com and garnered more than 15,000 views in 1 day. This website acts as a gatekeeper for videos and graphics with social messages. This site, and others like it, immediately generates views and can engage an entirely new audience that a California state-specific program would otherwise be unable to reach. These sites also open up opportunities for collaboration. Through Twitter and Facebook, the project has reached many diabetics and former diabetics who have created their own local “mom and pop” organic distribution companies throughout California, Vida said. The project has also engaged other young people and other storytelling organizations. Vida pointed out that The Bigger Picture is, in and of itself, a collaboration between the University of California, San Francisco, Center for Vulnerable Populations and Youth Speaks, a literary organization. He discussed the exciting cross-fertilization that occurred between the poets and Schillinger. Vida added that collaboration inherently strengthens projects, and the digital landscape can be used in many ways to expand audiences.

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Supporting Public Health Implementation and Research

DEPARTMENTS OF PUBLIC HEALTH: WORKFORCE DEVELOPMENT

*Don Bishop, Ph.D.
Minnesota Department of Health*

In 2012 the Minnesota Department of Health (MDH) identified health literacy as an opportunity to address health equity, Don Bishop explained. The Department benefitted from the initiative of Genelle Lamont, who was able to focus on health literacy for 1 year as she completed a DHPE (Directors of Health Promotion and Education) Health Promotion Policy Fellowship program. Subsequently, Lamont was hired by the MDH Oral Health program with funding in part to continue her work in health literacy.

The definition of health literacy found in the report *Health Literacy: A Prescription to End Confusion* (IOM, 2004), focuses on individuals and their empowerment, which, while appropriate in the clinical context, does not work as well for public health, especially at the state level, Bishop said. Health departments are often addressing systems issues and communicating with decision makers and power brokers rather than individuals. The World Health Organization (2009) recommended that the definition of health literacy be expanded in scope to include social determinants of health. But the definition proposed by Freedman is more applicable to public health, Bishop said, because it has a focus on groups and the community (Freedman et al., 2009). As stated in an earlier presentation by Schillinger, Freedman defines public health literacy as “the degree to which individuals

and groups can obtain, process, understand, evaluate, and act on information needed to make public health decisions that benefit the community.”

Bishop said he would make one change to Freedman’s definition. Instead of saying “the community,” he would say “their community” because, in his opinion, public health literacy is also about empowering individuals and groups within a community to develop the necessary skills and influence for working with key decision makers so that policy choices will be made toward the betterment of their community.

Bishop highlighted barriers to health literacy that have been documented in the literature (Zarcadoolas et al., 2003) include the following:

1. Complexity of written health information in print and on websites.
2. Lack of health information in languages other than English and inadequate translations.
3. Lack of cultural appropriateness of health information.
4. Inaccuracy or incompleteness of information in mass media.
5. Low-level reading abilities, especially among undereducated, elderly, and some segments of ethnic minority populations.
6. Lack of empowering content that targets behavior change as well as direct information (social marketing strategies).

Bishop said the Minnesota Department of Health is addressing the lack of cultural appropriateness of health information (item number three) because of the large and growing immigrant population in the state. In recent years there has been an influx of individuals from East and West Africa. He added that there is an established Hmong population from Laos and Vietnam and a rapidly growing Hispanic population.

To illustrate some of the challenges of working with the state’s immigrant population, Bishop described a Diabetes Prevention Program that had been successfully used with the uninsured and Medicaid populations. When implemented within the Somali population, the program had to be adapted several times before it engaged the audience. The sessions had to be shortened, rearranged, and made to be more hands-on with the use of graphic materials. The results, in terms of weight loss and physical exercise, were disappointing; however, there was some improvement in body mass index at the conclusion of the modified program. Bishop suggested that a research study is warranted to see if the incorporation of some health literacy principles into a redesign of the program would improve its effectiveness.

Bishop described some of the sociodemographic characteristics of Minnesota that are barriers to health literacy:

- By 2030, the number of Minnesotans over age 65 will double so that the elderly will represent 20 percent of the population. He

said that poorly educated rural Minnesotans are a potential target group for health literacy interventions.

- The state's schools have become increasingly segregated with, in Bishop's opinion, charter schools diverting resources from the public schools. A student's worldview is narrower in a segregated school environment.
- In 2012, half of students of color graduated from high school in 4 years. For the white population, the rate was 84 percent.
- Homeownership is nearly twice as high in the white, non-Hispanic population (76 percent) than it is in populations of color (39 percent).
- Roughly 25 percent of the foreign-born adult population (of any race) lack a high school degree (or equivalent) as compared to 6 percent who were born in Minnesota. Of all the African American children in the state, 35 percent have a foreign-born parent. Among children under age 20, one in six is the child of an immigrant; for children under age 5, it is one in five.
- In 2011, among those under age 65, 29 percent of Hispanics and 25 percent of African Americans who were foreign born lacked health insurance.
- Minnesota includes 12 Native American reservations. Many Native Americans lack health insurance (23 percent), but most have access to the Indian Health Service.

Bishop said the Patient Protection and Affordable Care Act, including an expansion in Medicaid coverage for those living below 138 percent of the federal poverty level, is expected to reduce the number of Minnesota residents who are uninsured by half (from 485,000 in 2010 to between 159,000 and 254,000 in 2016).

Using data from the 2007-2011 American Community Survey, areas projected to have low health literacy were mapped by Census tract (see Figure 5-1). A low health literacy composite score (from 0 to 6) was calculated that considered six sociodemographic attributes of Census tracts. Areas that were projected to have the lowest health literacy were considered to be those tracts with two to six of the following attributes:

1. Fewer than 25 percent of residents were non-Hispanic white.
2. More than 15 percent of residents reported that they spoke English "less than very well."
3. More than 20 percent were foreign born.
4. More than 16 percent were living in poverty.
5. More than 23 percent were 65 or older.
6. Fewer than 75 percent had completed more than a high school education.

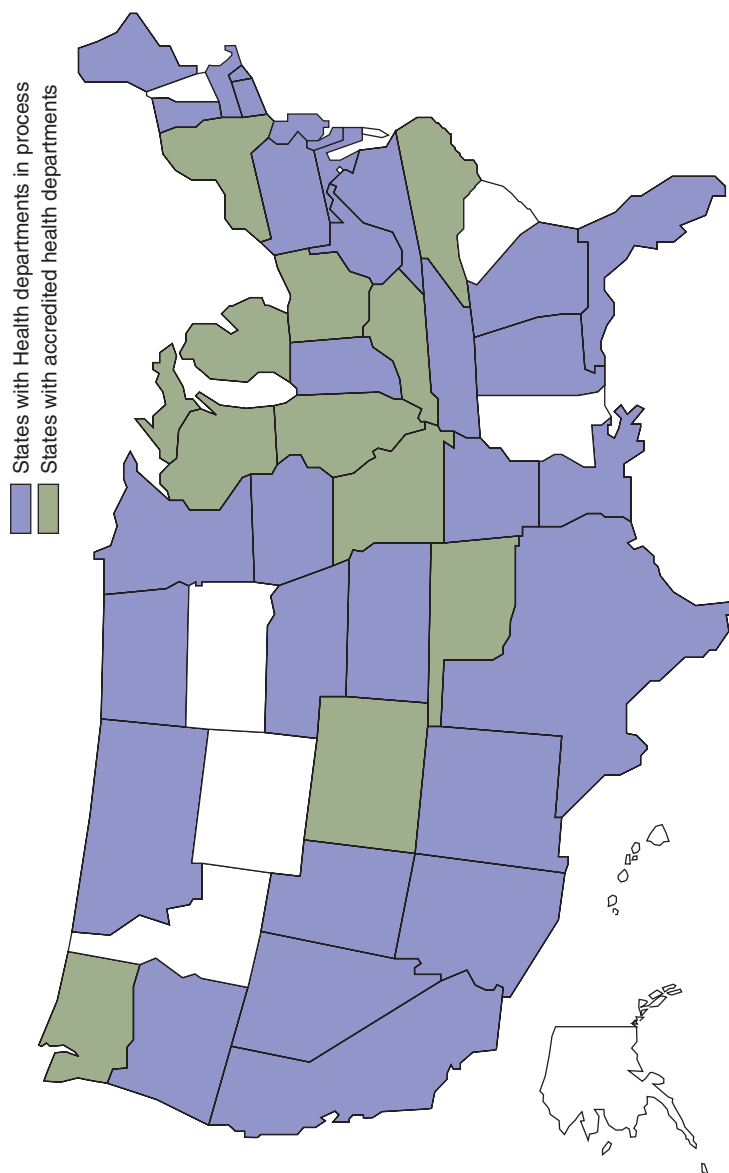


FIGURE 5-1 Status of accreditation of public health departments.
NOTE: Distribution of Health Departments map is updated weekly on the PHAB website under *News, Latest News and Events*, <http://www.phaboard.org/distribution-of-health-departments-in-e-phab>. Reprinted with permission.
SOURCE: PHAB, 2011.

The cities of Minneapolis and St. Paul were found to have a much higher prevalence of low health literacy relative to the rest of the state. Seventy Census tracts (65 within the Twin Cities Metro Area) had at least three or more risk factors, with poverty, limited English, and being foreign born seen in combination in 80 percent of those tracts. Age (over 65 years) was a factor in only one of those tracts. Throughout the more rural parts of Minnesota, 17 tracts met two or more of the risk criteria, with poverty being present in 90 percent and age in 50 percent of those tracts.

Bishop described an intervention used within an East African community to help residents understand and use the U.S. health care system. Trained community health workers made home visits and explained how primary care and urgent care visits could be used instead of the emergency room. This pilot program included more than 500 visits to community members that reduced emergency room visits by half and cut per-patient cost by more than 40 percent. One aspect of the program that was particularly effective was a nurse telephone line that included bilingual staff, Bishop said.

In March 2013, the Center for Health Promotion held a 1-day health literacy workshop. The goal of the workshop was to create a public health workforce at the Minnesota Department of Health that was fluent in health literacy principles and best practices. The learning objectives included the following

1. Define health literacy and describe conceptual models.
2. Discuss the individual, medical, public health, economic, and political importance of health literacy.
3. Identify populations vulnerable to low health literacy rates.
4. Describe effective use of theory-based models in the design and evaluation of culturally sensitive health-literate materials.
5. Give examples of basic concepts for communicating with a diverse audience (e.g., cultural competency, participatory action and learning).
6. Apply lessons learned from the workshop to current public health work for improvement and use in future work.

All workshop participants completed the online health literacy training course available through the Centers for Disease Control and Prevention (CDC) (<http://www.cdc.gov/healthliteracy>). For many participants, this was their first exposure to health literacy. The workshop participants also reviewed the guide at the CDC website, *Simply Put: A Guide for Creating Easy-to-Understand Materials*. The participants were asked to assemble a work team from their program area (e.g., heart disease, stroke, diabetes,

BOX 5-1
Center for Health Promotion
Health Literacy Workshop Agenda

Morning

- Health literacy overview: Don Bishop, Ph.D., Minnesota Department of Health
- Using health behavior theory to target, design, and evaluate health messages: Marco Yzer, Ph.D., University of Minnesota
- Implementing health literacy in a state public health department: Jennifer Dillaha, M.D., Arkansas Department of Health

Lunch

- Video Screening: Say It Visually!: Stan Shanedling, Ph.D., Minnesota Department of Health (<http://www.health.state.mn.us/cvh>) (several 20-second public health messages were shown)

Afternoon

- Break-out group activity building on preworkshop homework applying health literacy tools/strategies to existing Minnesota Department of Health activities: led by Alisha Elwood, M.A., LMFT, Minnesota Health Literacy Partnership, Blue Cross Blue Shield Minnesota
- Panel discussion: Communicating with a diverse audience (Panel: Genelle Lamont, Moderator, M.P.H., DHPE Fellow; Maria Veronica Svetaz, M.D., M.P.H., Hennepin County Medical Center; Sara Chute, M.P.P., Minnesota Department of Health; Mary Beth Dahl, R.N., Stratis Health)
- Wrap-up and final thoughts

SOURCE: Bishop, 2013.

oral health), select a communication item from their area, test it for health literacy, and then try to improve it.

The workshop had 85 participants. The agenda for the workshop is shown in Box 5-1. Bishop said the workshop was well received, but that participants would have liked additional time for practice and feedback with the training exercises. There are plans to develop a standard course that would be available in the health department for new staff and continuing education. In addition, to further advance health literacy at the Minnesota Department of Health, there are plans to

- create a health literacy committee;
- work toward creation of a full-time health literacy coordinator;

- develop a health literacy guidance document;
- develop and formalize staff training curricula in health literacy;
- develop staff competencies and performance measures and monitor written and oral communications for health literacy (a checklist);
- conduct regional health literacy workshops for local public health agencies and communities; and
- develop a State Health Literacy Action Plan with Minnesota partners.

Bishop highlighted the need to consider health literacy as a part of health equity and mentioned that health literacy could be integrated into an upcoming Health Equity Report to the state legislature.

ACADEMIA: PROFESSIONAL TRAINING AND CERTIFICATION

Olivia Carter-Pokras, Ph.D.
University of Maryland School of Public Health

Carter-Pokras said she has worked in public health education and training for three decades, the past 10 years of which have been spent in academia, including 6.5 years in an accredited school of public health. She currently serves on the Education Board for the American Public Health Association (APHA).

The Council on Education for Public Health (CEPH) is the accrediting body for public health schools and programs. The Council has accredited 51 schools and 102 programs, and is reviewing 30 applications for accreditation. According to the Council's most recent data, more than 10,000 public health students graduated in 2009. Enrollment in nonaccredited public health programs exceeded that of accredited programs. Among graduates of accredited programs, 6,700 earned a master's of public health (M.P.H.) degree. Twenty schools and 8 programs have undergraduate programs in public health. Carter-Pokras added that public health is one of the fastest growing majors in the country. In fall 2013, CEPH finalized procedures for accreditation for new undergraduate programs.

The Association of Schools and Programs of Public Health has developed a core competency model that includes a section on health literacy. Under its competency related to diversity and culture, the Association states that a graduate of an M.P.H. program should be able to explain why cultural competence alone cannot address health disparity. Graduates should also be able to differentiate among the terms "linguistic competence," "cultural competency," and "health literacy" in the context of public health practice. The Association's study guide for students planning to take the

examination for certification in public health does not include the definition of health literacy. The study guide does, however, include the definitions of linguistic competence, cultural competence, and cultural and linguistic competence. In Carter-Pokras' view, this represents a shortcoming and something that could be corrected.

Carter-Pokras, as a graduate of the Bloomberg School of Public Health at Johns Hopkins University, investigated how health literacy was addressed at the school. Carter-Pokras found that within the M.P.H. competencies, there is a section called social and behavioral competencies. There is no specific mention of health literacy, but communication issues are addressed. According to the competencies, graduates with an M.P.H. from Johns Hopkins should be able to "formulate communication strategies for improving the health of communities and individuals and preventing disease and injury."

According to Carter-Pokras' discussions with teaching staff at Johns Hopkins, health literacy is discussed briefly in two of the required courses—Tools of Public Health Practice and Decision Making, and Problem Solving in Public Health. Neither of the courses has assigned readings on health literacy. Instead, the topic is embedded in discussions related to communication. An elective health literacy course is offered.

Carter-Pokras said that the absence of a focus on health literacy at Johns Hopkins is likely not unique and that similar findings would probably be observed in schools across the country. She talked to a site visitor for the CEPH accreditation process and learned that during site visits, specific content areas under diversity and culture are not examined in detail.

Turning to undergraduate public health education, Carter-Pokras described CEPH's new guidelines for accreditation as having a section on skills, domains, cross-curricular concepts, and diversity. She noted that all of these topics pertain to health literacy. For example, under skills, the ability to communicate public health information to diverse audiences is included. The guidelines do not explicitly say health literacy, but it fits well under these sections. CEPH has provided some examples of competencies for undergraduate public health programs. For example, Temple University includes the competency, "differentiate among linguistic competence, cultural competency, and health literacy in public health practice." Temple offers several courses that could include health literacy, including "Ethnicity, Culture, and Health" and "Health Communication."

Carter-Pokras next addressed the issue of whether schools with public health programs are meeting the needs of the workforce. She discussed the status of accreditation of public health departments as of November 2013 (see Figure 5-1). The map in Figure 5-1 shows those states that are accredited (green) and those that are in the process of becoming accredited (blue). Carter-Pokras noted that the accreditation process provides an

BOX 5-2
Accreditation Standards for Public Health Agencies

- Standard 3.1: Provide health education and health promotion policies, programs, processes, and interventions to support prevention and wellness.
—Health literacy should be taken into account, and information should be provided in plain language with everyday examples.
- Standard 3.2: Provide information on public health issues and public health functions through multiple methods to a variety of audiences.
—Produce materials that are culturally appropriate in other languages, at low reading level, and/or address a specific population that may have difficulty with the receipt or understanding of public health communications.
- Standard 7.2: Identify and implement strategies to improve access to health care services.
—Lead or collaborate in culturally competent initiatives to increase access to health care services for those who may experience barriers due to cultural, language, or literacy differences.
- Standard 11.1: Develop and maintain an operational infrastructure to support the performance of public health functions.

SOURCE: PHAB, 2011.

opportunity to promote health literacy because several standards pertain to health literacy (see Box 5-2). Carter-Pokras indicated that Standard 11.1 is where training fits because, in her view, it is an essential component of operational infrastructure.

Carter-Pokras said the Council on Linkages Between Academia and Public Health Practice includes 18 organizations interested in how public health training is meeting workforce needs. The Council has identified the following core competencies for public health professionals:

- Communication skills
 - Tier 1 (entry level): Identifies health literacy of populations served (e.g., ability to understand and use available health information)
 - Tier 2 (program manager/supervisor): Assesses health literacy of populations served

- Tier 3 (senior manager/executive): Ensures that the health literacy of populations served is considered throughout all communication strategies
- Cultural competency
 - All tiers: Incorporates strategies for interacting with persons from diverse backgrounds (e.g., cultural, socioeconomic, educational)

Carter-Pokras described some materials from *Día de la Mujer Latina*, an organization that, as part of its mission, trains Promotores or community-based health educators (<http://diadelamujerlatina.org/promotores/training>). When outlining their core competencies, this group lists health literacy and the CLAS standards (Culturally and Linguistically Appropriate Services) as components of the “communication skills” competency. Carter-Pokras has found that health literacy is often covered in training programs under the areas of cultural competency, health equity, or health disparities. She recommends working with individuals in these areas to incorporate health literacy into their training instead of trying to promote a new mandate for health literacy training. Health literacy and cultural competency can both be appropriately addressed under the rubric of communication skills and interpersonal skills.

As another example of continuing education, Carter-Pokras described a health literacy initiative at the New York City Health Department. The health department received outside funding for 3 years to improve its ability to communicate effectively with functionally illiterate adults. Workshops were held to cover topics such as cultural competency, easy writing, language issues (interpretation and translation), and communication. The training at both the basic and advanced levels reached 800 staff members. Satisfaction with the program was assessed, but there was no evaluation of the program’s long-term impact, for example, to see if it changed trainee behavior and practice. At the conclusion of the 3-year funding cycle, the health literacy training stopped.

Carter-Pokras said there is a need for the topics of health literacy and cultural competency to be integrated within training programs and that such integrated curricula need to be evaluated. With support from the National Institute of Minority Health and Health Disparities, experts in cultural competency, health literacy, and health disparities were convened to discuss their common aims, both programmatically and from a research perspective. Carter-Pokras noted that there are common themes within the two areas of health literacy and cultural competency, and the overarching goal of training in these areas is to reduce disparities. The two topics also rely on a common communication skill set aimed at improving the quality of care. Carter-Pokras observed that curricular time is limited and there is

resistance to adding more to what is already being demanded. She added that training has to make efficient use of limited time. In collaboration with the Maryland Department of Health and Mental Hygiene, and with input from these meetings of experts, a primer was developed that identified core competencies and enumerated relevant resources (<http://dhmh.maryland.gov/mhhd/CCHLP/SitePages/Home.aspx>). One of the resources identified in the primer is the online training for health professionals available through the Health Resources and Services Administration that integrates cultural competency and health literacy.

Research questions were also identified through these meetings that pertain to both health literacy and cultural competency (Lie et al., 2012), including the following:

- What are “best practices” in health literacy and cultural competency training?
- What are effective teaching methods?
- What faculty development is necessary?
- How can we include community stakeholders for health professional training?

Carter-Pokras observed that many players are involved in public health education and health literacy. She added that the requirements for students enrolled in public health programs are not yet synchronized with workforce needs. She has found that health literacy education is variable in public health schools and programs and that education in cultural competency or communication may cover aspects of health literacy. However, in her view, there is much work to be done before the topics are well integrated. For example, she reviewed the indexes of textbooks focused on health disparities and cultural competency that were on display at the November 2013 annual meeting of the APHA and found that none mentioned health literacy. It is imperative that those working on cultural competency and health literacy collaborate and work toward their common goals, Carter-Pokras concluded.

DISCUSSION

Ruth Parker, roundtable member, asked the panel whether a good workforce needs assessment has been completed to inform public health education curricula. Bishop replied that although there is an awareness of the need for such an assessment at the Minnesota Health Department, one has not been performed. He added that in Minnesota, the state agency is separate from the local public health departments. When the local departments heard about the health literacy workshop that was held for staff at

the state health department, they indicated that they also needed training and asked for it. Bishop said the state health department considered conducting regional workshops, but was not sure that the expertise was available locally to offer such workshops. Bishop added that financing such training has become more difficult. The Center for Health Promotion used to have a budget of about \$10 million, but it is down to \$6 million and is expected to decline even further. Bishop said that trying to bring in outside expertise for health literacy training is, therefore, very difficult.

Carter-Pokras pointed out that as part of the public health accreditation process, schools and programs are supposed to conduct a needs assessment that involves contacting potential employers to identify needed areas of training. They are also supposed to check with alumni to find out if, upon graduation, they were well equipped with the skills needed for their job. She gave an example of feedback from a graduate from the University of Maryland's Department of Behavioral and Community Health. When asked about areas of training that could be augmented, this graduate said that in her experience, students are not well prepared to work in low-resource areas. For example, students may, during their training, learn to use qualitative software such as In Vivo, but find that their work environments cannot afford to pay for such software. In other environments, the computers are old and not able to run the software. In general, Carter-Pokras said that students learn about best practices, but are not prepared for the financial and other limitations they encounter in public health settings. This graduate also suggested that the technical jargon and language used to describe research findings and methods need to be simplified, perhaps using diagrams and plain language, so that they can be understood. The graduate observed that it is not just people with low literacy who need such simplified messages. Relatives and members of the community who may have graduated from high school often have difficulty understanding the work of public health practitioners. Carter-Pokras reiterated her point about the accreditation process—reviewers look to see whether the necessary components of a program are in place and not how such components are developed.

Dillaha asked Bishop whether there had been any pushback following the health literacy workshop and whether the workshop had had an impact on the health department's centers. Bishop replied that not as much has happened following the workshop as he had hoped, in part because of limited staffing. However, staff who are very interested in health literacy have been hired. The white paper that will be written for the legislature in 2014 will provide an opportunity to raise awareness of health literacy and how it relates to social determinants of health. He added that the Office of State Health Improvement was recently awarded \$20 million a year to support community health programs. Bishop said that building a health literacy focus into these programs could greatly improve program outcomes.

McGarry asked the panel whether the Certification for Health Educa-

tion Specialist (CHES) pays enough attention to health literacy. Carter-Pokras did not comment on CHES, but said that in her view the certification for public health exam does not sufficiently cover health literacy. She added that the certification requirement for public health programs barely covers issues related to diversity and culture, and students are not getting sufficient exposure to these areas.

McGarry asked the panel whether, in the context of the patient-centered medical home, health coaches and health educators who are trained in public health are the optimal providers to promote health literacy in clinical environments and public health programs. Carter-Pokras replied by emphasizing the need to look at process and systems in promoting health literacy. She said the entire system needs to be responsive to health literacy and there should not be a focus on just one discipline as being primarily responsible. In her view, everyone in schools of public health and all public health workers should be exposed to health literacy and understand how it fits into their work. Bishop added that the scope of health literacy needs to be broadened and fully incorporated into the mission of health departments. Bishop said that the Association of State and Territorial Health Officials would be a good partner in terms of furthering health literacy in public health departments and programs.

Rob Logan from the National Library of Medicine commented that the lack of health literacy-related curricular materials in schools of public health likely explains some of the deficits seen within public health programs. He asked the panel to comment on the courses on health literacy that are offered to undergraduates not associated with a public health program or track. Carter-Pokras replied that some of these courses help undergraduates improve their own health literacy and their ability to search and understand health information for themselves and for their loved ones. Students in public health should acquire these skills, and in addition, be able to improve the health literacy of the populations they will eventually serve. Logan added that he is interested in finding examples of model health literacy efforts directed to elementary, high school, and undergraduate students.

Neuhauser raised the issue of missed opportunities and highlighted the need to consider health literacy in the context of the accountable care organizations created through the Patient Protection and Affordable Care Act. In her view, not enough attention has been paid to health literacy in these organizations and, she suggested, health competencies should be developed for them. Carter-Pokras said that in her experience, individuals and organizations do not want to be confronted with yet another set of competencies. She has found that a single set of core competencies that addresses both cultural competency and health literacy is responsive to this sentiment. Bishop agreed that incorporating health literacy into programs focused on diversity issues, such as the Many Faces conference in Minnesota, is desirable.

THE LONG VIEW

Introduction

*Michael Villaire, M.S.L.M.
Institute for Healthcare Advancement*

Villaire introduced Cecilia Doak, who he described as a pioneer and one of the founders of health literacy. She and her husband, Leonard Doak, wrote what is considered the ultimate document in health literacy, *Teaching Patients with Low Literacy Skills*. This seminal work was published in 1985 and reprinted in 1996. It is no longer in print, but it can be downloaded from the Harvard School of Public Health website.¹

Villaire described the “fortuitous pairing” of the Doaks. Cecilia had focused professionally on public health and patient education, while Leonard came from an adult education and literacy tutoring background. Villaire said one of the attributes of this couple was their spirit of inquiry. They posed questions, made observations, and then got to work. Through their nonprofit organization Patient Learning Associates they presented more than 200 workshops on health literacy for groups of doctors and allied health personnel. Over the years, they analyzed and rewrote more than 2,000 health instructions. A key component to their evaluations was asking the people who had received the materials if they worked. These evaluations led Leonard, in particular, to appreciate the role of pictures in educational materials.

Villaire discussed the creation of the Leonard Doak Memorial Health Literacy Scholarship in 2012 to honor the recently deceased Doak. The first scholarship was presented at the Institute for Healthcare Advancement Health Literacy conference held in May 2013. This scholarship will provide training for students who will subsequently promote health literacy in underserved areas.

Presentation

Cecilia C. Doak, M.P.H.

Doak described some of her early work in health literacy. In June 1978, she and her husband Leonard delivered the first public health address on the problem of health literacy at the Western Branch Public Health Association meeting. The paper, “Health Education for Illiterate Adults,” signaled the

¹ The book, *Teaching Patients with Low Literacy Skills*, can be downloaded at <http://www.hsph.harvard.edu/healthliteracy/resources/teaching-patients-with-low-literacy-skills> (accessed July 25, 2014).

beginning of the Doaks' long career in health literacy. Doak said her husband's interest in health literacy stemmed from his volunteer work. Upon retiring as an electrical engineer, he became a volunteer tutor and taught adults how to read and write. Doak described her early career as a Commissioned Officer in the U.S. Public Health Service working on continuing education for physicians. When she retired, she asked her husband, "What do your students do when they go to the doctor?" He replied that his students "fake it" to avoid embarrassment. The low literacy adults feared that doctors would not treat them if the doctors knew the patients did not understand what the doctors were saying. This realization was the impetus for the Doaks' subsequent work on health literacy.

Doak described an early study completed in 1979 on patient comprehension. This assessment was conducted at the Public Health Service Hospital in Norfolk, Virginia. The study focused on the measurement of comprehension and listening skills. She said the research and the practices of the reading community and the studies in adult education provided the knowledge and skills necessary to complete this work.

Doak spoke about working with Dr. Tom Stitch and his interest in the literacy classes that were being held in group settings. The move to group classes was in response to the great demand for literacy training experienced in the inner parts of Washington, DC, and other cities. In addition to working with low literacy individuals, Doak described working with professionals. The Doaks were sought out by many organizations in need of health literacy training for their staff members. These organizations included the National Institutes of Health, Centers for Disease Control and Prevention, Johns Hopkins University, and many public health federal and state agencies, hospitals, clinics, and medical centers. There was great demand for their training. Doak noted that the term "health literacy" was probably coined in the early 1980s.

From a historical point of view, tremendous progress in health literacy efforts has been made, Doak said. She noted the existence of excellent training and research programs as described throughout the Institute of Medicine (IOM) workshop. She discussed the importance of collaboration between the health literacy and adult education communities. The need for such partnerships was called for over 10 years ago with the report *Communicating Health: Priorities and Strategies for Progress* (HHS, Office of Disease Prevention and Health Promotion, 2003). The IOM report *Health Literacy: A Prescription to End Confusion* (2004) also underscored the importance of these partnerships. Doak said there are good examples of collaboration between health literacy and adult education. In particular, she cited the Health Literacy Study Circles developed by Dr. Rima Rudd (http://www.ncsall.net/fileadmin/resources/teach/nav_ch1.pdf). In Doak's view, this project provides an outstanding example of how to design and implement the health literacy components of the tasks that adults are expected to

perform. This program focuses on the goals of the literacy demand placed on individuals and the actions necessary for the individual to meet literacy challenges. Doak said this focus is one of the most important missing links in a typical patient education program.

Collaboration in other arenas is also important, Doak said. She cited her research collaboration with Dr. Peter Houts. They found that the use of pictures in educational materials enhanced subjects' attention, comprehension, recall, and adherence (Houts et al., 2005). Technology is another area where collaboration and research are needed, said Doak. She cited a paper in the November 2013 issue of *Scientific American* titled "Why the Brain Prefers Paper" (Jabr, 2013). According to this paper, while e-readers and tablets are becoming very popular, reading on paper still has its advantages.

Doak concluded that the future for health literacy is strong and wide open, and will always depend on thoughtful attention. She closed with her favorite quotation: "It's not what they read, it's what they remember that makes them learned."

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6

Reflections on the Presentations and Discussions

Isham invited members of the roundtable to reflect on the day's proceedings. Rudd was impressed with the insightful presentations and said the case studies presented deserve careful examination. She suggested deconstructing these case studies by asking questions such as "Why did you do X first and not Y? How did you do A, B, and C?" In her view, such an analysis will begin to uncover optimal strategies and guide further action.

Alvarado-Little reflected on her experience as a spoken language interpreter and the need to focus on next steps so that there is a plan in place to address the needs of those with low health literacy. She described going into a room with a doctor, providing interpretation services for a patient and family member, and at the conclusion of the visit, having the doctor turn to her and ask, "Do you think they understood everything?" Her response was, "Well, if you're asking me, we should go back in." Alvarado-Little said that from her perspective, there is much work to be done.

McGarry said that during the planning phase of the workshop, he was concerned that health literacy would not be demonstrated adequately in the public health sector. However, he has learned through Pleasant's work and the workshop presentations that health literacy in the context of public health addresses a different set of issues from health literacy in a clinical context. He noted that there are some commonalities. In his view, health literacy needs to be prioritized by public health departments, perhaps within their communication divisions. McGarry added that the project on integrating primary care in public health mounted by the Association of State and Territorial Health Officers offers a great opportunity for the medical and public health communities to work together to achieve common health

literacy goals. Because many health departments provide clinical preventive services and well-child visits, McGarry said the successful Reach Out and Read Program could be expanded substantially in these environments.

Parnell concluded from the presentations that a focus on working in partnerships and through collaboration is needed to find common ground. She added that innovation will help move the health literacy agenda forward, as will adoption of evidence-based best practices. Parnell agreed with Alvarado-Little's comments and said that cultural humility and access to language services are an essential part of health literacy.

Fowler observed that there are many opportunities to promote health literacy within public health departments. She was impressed with the programs that have been put in place in Arkansas, a state with few resources and with communities with unique health literacy challenges, for example, Appalachia. In her view, the health literacy messages conveyed by the poets featured in the workshop were an excellent example of using innovative communication approaches. Based on the day's proceedings, Fowler concluded that the definition of health literacy needs to be updated. She said any updating process would have to consider the many possible ways to communicate with different populations. Fowler reiterated some of the opportunities presented by the Patient Protection and Affordable Care Act (ACA), for example, through accountable care organizations and patient-centered medical homes. She added that there is also value-based purchasing for hospitals under the ACA and, according to this new financing mechanism, 30 percent of the bonus payments to hospitals will be based on patient satisfaction. She said there will be new penalties for hospitals that have higher rates of readmissions. Readmissions are sometimes the result of patients not following directions and not taking their medication because of poor health literacy. Finally, Fowler mentioned that the ACA includes a requirement for health plans to use plain language when describing health benefits and options. For example, the plans will have to provide information on typical out-of-pocket costs related to three common conditions so that individuals considering their insurance options will better understand their coverage.

Robinson said she appreciated learning about oral health literacy issues from Horowitz. She has found many similarities between the issues raised within the health and public health communities and oral health. She pointed out that dental disease is essentially a chronic disease that can be managed in ways that are similar to those used for other chronic diseases. She added that there are many opportunities to work with colleagues and other disciplines to further the health literacy agenda within dentistry. Robinson observed a crosscutting issue across all the workshop panels—champions are needed who can shepherd the cause and provide leadership in their particular sphere of influence on both a community and a systems

level. She described a presentation given by a social scientist at Stanford University, Hayagreeva Rao, at a prevention summit she recently attended that was hosted by the American Dental Association. In his remarks, Rao stated that to have a successful social campaign, an “air war” and a “ground war” are needed. The air war prepares the way for the success of the ground war. Robinson likened the concept of the air war to policies and systems that are in alignment to promote best practices and health literacy. She said examples of the ground war would include community activities such as the poets’ workshops in the Bay Area and the activities described as part of the case studies in Arkansas, Louisiana, and Nebraska. The presentations by the young poets represent a powerful experience that uses emotional content to pull the audience in and prepare them to hear the message. In effect, such approaches make the message very “sticky.” Robinson said she agreed with Rudd that we cannot wait for the educational sector to inform the public. People are dying. This is a call to action. Public health departments play a major role in this process, but they require resources to become fully equipped to assume these responsibilities, Robinson said.

Hall observed that there was a recurring theme throughout the day, “What gets measured gets managed.” In the context of informed consent, she noted that such consent was obtained to protect providers and organizations from lawsuits. She asked, “What if the consent process was designed and measured in a way that protected the patient and served to truly educate the patient?” She suggested that the development of metrics and the act of measuring could be an effective driver of change. In her experience, change does not happen until there is a metric assigned to the behavior or activity. Once the metric is in place, people start to buy in because they understand the importance and value of the behavior being measured. In this world of competing priorities and information overload, introducing health literacy to an organization is all too often perceived as yet another work stream. Adoption of health literacy would be more likely, she said, if it is introduced and integrated with other programs and services for which there are metrics.

Logan found Rudd’s focus on the importance of community and civic engagement to be critical to the success of health literacy efforts. He said that Neuhauser nicely operationalized the process of engagement in the seven steps that she described as essential to the success of a health communication intervention.

Parson summarized in three words the main points she took away from the workshop: communication, partnership, and innovation. She reiterated a point made by Rudd that any communication strategy has to focus on “who it should be by” and “who it should be for.” She said communications must be designed so that they effectively reach diverse populations. Parson also found illuminating the presentations on new technology and social

media that encourage participation of young people and novel approaches to communication. She added that communication and education need to begin in preschool and continue throughout the educational trajectory.

Wayte said he benefitted from Horowitz's description of ways to encourage mothers to adopt good oral health habits for their infants. He said that in the area of heart disease and stroke, there are also teachable moments that can motivate individuals to create new habits. The work of the poets as part of The Bigger Picture project is inspiring, he said. His organization is also relying on social media campaigns, health technology, and art to communicate public health messages, especially in the area of women's health.

Rush observed that health insurance companies and others have many messages they want to communicate. He learned from the presentations that success hinges on how messages are delivered and how consumers are involved in understanding and crafting the messages. He noted that it is not what individuals read, but what they remember that is important. Rush found that the workshop has provided a great impetus for collaborations among health literacy, public health, and the health system to further improve communication through simple, accessible, understandable, and actionable ways. He added that there are also opportunities for collaboration on research to determine the impact of health literacy interventions and public health messages.

Parker reiterated the need for public health literacy measures and the sentiment that "what gets measured gets done." She noted that a publication she coauthored in 2005 with Julie Gazmararian, Jim Curran, and Barbara DeBuono discussed the need for such measures. Parker said there is an opportunity to develop such measures with the implementation of the ACA.

Brach said that health literacy in the context of public health or health care have much in common. For example, she said, they both need to address workforce training issues; involve the communities they serve and the target audiences of their messages; use models and tools to make their work easier; and address the challenges of adoption and dissemination. She found it heartening to see how the attributes of a health-literate organization, which was developed with health care delivery organizations in mind, appeared to have relevance and be helpful to those leading the way in public health.

Pleasant raised the issue of the medical and social needs of the more than 10 million individuals who are incarcerated, many of whom are of low health literacy. He said there is a potentially great opportunity to address health literacy in a public health context with this population. He reported that individuals in jails and prisons account for 19 percent of all HIV cases, 30 percent of all hepatitis C cases, and 15 percent of all hepatitis B cases.

He added that more than 30 percent of this population suffers from a mental health condition, and more than half have some form of addiction. In his opinion, attention to this population provides an incredible opportunity to advance not only public health, but to prove the validity and usefulness of health literacy. He indicated that this topic would be timely for graduate students to consider.

Pleasant said the intention of the commissioned paper was to perform a critical analysis to illustrate the opportunity that health literacy presents to improve public health at a lower cost. He added that there was no intention to criticize public health. He said the authors of the commissioned paper decided to characterize the extent to which public health departments had decided that health literacy was important enough to highlight so that when the investigators called or e-mailed, their front office person would be able to identify someone connected to health literacy within the organization. He pointed out that if the health department did not answer the survey, or could not identify such a person, it did not necessarily mean that the health department was not involved in health literacy activities.

In Pleasant's opinion, health literacy should be highlighted as an important and critical part of the mission of public health. On the topic of health literacy training, Pleasant noted that the Ohio State University College of Nursing will soon have an undergraduate degree in health and wellness innovation and health literacy. There is also a university-wide health wellness initiative called Buckeye Wellness.

In response to Isham's invitation to audience members to pose questions, Marie Fongwa, a member of the audience, discussed the importance of integrating the topics of health literacy, cultural competence, and health disparities into program planning. She cautioned that health literacy is not just a concern of ethnic or racial minority groups, however. Many individuals, even those who are highly literate, cannot interpret the health care jargon. She noted that health literacy is part of being culturally competent. Audience member Shanpin Fangchiang agreed and said everyone can be considered a learner. She added that health literacy could be incorporated into several areas within a school's curriculum.

Carter-Pokras said that public health and health literacy will be major themes at education sessions at the 2014 American Public Health Association meeting in New Orleans.

Bishop discussed the role of communications offices within health departments. Many of these offices have a public relations function and so do not have a health literacy focus. He said that ideally, communication offices would be involved in health literacy and would have staff that could offer expertise and assistance to other offices within health departments. He said such in-house expertise could help with politically charged issues such as gun control and water fluoridation. His state is addressing proposed

changes to the level of fluoride in drinking water and the public is seeing competing messages from the government and advocacy groups about the benefits and risks of fluoride. Educating the public on these complex issues is challenging and in need of communication and health literacy expertise.

Dillaha said cultural competency and health literacy encompass the notion of equal opportunity for health and respect for all persons.

Isham observed that in its early days, health literacy addressed issues related to the communication between individual patients and providers within the health care system. Health literacy in the context of public health is different insofar as it addresses the health of populations in diverse geographic settings. He found this concept well illustrated in Bird's presentation when she said that an individual living in an area with relatively high health literacy benefits from the knowledge and ability of friends and neighbors. In contrast, those living in areas of low health literacy may not benefit from such interactions and, in fact, such interactions may be counterproductive. Isham added that what happens in populations actually matters to individuals in those populations. In addition, it is not just interventions that affect the ability of individuals to act on their own behalf, but also interventions that change the environment in which individuals live. This is an area that needs more attention, said Isham.

Isham said that Pleasant's background paper provided important information on the crisis facing contemporary public health departments in terms of both resources and skills. The attributes of a health-literate health care organization need to be adapted and expanded to be relevant to public health organizations, Isham said. These attributes may vary for federal, state, or local organizations. He said he was at times optimistic when hearing about the present state of health literacy training, but was left concerned at the conclusion of the workshop about opportunities for preparing the future public health workforce. Lastly, there is wide variation in definitions of public health literacy that are used across the country, and reaching a consistent view of the concept is one of the many challenges ahead, Isham said.

Appendix A

Meeting Agenda

Implications of Health Literacy for Public Health
November 21, 2013

Arnold and Mabel Beckman Center
100 Academy Drive
Irvine, CA 92612

- 8:30-8:45 Welcome, Workshop Overview, Introduction of First
Three Speakers
George Isham, M.D., M.S., Roundtable Chair
- 8:45-10:00 Panel: Health Literacy and Public Health: An Overview
- 8:45-9:00 Public Health Literacy
Rima Rudd, Sc.D.
*Senior Lecturer on Health Literacy, Education, and
Policy*
Harvard School of Public Health
- 9:00-9:15 Reframing Health Literacy as a Public Health Issue
Chloe E. Bird, Ph.D.
Senior Social Scientist
The RAND Corporation
- 9:15-9:30 Presentation of Commissioned Paper
Andrew Pleasant, Ph.D.
Senior Director for Health Literacy and Research
Canyon Ranch Institute
- 9:30-10:00 Discussion

98	<i>IMPLICATIONS OF HEALTH LITERACY FOR PUBLIC HEALTH</i>
10:00-10:15	BREAK
10:15-12:00	Panel: Current Health Department Efforts in Health Literacy
10:15-10:20	Introductions
10:20-10:40	Louisiana <i>Torrie T. Harris, Dr.P.H., M.P.H.</i> <i>Division Director</i> <i>Louisiana Public Health Institute</i>
10:40-11:00	Nebraska <i>Susan Bockrath, M.P.H., C.H.E.S.</i> <i>Health Literacy Consultant</i> <i>Project Director, NALHD Outreach Partnership to Improve Health Literacy</i>
11:00-11:20	Arkansas <i>Jennifer Dillaha, M.D.</i> <i>Medical Advisor for Health Literacy and Communication</i> <i>Arkansas Department of Health</i>
11:20-12:00	Discussion
12:00-1:00	LUNCH
1:00-2:45	Panel: Health Literacy Facilitates Public Health Activity (each presenter will have 20 minutes)
1:00-1:05	Introduction of Speakers
1:05-1:25	Applying Health Literacy Principles to Public Health Efforts in Preparedness and Nutrition <i>Linda Neuhauser, Ph.D.</i> <i>Clinical Professor, Co-Principal Investigator,</i> <i>Health Research for Action</i> <i>University of California, Berkeley, School of Public Health</i>

- 1:25-1:45 Chronic Disease Prevention
Jennifer Cabe, M.A.
Executive Director
Canyon Ranch Institute
- 1:45-2:05 The Bigger Picture: Harnessing Youth Voices to Improve
Public Health Literacy in Diabetes
Dean Schillinger, M.D.
Professor of Medicine, University of California,
San Francisco
Chief, Internal Medicine, San Francisco General
Hospital
- Poets Jose Vadi and Gabriel Cortez*
- 2:05-2:25 Oral Health
Alice M. Horowitz, Ph.D., R.D.H.
Research Associate Professor
University of Maryland School of Public Health
- 2:25-2:45 Discussion
- 2:45-3:00 BREAK
- 3:00-4:00 Panel: Supporting Public Health Implementation and
Research
- 3:00-3:05 Introduction of Speakers
- 3:05-3:20 Departments of Public Health: Workforce Development
Don Bishop, Ph.D.
Chief, Center for Health Promotion
Minnesota Department of Health
- 3:20-3:35 Academia: Professional Training and Certification
Olivia Carter-Pokras, Ph.D.
Associate Professor
University of Maryland School of Public Health
- 3:35-4:00 Discussion

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IMPLICATIONS OF HEALTH LITERACY FOR PUBLIC HEALTH

4:00-4:15

The Long View

Introduction by *Michael Vailaire, M.S.L.M.,*

Institute for Healthcare Advancement

Presentation by *Cecilia C. Doak, M.P.H.*

4:15-4:45

Reflections on the Day (RT members are each asked to identify one key point from the day's presentations)

4:45-5:15

Participant Discussion

5:15

ADJOURN

Appendix B

Speaker Biosketches

Chloe E. Bird, Ph.D., is a senior sociologist at the RAND Corporation, where she studies gender differences in physical and mental health and social determinants of health. She is also a professor at the Pardee RAND Graduate School. She is Principal Investigator of a study of the impact of neighborhoods and behaviors on allostatic load and morbidity and of a study funded by the National Heart, Lung, and Blood Institute of neighborhood effects on incident cardiovascular disease among women based on data from the Women's Health Initiative. In her book *Gender and Health: The Effects of Constrained Choice and Social Policies* (Cambridge University Press, 2008), Dr. Bird and coauthor Patricia P. Rieker highlight promising new approaches to integrating biological and social research and provide examples of innovative developments that transcend the long-standing, discipline-focused division of labor in the research community. Dr. Bird received her Ph.D. from the University of Illinois at Urbana-Champaign.

Don Bishop, Ph.D., is director of the Center for Health Promotion at the Minnesota Department of Health and an adjunct associate professor at the University of Minnesota School of Public Health. He is a past president of the Directors of Health Promotion & Education, a national association of state health promotion directors. At the Minnesota Department of Health, he oversees the Heart & Stroke, Diabetes, Injury & Violence, and Oral Health state programs. He has served as principal investigator on several National Institutes of Health (NIH) research studies to design and test behavioral and environmental change programs that support healthy dietary choices and increased physical activity in preschool and primary

school settings with diverse student populations. These programs include WOLF (Work Out Low Fat), LANA Preschool Program (Learning About Nutrition through Activities), and American Indian Children Walking for Health. Dr. Bishop received his doctorate in psychology from North Carolina State University and was a postdoc in health psychology at Washington University in St. Louis.

Susan Bockrath, M.P.H., has worked for the past two decades to improve health care and educational opportunities for individuals and communities in Georgia, Minnesota, Missouri, Nebraska, and Rhode Island. Since 2006, Bockrath has developed and implemented several health literacy programs and curricula for English-language learner (ELL) adults. More recently her work has focused on building health professionals' and educators' health literacy skills as well as improving their access to related resources and support.

Bockrath is a founding member and current chair of Health Literacy Nebraska. She is also the owner of the consulting firm, ELL Health Literacy, where she provides project management and evaluation services to clients in public health and health care. Since 2012, the biggest portion of her work has been as project director to the Outreach Partnership to Improve Health Literacy (OPIHL). In that role, she provides health literacy training, resources, and technical assistance to rural local health departments and their partners, serving 84 counties across Nebraska. OPIHL is a project of the Nebraska Association of Local Health Directors and is funded by the Health Resources and Services Administration's Rural Health Care Services Outreach Program. She holds a master's degree in public health from the Emory University Rollins School of Public Health and has completed doctoral coursework in Health Promotion and Disease Prevention Research at the University of Nebraska Medical University College of Public Health.

Jennifer Cabe, M.A., leads strategic and operations functions for Canyon Ranch Institute, a 501(c)3 nonprofit public charity. Canyon Ranch Institute catalyzes the possibility of optimal health for all people by translating the best practices of Canyon Ranch and our partners to help educate, inspire, and empower every person to prevent disease and choose a life of wellness. Partners include The Clorox Company, The George Washington University, LIVESTRONG, and the University of Arizona. Cabe joined Canyon Ranch Institute in 2007, and was elected to the Board of Directors in 2011.

Cabe previously served in the Office of the Surgeon General as communications director and speechwriter for U.S. Surgeon General Richard H. Carmona. In that capacity, she developed health literacy initiatives with advocacy groups, community leaders, health professionals, policy makers, and the public. In 2005, Cabe was awarded the Surgeon General's Medal-

lion, which is the highest honor that the U.S. Surgeon General can confer. She also received the prestigious U.S. Department of Health and Human Services Honor Award for her role in developing the “U.S. Surgeon General’s Family History Initiative.” In 2006, she was awarded the NIH Team Merit Award for her work on The Cancer Genome Atlas, a collaboration of the National Cancer Institute and the National Human Genome Research Institute. Prior to joining the Office of the Surgeon General, Cabe was communications officer at the NIH Fogarty International Center.

Cabe is currently a member of the faculty of The Ohio State University College of Nursing. She is also chair of the National Call to Action on Cancer Prevention and Survivorship Council of Experts and serves on the advisory board of the Partnership to Fight Chronic Disease. She is also on the advisory board for Time to Talk **CARDIO**, an online health literacy program that received the Institute for Healthcare Advancement’s (IHA’s) Health Literacy Innovation Award in 2010. Cabe earned a B.A. in English and communication at Trinity University in San Antonio, Texas, and an M.A. in public communication at American University.

Olivia Carter-Pokras, Ph.D., is an associate professor in Epidemiology at the University of Maryland College Park School of Public Health (UMCP-SPH). A health disparities researcher for three decades in the federal government and academia, Dr. Carter-Pokras has been recognized by the Governor of Maryland, Surgeon General, Assistant Secretary for Health, and Latino Caucus of the American Public Health Association (APHA) for her career achievements in improving health care quality for Latinos, improving racial and ethnic data, and developing health policy to address health disparities. While at UMCP-SPH, she has focused her research, service, and education efforts on supporting translation of epidemiologic research into policy and practice to improve Latino population health. Dr. Carter-Pokras is an elected Fellow of the American College of Epidemiology and a member of the APHA’s Education Board. She currently chairs the American College of Epidemiology’s Policy Committee, and has served on the Institute of Medicine’s (IOM’s) Advancing Pain Research, Care, and Education Committee. A long-time member of Montgomery County, Maryland’s Latino Health Steering Committee, Dr. Carter-Pokras conducts health assessments of Latinos in Montgomery County and Baltimore in close partnership with local government and community-based organizations. She has led NIH-funded research projects to develop cultural competency and health literacy curricula, and addressed oral health of Latino and Ethiopian children and their mothers. She is the evaluation director for the Centers for Disease Control and Prevention–funded Prevention Research Center at the University of Maryland. Dr. Carter-Pokras has published more than

55 peer-reviewed journal articles, and her research has played a critical role in national recognition of health disparities experienced by Latinos. Dr. Carter-Pokras lectures on chronic disease epidemiology, epidemiologic methods, cultural competency, and health disparities to public health students and health professionals.

Jennifer Dillaha, M.D., is director of the Center for Health Advancement for the Arkansas Department of Health. Since joining the department in 2001, she has played a leading role in the agency's health promotion efforts, using a life-stage approach that focuses on population-based interventions to reduce the burden of chronic disease among all Arkansans. Under her leadership, the department has made improving health literacy a crosscutting strategic priority that is fundamental to its prevention efforts. Dr. Dillaha is a physician with specialty training in internal medicine and subspecialty training in infectious diseases and in geriatric medicine. She also has faculty appointments as an assistant professor in the University of Arkansas for Medical Sciences College of Public Health and College of Medicine.

Cecilia C. Doak, M.P.H., has had a dual career: her first was as a commissioned officer in the U.S. Public Health Service, serving as a health educator in the Indian Health programs, and later as director of education for the Cancer Control Program. This included work on the initial pap test program and anti-smoking education. She was one of the first two women to receive the Surgeon General's Commendation Medal for her work. With husband Leonard, they formed the nonprofit Patient Learning Associates. Together they presented more than 200 1- and 2-day workshops on health literacy for groups of doctors and allied health personnel. Over the years, they analyzed more than 2,000 health instructions in nearly all media. Doak is the lead author of their book *Teaching Patients with Low Literacy Skills*, which received a Book of the Year Award from the *American Journal of Nursing*.

Torrie T. Harris, Dr.P.H., M.P.H., is the division director for community health at the Louisiana Public Health Institute in New Orleans. Dr. Harris oversees the growth and development of community health programs that promote and improve health and quality of life at the state, local, and neighborhood levels in Louisiana. Through public-private partnerships with government, foundations, academia, and community groups, the Community Health Division implements programs such as the Louisiana Campaign for Tobacco-Free Living, Healthy New Orleans Neighborhoods Projects, Bike and Pedestrian Safety Infrastructure, and the Centers for Community Capacity. Previously, Dr. Harris served as the director of

Kentucky's Office of Health Equity and was an assistant professor at the University of Kentucky College of Public Health, teaching courses on health disparities, public health leadership, and cultural and linguistic competency. While in Kentucky, Dr. Harris led initiatives to enhance health department organizational capacity to offer culturally appropriate services to disadvantaged populations. She also developed a statewide health equity coalition that influenced a focus by the state health department on health literacy to improve access to quality health care. Dr. Harris obtained her Doctorate in Public Health in Health Behavior at the University of Kentucky and completed a Postdoctoral Fellowship in Public Health Systems and Services Research. Dr. Harris also obtained a master's of public health in maternal and child health from Tulane University School of Public Health and Tropical Medicine and a B.S. in chemistry from Xavier University of Louisiana.

Alice M. Horowitz, Ph.D., RDH, is a research associate professor at the University of Maryland School of Public Health. Formerly she was a senior scientist in the Division of Population and Health Promotion Sciences at the National Institute of Dental and Craniofacial Research (NIDCR). She was a primary architect of the Maryland State Oral Cancer Prevention and Early Detection coalition. She initiated both state and national research on what health care providers and the public know and do about oral cancer prevention and early detection. She has initiated statewide research on what the public knows and does about preventing dental caries and their perceptions of communication skills of dental providers, and on health care provider (physicians, nurse practitioners, dentists, and dental hygienists) reported use of recommended communication practices. She served as the NIH lead for the *Healthy People 2010* oral health chapter and worked on *Healthy People 2000*. She organized the NIDCR's workshop on oral health literacy and coauthored the resultant findings. She has published more than 125 scientific papers and book chapters and is the recipient of numerous awards. Dr. Horowitz holds a Ph.D. in Health Education from the University of Maryland, College Park.

Linda Neuhauser, Dr.P.H., M.P.H., is a clinical professor of Community Health and Human Development at the University of California (UC), Berkeley, School of Public Health. Her research, teaching, and practice focus on translating research findings into improved health programs and policies. She uses participatory approaches to create communication that is relevant to the literacy levels, languages, cultures, and functional needs of the intended audiences. She is internationally known for her success in helping government agencies, community programs, and private industry understand and design better health communication. She is the recipient of numerous awards, including the Charles Atkin Outstanding Translational

Health Communication Scholar Award, Archstone Foundation Award for Excellence, IHA First Place Health Literacy Award for Published Materials, and Pfizer Visiting Professor of Health Literacy Award.

Dr. Neuhauser is Principal Investigator of the UC Berkeley Health Research for Action Center, which works with diverse groups to research health issues and to codesign and evaluate multimedia health communication resources, which have now reached more than 40 million households in the United States and overseas. She has served on federal task forces on e-health communication; was a participant in the Surgeon General's Workshop on Health Literacy and the federal Quality Health Website Usability Panel; and was a founding member and is currently an ad hoc advisor to the U.S. Food and Drug Administration's Risk Communication Advisory Committee. She was previously a health officer in West and Central Africa with the U.S. Agency for International Development.

Andrew Pleasant, Ph.D., has had an interest in communication, literacy, and social change started while working on his parents' small-town weekly newspapers. That early inspiration underpins his ongoing professional practice and research in health literacy; science, risk, and environmental communication; and social marketing.

He joined Canyon Ranch Institute in 2009. Canyon Ranch Institute catalyzes the possibility of optimal health for all people by translating the best practices of Canyon Ranch and its partners to help educate, inspire, and empower every person to prevent disease and choose a life of wellness. He is responsible for advancing the role of health literacy across Canyon Ranch activities. He also leads all research and evaluation activities, and is the program manager for partnerships with Time to Talk CARDIO, BSCS, The Cleveland Clinic, and The Clorox Company. Dr. Pleasant also has a faculty appointment with The Ohio State University College of Nursing.

Dr. Pleasant has led and participated in hundreds of presentations and trainings in the United States and around the world, primarily on health literacy and science, risk, and environmental communication. He has taught at Cornell University, Brown University, and Rutgers University. He served as a temporary advisor at the World Health Organization Health InterNetwork in Geneva, Switzerland, where he reviewed and evaluated the long-term sustainability and local ownership of the Health InterNetwork India pilot project.

Dr. Pleasant has published numerous peer-reviewed journal articles and technical reports, and is coauthor of the book *Advancing Health Literacy: A Framework for Understanding and Action* (2006). He has served on several advisory board committees, including the Community Advisory Committee of Horizon NJ Health, New Jersey's largest health care management company; the New Jersey health literacy coalition; and

the Mayibuye Wetlands Programme in Soweto, South Africa. He is also a member of the scientific committee of the Public Communication of Science and Technology Network and represents Canyon Ranch Institute on the IOM's Roundtable on Health Literacy. During his earlier career as a journalist, he received numerous awards for photojournalism and reporting on national and international topics. He earned a bachelor's degree in journalism from Arizona State University; a master's degree in environmental studies from Brown University; and a doctorate in communication from Cornell University.

Rima Rudd, Sc.D., M.S.P.H., is the senior lecturer on Health Literacy, Education, and Policy at the Harvard School of Public Health. Her work centers on health communication and on the design and evaluation of public health community-based programs. Since 1988, she has been teaching courses on innovative strategies in health education, program planning and evaluation, psychosocial and behavioral theory, and health literacy. Her research inquiries and policy work are focused on literacy-related disparities and barriers to health programs, services, and care, and she works closely with the adult education, public health, oral health, and medical sectors.

Dr. Rudd wrote several reports that helped shape the agenda in health literacy research and practice. They include the health literacy chapter of the U.S. Department of Health and Human Services report *Communicating Health: Priorities and Strategies for Progress* (2003) and helped shape the 2010 *National Call for Action*. She coded all health-related items in the international surveys for assessments of adult literacy skills, enabling the United States, Canada, Australia, New Zealand, and other countries to assess national health literacy skills. She authored the Educational Testing Services report *Literacy and Health in America* (2004) and contributed to other national assessments. Dr. Rudd provided two in-depth literature reviews (Review of Adult Learning and Literacy, volume 1 in 2000 and volume 7 in 2007). She served on the IOM Committee on Health Literacy, the National Research Council Committee on Measuring Adult Literacy, the NIDCR Workgroup on Oral Health Literacy, and the Joint Commission Advisory Committee on Health Literacy and Patient Safety. She contributed to the ensuing reports and white papers as well as to several IOM Roundtable on Health Literacy publications. She has received national and international awards for her work in health literacy. Most recently, the University of Maryland named a doctoral scholar's award in her honor.

Dean Schillinger, M.D., is Professor of Medicine in Residence at the University of California, San Francisco (UCSF), and chief of the UCSF Division of General Internal Medicine at San Francisco General Hospital (SFGH). He is a practicing primary care physician at SFGH, an urban public hospi-

tal, where he sees patients, teaches in the primary care residency program, and conducts research. Dr. Schillinger also serves as chief of the Diabetes Prevention and Control Program for the California Department of Public Health. He conducts research related to health care for vulnerable populations, and is an internationally recognized expert in health communication science. His work focuses on literacy, health communication, and chronic disease prevention and management. He has been honored with the 2003 Institute for Healthcare Advancement Research Award; the 2008 Research Award in Safety and Quality from the National Patient Safety Foundation; the 2009 Engel Award in Health Communication Research; and the 2010 Outstanding Bay Area Clinical Research Mentor. He authored a 2012 commissioned IOM paper on the attributes of Health Literate Healthcare Organizations. Dr. Schillinger is the founding director of the UCSF Center for Vulnerable Populations, whose mission is to carry out innovative research to prevent and treat chronic disease in populations for whom social conditions often conspire to both promote chronic disease and make its management more challenging. Dr. Schillinger currently directs the Center for Vulnerable Populations Health Communications Program.

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Appendix C

A Prescription Is Not Enough: Improving Public Health with Health Literacy¹

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A PRESCRIPTION IS NOT ENOUGH: IMPROVING PUBLIC HEALTH WITH HEALTH LITERACY

Health literacy is always present, but too often neglected. This article focuses on the use—and the lack of use—of health literacy within efforts to address public health in the United States. In particular, this article focuses on efforts within state, local, tribal, and territorial public health organizations. Overall, while a growing body of evidence strongly suggests that health literacy can be effective in public health when explicitly addressed, the concept and associated best practices of health literacy do not seem to be consistently or universally used within public health organizations. As a result, the effectiveness of public health efforts is reduced and public health suffers.

Successfully integrating the best practices and knowledge of health literacy into public health practice is likely the most significant opportunity that currently exists to improve individual, community, and public health.

The overall body of evidence regarding health literacy has clearly advanced to the point where it is logically impossible to conceive of a situation wherein health literacy is not at least a partial determinant of public health status. More likely, as more and stronger evidence is clearly war-

ranted, health literacy is among the strongest determinants of public health in the United States.

A practical corollary of that observation is that health literacy should be an explicit component of the design of all public health interventions and robustly embedded within the structure and function of public health organizations. Neither of those attributes seems to be the case universally in the vast majority of public health organizations at this point in time across the United States. Exceptions do exist, and this article explores three examples through a case study approach.

In 2000, nearly 14 years ago, Donald Nutbeam wrote as the first line of an article proposing that health literacy is an explicit goal of public health, but “health literacy is a relatively new concept in health promotion” (Nutbeam, 2000). Health literacy is no longer a new idea in health promotion, public health, or clinical practice. However, the uptake of health literacy into actual application through organizational structure and daily practice remains in its infancy. Perhaps efforts like the recent paper by Brach and colleagues (2012) focusing on the attributes of a health-literate organization will have a positive effect on this situation.

However, as this article will illustrate, public health departments currently seem not to be universally or explicitly addressing health literacy. IOM reports focused on public health, such as the recently released *U.S. Health in International Perspective: Shorter Lives, Poorer Health*, also fail to explicitly mention health literacy. Although the content of that report makes the importance of health literacy exceeding clear, health literacy as an approach to improving public health is not explicitly addressed (NRC and IOM, 2013).

In 2006, a report about the U.S. Surgeon General’s Workshop on Improving Health Literacy concluded with several observations from then-Acting Surgeon General Kenneth Moritsugu:

First, that we must provide clear, understandable, science-based health information to the American people. In the absence of clear communication and access, we cannot expect people to adopt the health behaviors we champion. Second, the promises of medical research, health information technology, and advances in healthcare delivery cannot be realized if we do not simultaneously address health literacy. Third, we need to look at health literacy in the context of large systems—social systems, cultural systems, education systems, and the public health system. Limited health literacy is not an individual deficit but a systematic problem that should be addressed by ensuring that healthcare and health information systems are aligned with the needs of the public and with healthcare providers. Lastly, more research is needed. But there is already enough good information that we can use to make practical improvements in health literacy. (Office of the Surgeon General, 2006)

Now, 8 years later, those four recommendations, by and large, remain unfulfilled. What we know is possible through the limited yet growing body of research on health literacy is still not being put into place in the United States. Other work indicates that the United States remains ahead of much, but not all, of the world in regard to putting health literacy research into practice. However, were data sufficient, that difference would likely not be statistically significant (Pleasant, 2013a,b).

For example, health literacy can, and should, inform the redesign of health systems in order to produce both savings in costs and improvements in health outcomes—yet the public health system has by and large not embarked on that effort. Some clinical care systems have begun that process (Pleasant, 2013a,b). In fact, efforts to improve the design and function of the U.S. health system continue to meet uninformed resistance reflecting political interests rather than the interest of public health.

Regardless of the underpinnings of any individual or institutional resistance to embracing the best practices of health literacy in public health efforts, the overarching reality is that the time is ripe for the field of health literacy to increasingly engage with public health efforts. Every indication is that now is an opportune time to fully realize the potential of health literacy to lower costs while improving the overall health and well-being of the U.S. population.

Although more research is certainly needed, we now have 8 more years of research since the Surgeon General’s Workshop on Improving Health Literacy. That research indicates more explicitly and robustly that public health efforts need to engage with the field of health literacy in order to effectively and efficiently reach the mutual goal of a healthy public.

What Is Health Literacy?

“Health literacy” has been variously defined by different perspectives at different times. The presence or absence of public health within those definitions is, in fact, one of the bases for critical analysis of those varying definitions.

For instance, the most cited definition within the United States to date is the definition proposed in the IOM’s initial report on health literacy that was published in 2004 (IOM, 2004). That volume, *Health Literacy: A Prescription to End Confusion*, used the definition presented by the National Library of Medicine and also used in *Healthy People 2010* and *2020* efforts (Selden et al., 2000). That approach defines 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.”

While neither the first IOM report on health literacy nor the defini-

tion of health literacy put forth in that volume exclude public health, they also do not explicitly embrace public health. There is not a chapter in the volume explicitly focused on public health applications of health literacy. There are chapters about defining the concept of health literacy, the extent and associations of limited health literacy, culture and society, educational systems, and health systems—but nothing squarely focused on public health.

What is also missing from that definition is an explicit acknowledgment that successful outcomes from health literacy result from both the supply of behavioral skills of individuals as well as the demand for those skills that is created by the U.S. health care system. The focus of that definition is also solely on the individual. There is no reference to sharing capacity across families, communities, or other social groupings—an important consideration in public health. There is no true reference to the abilities of individuals to navigate systems—another important consideration in public health.

The phrase “public health” appears only 46 times (excluding references) in that 345-page volume. By comparison, the combined use of the words “doctor” and “physician” roughly double that count. The word “hospital” appears nearly twice as often as “public health” and the word “medicine” appears roughly three times as frequently throughout the text. The phrase “public health” does not appear in the index of the volume. Further examples, illustrating perhaps not the explicit focus but the implicit emphasis of the volume, include “Medical Expenditure Panel Survey” with three entries reported in the Index, “Joint Commission on Accreditation of Healthcare Organizations” with five entries, and “National Committee for Quality Assurance” with six entries.² Overall, the volume is framed largely to focus on the clinical, versus public health, context. This is true from the very beginning of the volume as the title explicitly states that a prescription is needed versus—in the common parlance of public health—a program.

One small effort that has moved toward a more explicit inclusion of public health within a definition of health literacy is the Calgary Charter on Health Literacy. The Charter is a freely accessible result of an international effort to advance health literacy that offers all interested parties a chance to perform their own peer review and sign on to the Charter at http://www.centreforliteracy.qc.ca/health_literacy/calgary_charter. The definition of health literacy that the Charter proposes is a testable model of health

² For comparison purposes, the 1988 National Academy Press publication titled *The Future of Public Health* does not contain the word “literacy” or the phrase “health literacy.” In the 2013 National Academies Press publication titled *Public Health Linkages with Sustainability: Workshop Summary*, the phrase “health literacy” appears three times. Progress is slow, but it is occurring.

literacy that can produce successful outcomes of the relationship between the supply and demand of health literacy that is central to public and individual health (Coleman et al., 2009). This approach is as much about what people do with the set of behavioral skills that support their health literacy as it is about the level of those skills they may possess. This definition clearly indicates that health professionals can help the public to (or the public at various skill levels can) achieve positive health outcomes by directing the skills they do possess to find, understand, evaluate, communicate, and use information to make informed decisions about their health.

The Calgary Charter formally defines health literacy as “health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills” (Coleman et al., 2009).

That approach lays out a model of health literacy more in the mode of a theory of behavior change than a label that hopes to aggregate a broad set of skills and abilities. Health literacy, and literacy, are behaviors. Thus, behavior change is the outcome of improved health literacy. Behavior change is a highly targeted and valued outcome in public health efforts as well.

Research by many scholars makes it precisely clear that health literacy interventions must include a keen awareness of fundamental literacy, scientific literacy, cultural literacy, and civic literacy. That essential truth could not be more necessary than in efforts to improve public health. In fact, if the language fails, if the effort is not evidence based, if culture is not considered, or if people are not engaged and empowered, then interventions will fail to improve public health (Zarcadoolas et al., 2006).

What Is Public Health?

Although health literacy is a relatively new concept, the idea of public health has a much longer history. In 1920, C. E. Winslow offered one of the earliest definitions of public health, which is still among the most frequently cited today, yet has essentially not been addressed within the literature on health literacy (IOM, 1988). Winslow’s definition posits that “public health is the science and art of preventing disease, prolonging life and promoting health and efficiency through the organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organization of medical and nursing services for the early diagnosis and preventive treatment of disease, and the development of social machinery which will

ensure to every individual in the community a standard of living adequate for the maintenance of health” (Winslow, 1920b).

In that same year, Winslow also offered a comparable, yet slightly different, definition of public health as “the science and art of preventing disease, prolonging life, and promoting health through the organized efforts and informed choices of society, organizations, public and private, communities, and individuals” (Winslow, 1920a).

While both definitions clearly assert the need for an organized effort, the second definition introduces the need for an informed choice and a range of levels—from the individual to society—wherein that informed choice may occur. That, as discussed earlier in this article, extends beyond the most cited definition of health literacy to date, which maintains a sole focus on the individual and an “appropriate” choice.

Winslow also asserted, more than 90 years ago, that “the public health campaign of the present day has become preeminently an educational campaign. There are those who maintain that because the public health authority alone possesses the power to enforce regulations with the strong arm of the law such authorities should confine themselves to the exercise of police power, leaving educational activities to develop under the hands of private agencies. The actual amount of lifesaving that can be accomplished by purely restrictive methods is, however, small, and such exercise of police power as may be necessary can only gain in effectiveness if it forms an integral part of a general campaign of leadership in hygienic living” (Winslow, 1920b, p. 26). It seems that an early pioneer in defining public health depicted a stronger role for health literacy than current public health organizations do today.

That tension Winslow described nearly 100 years ago—between an educational effort eliciting voluntary participation and a top-down regulatory effort—remains at much of the forefront of public health today. Perhaps the most current manifestation of that debate emerged recently with then-New York City Mayor Michael R. Bloomberg proposing a ban on carbonated beverages greater than 16 ounces in size at restaurants, theaters, and food carts.

Health literacy, it is worth noting, can provide an effective resolution to that ongoing debate. Given Winslow’s preference for what he termed educational versus “restrictive methods,” it seems relatively safe to assume he would agree with that proposition. The critical difference, and one that seems safe to assume Winslow would approve of, is that health literacy poses the outcome of an engaged individual empowered to make well-informed decisions about health whereas regulation poses the outcome of a compliant individual.

Nearly 70 years after Winslow penned his definitions of public health, the IOM published *The Future of Public Health*, which defined public

health as an “organized community effort to address the public interest in health by applying scientific and technical knowledge to prevent disease and promote health” (IOM, 1988, p. 7). The passage of nearly a century seems to have not withered the usefulness and appropriateness of much of Winslow’s definitions of public health. Health literacy, in comparison, seems to be in a pre-Winslow stage in regard to the development of a broadly accepted and used formal definition.

Another overlap is worthy of mention between Winslow’s approach to public health and current approaches to health literacy. As Roter and colleagues (2001) noted, “Winslow, an advocate for public education as early as the 1890s, maintained: ‘the discovery of popular education as an instrument of preventive medicine, made by the pioneers in the tuberculosis movement, has proved almost as far-reaching in its results as the discovery of the germ theory of disease thirty years before.’”

If there is a “golden rule” to health literacy, it is to involve people early and often in their own health. That means health professionals will engage with the whole person, versus just diagnosing and treating a disease. Involving people early and often also inevitably shifts the focus to prevention rather than treatment of an illness after it manifests. Therefore, an emphasis on health literacy should inherently result in an emphasis on prevention. The early years of well-intentioned health literacy research that focused solely on clinical care settings were not wasted, but they were simply not based on an integrative approach to health that addressed the whole person’s life, intentions, and environment. Health literacy and, by extension, prevention is the missing gap in the design of the current U.S. “sick care” system where only a pittance of efforts focusing on prevention are reimbursable from insurers and governmental systems, which spend the majority of their efforts and funds (and thus creation of potential profits) on “sick care” rather than on promoting health and preventing disease, disability, and early death.

Prevention, health literacy, and reducing health care costs are integrally related. Ultimately, public health may be best differentiated from clinical medicine through the emphasis on prevention and targeting multiple social and environmental determinants of health versus a priority on treatment of the diagnosed individual (IOM, 1988). Collaboration and coordination between the two approaches is clearly necessary, but an appropriate balance is lacking in the United States and globally. Poor health literacy can be taken as one of many indicators of that imbalance.

Brief Review of U.S. Public Health Key Indicators

If the current state of public health in the United States is an indicator, and if the growing body of evidence regarding health literacy is not dis-

covered to be a false positive as methodologies continue to improve, much work remains to be accomplished in the field of health literacy. That work needs to be accomplished sooner rather than later as, according to a recent IOM report, the U.S. public health system and the state of public health in the country are not healthy. For example, the authors of this report (NRC and IOM, 2013) wrote that

- “The U.S. public health system is more fragmented than those in other countries” (p. 132).
- “Americans have had a shorter life expectancy than people in almost all of the peer countries. For example, as of 2007, U.S. males lived 3.7 fewer years than Swiss males and U.S. females lived 5.2 fewer years than Japanese females” (p. 2).
- “For decades, the United States has experienced the highest infant mortality rate of high-income countries and also ranks poorly on other birth outcomes, such as low birthweight. American children are less likely to live to age 5 than children in other high-income countries” (p. 2).
- “Deaths from motor vehicle crashes, non-transportation-related injuries, and violence occur at much higher rates in the United States than in other countries and are a leading cause of death in children, adolescents, and young adults” (p. 2).
- “Lung disease is more prevalent and associated with higher mortality in the United States than in the United Kingdom and other European countries” (p. 3).
- “Older U.S. adults report a higher prevalence of arthritis and activity limitations than their counterparts in the United Kingdom, other European countries, and Japan” (p. 3).
- “Childhood immunization coverage in the United States, although much improved in recent decades, is generally worse than in other high-income countries” (p. 118).
- “Since the 1990s, among high-income countries, U.S. adolescents have had the highest rate of pregnancies and are more likely to acquire sexually transmitted infections” (p. 2).
- “The United States has the second highest prevalence of HIV infection among the 17 peer countries and the highest incidence of AIDS” (p. 2).
- “Americans lose more years of life to alcohol and other drugs than people in peer countries, even when deaths from drunk driving are excluded” (p. 2).
- “For decades, the United States has had the highest obesity rate among high-income countries. High prevalence rates for obesity are seen in U.S. children and in every age group thereafter. From age

20 onward, U.S. adults have among the highest prevalence rates of diabetes (and high plasma glucose levels) among peer countries” (p. 3).

- “The U.S. death rate from ischemic heart disease is the second highest among the 17 peer countries” (p. 3).
- “Deaths and morbidity from non-communicable chronic diseases are higher in the United States than in peer countries” (p. 119).

Annually, three-quarters of U.S. health expenditures are spent on the treatment of chronic diseases—many of which are preventable (CDC, 2009). The United States spends more than 18 percent of our gross domestic product annually on sick care; 75 cents of every health care dollar is spent on treatment of chronic disease (CMS, 2011). Advancing health literacy to prevent disease and promote wellness is a proposition that is directly in line with the mission of public health organizations and has the added promise of not only improving health and well-being, but doing so at a lower overall cost over time.

The Fit Between Health Literacy and Public Health

The tools for public health efforts are traditionally limited to regulation, technology development, education, and persuasion. As discussed in this article, health literacy works to shift the emphasis toward the latter pair of education and persuasion versus technology and regulation. That is not to diminish the role of any, but to highlight the focus of health literacy. More importantly, health literacy may well be the best argument for the addition of engagement and/or empowerment as a core element of public health.

If there is one story to which all students of public health are exposed, it is the story of John Snow and the Broad Street water pump in London. This oft-told story of the “birth” of public health and epidemiology during a cholera outbreak in London in 1854 is largely focused on science-based regulation and top-down approaches. Snow took the data he had collected that supported his theory that a publicly accessible water pump was the source of cholera and city officials, begrudgingly, removed the handle from the water pump. As a result, the cholera epidemic was resolved.³

The core lesson of the story of John Snow and the Broad Street pump

³ An interesting aside: Some sources seem to so revere John Snow that he has been attributed with removing the pump handle himself rather than presenting his data (thus the birth of epidemiology specifically) to the Board of Guardians of St. James Parish. (In England, the parish is the first level of local government.) A majority of sources seem to agree that while the Board of Guardians is often described as being skeptical of Snow’s theory, they did order the pump handle removed.

handle is seemingly clear: Science-based regulation solves problems without public engagement or participation. However, it seems quite likely that the most frequent interpretation of the story is incomplete or at least somewhat misleading. Snow's work would never have occurred without the participation of the hundreds of people he interviewed in order to develop his theory of how cholera was being spread through an unsafe water supply. While seldom (if ever) discussed in this manner, Snow's work may also provide a first rough and incomplete example of community-based participatory research in a public health context. Snow clearly had to rely on the expertise of the public, including their health literacy skills, to help him to ascertain the relationship between the spread of cholera and use of the Broad Street water pump to obtain water.

At the individual level, just as John Snow did, public health efforts can target alone or in combination a person's knowledge, attitudes, beliefs, and behaviors by using a variety of tools ranging from regulation to education, persuasion, engagement—top-down and authoritative to community based and participatory. From that spectrum of possible public health targets, literacy is clearly a behavior. Reading, writing, and speaking are all behaviors. To make the much-discussed and -touted transition from learning to read to reading to learn is, in fact, a change in behavior. Thus, to improve literacy is to change behavior. Literacies are behaviors that people can perform at a wide range of skill levels. National surveys such as the National Adult Literacy Survey in 1994 and the National Assessment of Adult Literacy in 2004 clearly demonstrate that reality (Kirsch et al., 1993; Kutner et al., 2003).

As health literacy research and practice have developed over the past 20 years, it has become increasingly clear that few other factors have such a direct effect on an individual's capacities to influence his or her own, family's, and community's health. However, from the founding stories of public health to efforts ongoing today, a tension exists between the tools of top-down regulation and bottom-up empowerment. This tension is also reflected in the structure and functioning of public health departments—which vary greatly in the United States. The following set of case studies illustrates how health literacy can be effectively put in place across that spectrum.

While the potential usefulness of health literacy to public health seems somewhat straightforward, what is not known is the extent to which, and how, public health organizations conceive of and operationalize health literacy; organize and train staff to address health literacy within their mission; and approach development of materials with health literacy in mind. The following components of this article—through a case study approach, reporting on evidence gathered through direct query to state departments of public health and an online inquiry of public health professionals, and an

analysis of selected public health efforts and situations—attempts to begin to answer those questions. (We describe each methodology further in the following sections.)

CASE STUDY: LOUISIANA—THE POTENTIAL OF LEVERAGING PUBLIC HEALTH INSTITUTES

Laurie Martin, Sc.D., M.P.H.

Across the nation, there are currently 37 Public Health Institutes (PHIs) and countless other organizations with the staff and expertise to support state and local public health departments. The goals and objectives of these Institutes vary, though some are proving to be valuable assets to public health departments' efforts to address challenges related to low health literacy. This case study takes a closer look at a public health organization and a PHI in Louisiana, developed from a series of in-depth, semi-structured interviews with staff at both institutions.

Participants at this public health organization in Louisiana report that health literacy is conceptualized as “the understanding of the target audience they are trying to reach.” This understanding is reported to include both the public and the providers who deliver services. There is a firm belief that health literacy efforts must involve all stakeholders. “It’s not just about ensuring that the public understands, but that those providing care are also paying attention to health literacy. The patient can ask all the questions they want, but if the provider is not on the same wavelength, they are never going to meet the patient’s needs.”

Programs within the public health organization are reported to have been taking a more proactive approach toward health literacy over the past 12 months. Staff are reported to be taking steps to make sure that messages they create are clearly communicated and that materials are written at an appropriate reading level. However, public health organization staff consistently noted that this is not always an easy task.

For example, a public health organization staff member reported that, “In Louisiana, we have a lot of different cultures that come into play when we are looking at health literacy, as well as age differences, races/ethnicities, rural versus urban differences . . . these factors make it more complicated . . . it’s not just about the piece of paper they are handed that tells them about their medicine—it can be in an easy-to-use format, but that doesn’t mean it’s understood. There are other barriers that may break that communication and understanding down.”

Public health organization staff participating in this case study process stated that they believed there was a need for additional health literacy

training across all health departments, and that such training should occur at the regional level. They noted the important role that public health organizations have in reaching out to vulnerable populations.

One participant at this public health organization in Louisiana said, “I think individual departments across the country could do a better job of educating the public, they are the boots on the ground, and they can take the time to make sure that patients understand. But just because you work in the field doesn’t mean that you can translate that knowledge to the public.”

The recognition that not all staff have been trained in health literacy has prompted some programs within the public health department in Louisiana to partner with the local Public Health Institute. PHI staff report using social marketing methodology to “develop messaging to meet consumers where they are—so it is meaningful and impactful.” Though not explicitly referred to as health literacy in the trainings, there is recognition among PHI staff that social marketing involves the basic principles of health literacy. Staff engage members of the target audience to help refine messaging and materials that are easy to understand and actionable, and disseminates those messages and materials in ways that are accessible. Public health department staff also believed that involving the target audience was an important lesson learned for public health agencies by noting that “[they] should be part of the development of what you are trying to create.”

The principles of social marketing, which overlap a number of health literacy best practices, have been successful for several joint projects between the public health organization and the PHI in Louisiana. In a recent tobacco control program, for example, the PHI developed a media campaign to promote cessation among pregnant smokers. Working closely with the target audience, they developed a media campaign that was understandable and actionable to pregnant women, resulting in a significant increase in the average call volume to the local smoking cessation quitline.

Staff at both the public health organization and the PHI noted that a significant barrier to implementing activities that addressed the challenges of low health literacy was the lack of a formal methodology for “how to do it.” With the exception of social marketing, staff at both the PHI and the state health department agreed with this participant’s view that, “To my knowledge, there is not a tried and true process for developing materials with this principle in mind. There’s that Word program that can tell you the reading level, but that has a lot of limitations. You may understand the basic tenets of health literacy, but without formal education or training, it is more a philosophy than a practical daily process or approach. To me, there’s a lack of a clear process or methodology that one’s expected to go through to meet the tenets of health literacy and make it part of a development process.”

Collectively, a perceived lack of easily accessible and transferable methodology and a lack of local and regional training opportunities, coupled with the fact that public health organizations are under the control of state or local governments, generate the perception that public health organizations serve more of a gatekeeper role; that is, they focus more on what is said (topics) than how it is said (health literacy). The participants in Louisiana expressed a clear recognition that health literacy is important across public health organizations and the PHI. They report there is positive movement in the amount of attention being paid to health literacy within those organizations as well. However, there is clearly room for improvement. Partnering with local PHIs, academics, or nonprofit organizations that focus on health literacy may promote synergistic efforts and help to fill some of the current gaps on these issues. Such partnerships may be particularly beneficial in the short term, as these organizations often are more nimble in their ability to hire qualified staff quickly and to spend necessary resources to ensure that the activities they produce are accessible, understandable, and actionable. Such partnerships, however, should not preclude development of internal capacity within public health organizations as it may also prove more efficient and cost-effective for those organizations to bring health literacy expertise into their staff over the longer term.

CASE STUDY: NEBRASKA—THE STRENGTH OF WEAK TIES

R. V. Rikard, Ph.D.

Nebraska's sparse population density is a defining characteristic that shapes the public health system and the connection between public health and health literacy in the state.

There are a total of 77,421 square miles in the state of Nebraska, with a total population of 1,826,341 in 2010 (U.S. Census Bureau, 2010). Nebraska is the 43rd most populous state, with approximately 24 Nebraskans per square mile. For comparison, in Louisiana there are about 104 people per square mile while the New York City borough of Manhattan has more than 60,000 people per square mile.

This case study highlights the strength of Nebraska's statewide decentralized public health system to address health literacy in Nebraska. Geographic distance does not seem to limit the "strength of weak ties" and shared commitment (Granovetter, 1973) of public health and health literacy professionals to address health literacy, reduce health disparities, and improve population-level health outcomes in the state.

This case study is based on a series of in-depth, semi-structured interviews with the Nebraska Public Health Department staff, directors of local

public health departments or districts, and health literacy professionals. Background documents provided by Health Literacy Nebraska were also used.

The Nebraska Public Health System

Nebraska's public health departments are diverse in terms of organization, funding streams, and services provided in their districts. While public health departments are a fairly new resource across Nebraska, public health and health literacy professionals recognize the important connection between public health and health literacy.

Prior to 2001, only 22 of Nebraska's 93 counties were covered by a local health department or division. Legislative Bill 692, the Health Care Funding Act, was approved and enacted during the 2001 Legislative Session. The legislation directed Tobacco Master Settlement funds to support health-related activities in the state. As a result, all 93 of Nebraska's counties are now covered by 21 local public health districts or departments (see Figure 1). The number of counties covered by a health district ranges from 1 to 10 depending on population density, and all provide a range of public health services.

In May 2012, the Nebraska Association of Local Health Directors (NALHD) secured grant funding through the Health Resources and Services Administration's (HRSA's) Rural Health Care Services Outreach Program. The grant funds the NALHD Outreach Partnership to Improve Health Literacy (OPIHL) by providing Nebraska's public health workforce with technical assistance, training, and resources to address health literacy's effect on the health of individuals and communities in Nebraska.

The program's goals are fourfold over the 3-year funding period (2012-2015). The first is to delineate the health literacy education and training needs of Nebraska local and tribal health departments. The baseline survey results in 2012 revealed that participating health department staff had a need for increased knowledge and skills related to health literacy. Second, the baseline data guided the development and implementation of a comprehensive, evidence-based health literacy education and training program for local health department personnel. The third goal is to improve the health literacy of the rural populations participating in local health department programs by implementing tailored health literacy interventions that directly impact a specific population. The fourth, and ongoing, goal is to develop, disseminate, and promote a library of health literacy resources for all Nebraskans and other areas of the United States.

The participants interviewed for this case study pointed to the HRSA grant and OPIHL project as significant events that cemented the connection

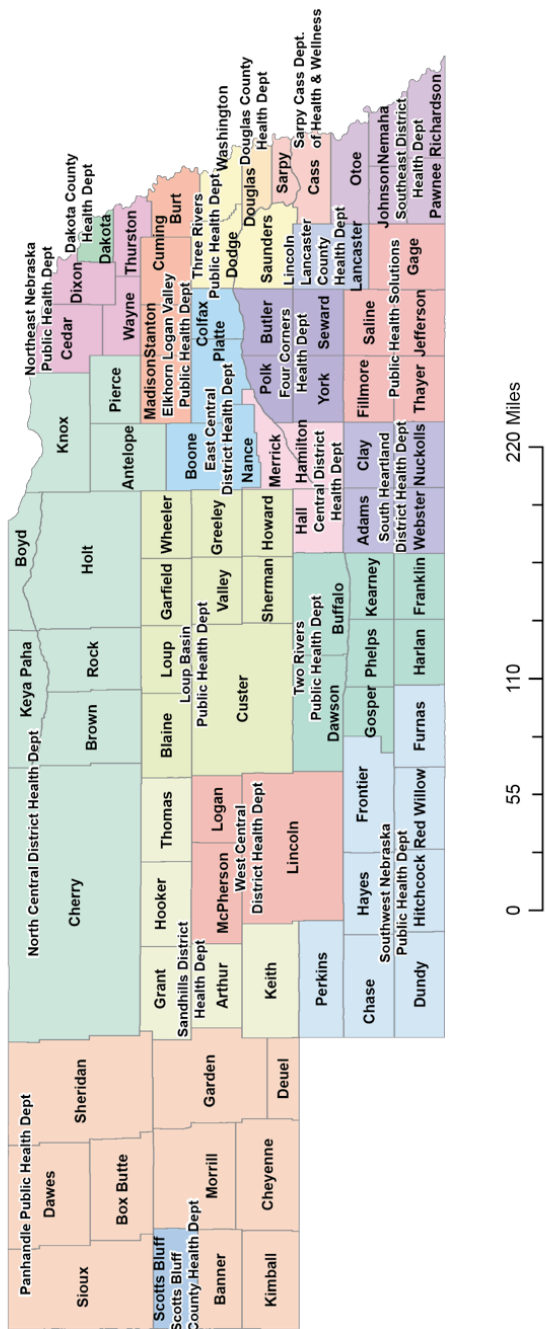


FIGURE 1 Public health departments in Nebraska.

between health literacy and public health in the Nebraska public health system.

Health Literacy and Public Health in Nebraska

The Steering Committee Chair for Health Literacy Nebraska provided contact information for many participants interviewed for this case study. A standard set of open-ended questions guided the interviews with participants, and the discussions lasted an average of 45 minutes. The semi-structured interview format allowed flexibility for the participant and the interviewer to have more of a conversation than a formal interview. Participant responses are summarized in the section below.

Regarding the definition of health literacy used, the majority of participants indicated that their health department defines health literacy as a means to communicate health information that the public will understand. However, the strongest theme in responses was not a focus on the inability of the public to understand health information; instead, the emphasis was placed on public health professionals not communicating information in a way that is understandable to the general public. Participants did not directly mention the IOM's definition of health literacy; however, they noted that the most recognized health literacy definition is too narrow and does not provide the flexibility to tailor information to a specific audience.

Participants broadly agreed that health literacy is not a question of patients *or* public health professionals, as many participants expressly indicated they believed that health literacy is a shared responsibility for patients as well as public health and health care professionals—and that the professionals face a larger responsibility to make information understandable. For example, a participant pointed out that “health literacy is bidirectional—the work to be done is not on the patient side. The provider side needs to communicate in a way the general public understands.” One participant pointed out that the health care system in the United States focuses on disease and illness rather than prevention and promotion. Moreover, the participant pointed out that public health professionals are taking the leadership role to focus on health literacy as a means to prevention by stating, “public health is the ‘paper clip’ to hold all information together.”

In addition, participants provided examples of steps that their public health departments have taken to make health information understandable to the general public. Examples included improving signage at their public health department, upgrading and sharing easy-to-understand brochures, redesigning the department's website, addressing the complexity of information regarding the Affordable Care Act and health insurance exchanges, and redesigning the health care system itself to try to reduce complexity.

Participants strongly indicated a widely shared view that health literacy

writer workshops, held in Nebraska as part of the HRSA grant, were valuable. In addition, access to and training to use the Health Literacy Advisor software reinforced the training from the health literacy writer workshops. A participant emphasized the importance of field-testing revised health information to ensure that the information was not so simple that it lost its usefulness to the public. Given that the OPIHL project is an ongoing initiative, participants noted that revising health information in their public health department is a primary focus at the current time. Yet, one participant pointed out a sustained public health department initiative by saying, “our health literacy project not only brought the language barriers to light, but we started a robust community health worker program as a result. We are now teaching a community health worker training course through a community college in Nebraska. It is a three-semester course and is the first in Nebraska.”

Reflecting on what health literacy best practices they might recommend to others, participants gave several pieces of advice primarily focused on public health organizations just beginning their efforts to address health literacy. One participant specifically stated, “You need a champion . . . bring in someone who has the health literacy knowledge base—someone who knows it, can teach it, and stays up to date on the literature.” Another participant said there is a need to have a revised definition of health literacy to guide public health agencies. Moreover, a revised definition requires consensus and engagement, specifically among national health policy leaders. Two participants mentioned the importance of attending a state or national health literacy conference such as the Institute for Healthcare Advancement (IHA) health literacy conference.

Another specific theme that emerged from the participants’ advice to other public health organizations is the importance of collaboration within and between public health agencies in the state as they begin their health literacy initiatives. According to the participants, this collaboration entails sharing documents and ideas, learning together, working together, and seeking out partnerships with other agencies/organizations.

In regard to what the field of health literacy could do to advance the role of health literacy in public health organizations, participants provided a clear message that they believed the best next step for the field of health literacy within public health is the creation of a health literacy organization. Such an organization should bring together interdisciplinary researchers to develop health literacy measures to determine if public health agencies are effectively reaching their communities. This type of organization, in participant’s views, could provide multiple publication venues for basic and applied research as well as evaluation of health literacy initiatives. Regional health literacy groups could provide an opportunity for collaboration among state agencies and provide access to expertise for public health

professionals who cannot afford to attend national conferences. Moreover, participants believed that a professional health literacy organization could gather and disseminate best practices and policies for public health agencies and practitioners. In sum, participants expressed their desire to form new ties with health literacy professionals in Nebraska, within regions, and across the United States.

CASE STUDY: ARKANSAS—COORDINATED, REASONABLE, AND REASONED STATEWIDE ACTION

Jennifer Cabe, M.A.

In June 2013, the Arkansas Department of Public Health issued a “State Health Assessment and State Health Improvement Plan” (hereafter referred to as “Assessment and Plan”). This case study relies heavily on that Assessment and Plan and on open-ended interviews with public health agency staff.

The Arkansas Department of Public Health does not provide a specific definition of health literacy, or refer to any definitions set forth by other organizations. Instead, this state’s health department describes health literacy through a conversational, even personal, tone. For example, the Assessment and Plan states: “Health literacy consists of a wide range of skills that people use to get and act on information so that they can live healthier lives. These skills involve reading, writing, listening, asking questions, doing math, and analyzing the facts.”

The Assessment and Plan also uses this conversational tone in describing the bidirectionality of health literacy: “Health literacy is also how well doctors, nurses, and other health care workers meet their patients’ needs and do it in a way that helps their patients know what they need to do to take care of themselves.”

The Arkansas Department of Public Health operates on the basis that low health literacy correlates with poor health. The state’s public health department staff members describe that poor health as being caused by both patient misunderstandings and health care system mistakes. The concept of bidirectional responsibility for health literacy is frequently echoed in conversations with public health officials in Arkansas. In these words in their Assessment and Plan: “The problem of low health literacy is solved when the health literacy of the health care system is in balance with the health literacy of the patients it serves.”

Consistent with that belief system, the responsibility for addressing the health needs of Arkansans through a health-literate public health approach is at the heart of this state health department’s view of its own purpose and

carries into its strategies and day-to-day operations and programs. That is explained in clear terms in the Assessment and Plan in this way: “When you put both sides of health literacy together, there is often a mismatch between the skills of the patients and the demands placed on them by the clinics, hospitals, and insurance companies. This imbalance can result from people having problems with reading, writing, doing math, listening, or asking questions. It can also result from the health system requiring people to do things that are simply too hard to do. In that way, the demands of the health care system are out of balance with the skills of the people it serves.”

The Arkansas Department of Public Health estimates there are 820,000 adults in Arkansas with low health literacy, or roughly 37 percent of Arkansas’ adult population (see Figure 2).

As Figure 2 illustrates, a minimum of 27.7 percent of every county’s population has low health literacy. One public health staff member explained that the state has a greater “portion” than the United States overall of people in groups who are more likely to have low health literacy, such as seniors, people with less than a high school education, and people who live in poverty.

Health literacy as one part of the solution to Arkansas’ high rates of chronic disease, infant mortality, and disability is expressed as not only an imperative, but a given. Thus, in Arkansas, efforts are ongoing to improve health literacy across the lifespan of its residents, and in each of its 75 counties. To multiply the effects of this work in a state that suffers from poor health metrics, it is notable that the Arkansas Department of Public Health has taken up the partnership model for advancing health literacy by joining forces with other statewide units. These include the Department of Education, as well as nongovernmental organizations, such as hospitals and nonprofit literacy councils. These partnerships are designed to multiply health literacy efforts across the state and throughout society more quickly.

For example, there are 30 Reach Out and Read programs in Arkansas that have so far reached about 40,000 children with books and early literacy advice at well-child visits, and more programs are planned in the coming year. In addition, the Arkansas Department of Public Health works with nonprofit literacy councils in more than 60 Arkansas counties to teach adult learners words and concepts related to health while they are learning to read.

Programs to train health professionals in health literacy are described as steadily growing in number, with an uptick having occurred in the past year by adding health literacy into existing continuing education sessions for health professionals. Health literacy is now included in sessions that are taught over closed-circuit television that can be watched from every county in the state.

In another nod toward inclusivity that required agreement about invest-

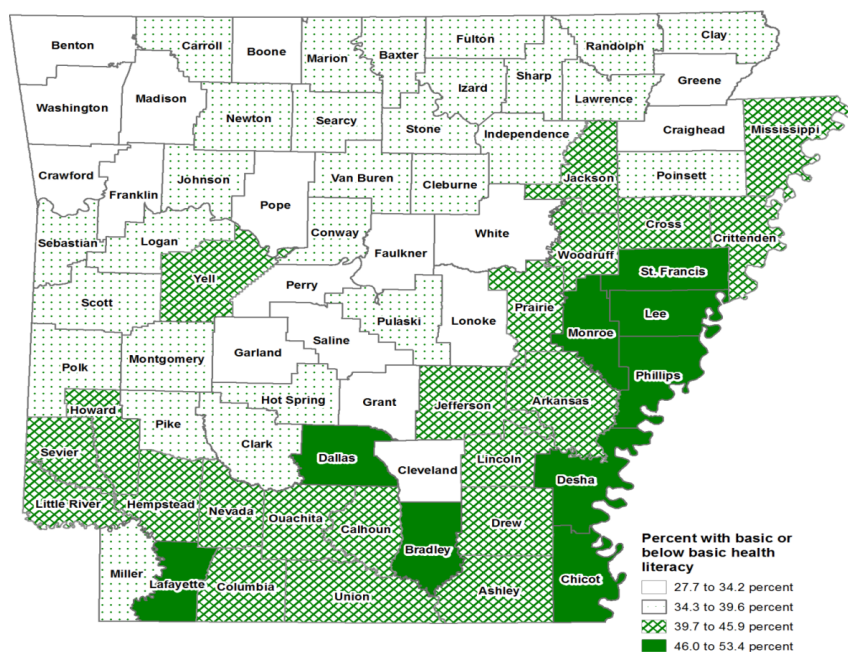


FIGURE 2 Percentage of Arkansas population with low health literacy.

ing resources, all eight of the University of Arkansas for Medical Science Regional Centers have received training in the Agency for Healthcare Research and Quality’s “Health Literacy Universal Precautions Toolkit,” with the stated goal of improving how Arkansas’ health care professionals talk with patients and how clinic systems and staff can make it easier for people to get the services they need when they need them.

Perhaps the broadest and most visible multi-sectorial approach to advancing health literacy in Arkansas was formed in 2009, and was catalyzed not only by Arkansas Department of Public Health staff and leaders, but also by volunteers, staff, and leaders of literacy organizations, universities, and health care organizations, as well as individuals who were not sponsored by or professionally affiliated with an organization, but who cared about health and health literacy. Today, the Partnership for Health Literacy in Arkansas is a true statewide coalition and has developed a state action plan with these seven goals, which are not listed in any particular order of importance:

- Share and promote the use of health literacy practices that are based on the best science available.
- Make health and safety information easy to understand so that people who need it can get it and use it to take action.
- Make changes that improve the health literacy of the health care system.
- Include health literacy in the lessons and curricula for all children in Arkansas, from infants in child care through college students.
- Work with the adult education system in Arkansas to improve the health literacy of the people in the communities they serve.
- Do research to better understand and measure what works to improve the health literacy of the public and the health care system.
- Build a network of health literacy partners committed to making changes at their organizations that will improve health literacy in Arkansas.

Finally, it is worth noting that in conversations with Arkansas clinicians, researchers, and administrators, they frequently mentioned that careful efforts were invested by the Partnership for Health Literacy in Arkansas to develop a model for a state action plan based on the National Action Plan to Improve Health Literacy. “The Arkansas Action Plan to Improve Health Literacy” is available at <http://phla.net>. This action plan is an interactive plan that includes the Partnership for Health Literacy in Arkansas’ seven goals listed above. It provides the opportunity for broad participation by multiple organizations, universities, and agencies, which can submit their own objectives for accomplishing the plan’s goals and strategies. This approach fosters buy-in from stakeholders across the Arkansas health literacy, medical, and population health communities, who can take steps to operate in their own spheres of influence to advance health literacy in the foreseeable future.

Public Health and Health Literacy: What’s Happening?

To further learn about the use, or lack of use, of health literacy within state, local, tribal, and territorial public health organizations, we set out to directly ask individuals working in public health about their attitudes and experiences regarding health literacy.

This effort proceeded simultaneously on two tracks. First, we attempted to directly contact every state’s public health department (and the District of Columbia). This effort used the main e-mail address, telephone contact information, or online contact forms found on the website of each state’s public health department. As needed, we made up to three follow-up attempts to contact each organization.

We asked a single, seemingly simple question, “Who is responsible for health literacy within your organization?”

To date, we have received replies from departments of health in 24 states (see Figure 3). We have received no response from 26 states and the District of Columbia, even though we used the primary point of contact provided to the public from every department of health.

Only 1 of the 24 state departments of public health that responded reported having an individual on staff whose title explicitly indicates health literacy is an area of responsibility. That state is Arkansas. Seven state departments of public health reported they have a designated point of contact or someone whose responsibilities include health literacy. Those states are Arkansas, Delaware, Florida, Georgia, Kentucky, Oklahoma, and Texas.

Seven state departments of public health reported that although they did not have a staff person in particular who was a point of contact or who worked primarily in health literacy, they made the point that health literacy is a part of their work. These states are Arizona, Colorado, Connecticut, Montana, New York, Ohio, and Oregon.

Ten state departments of public health reported that they did not fit the

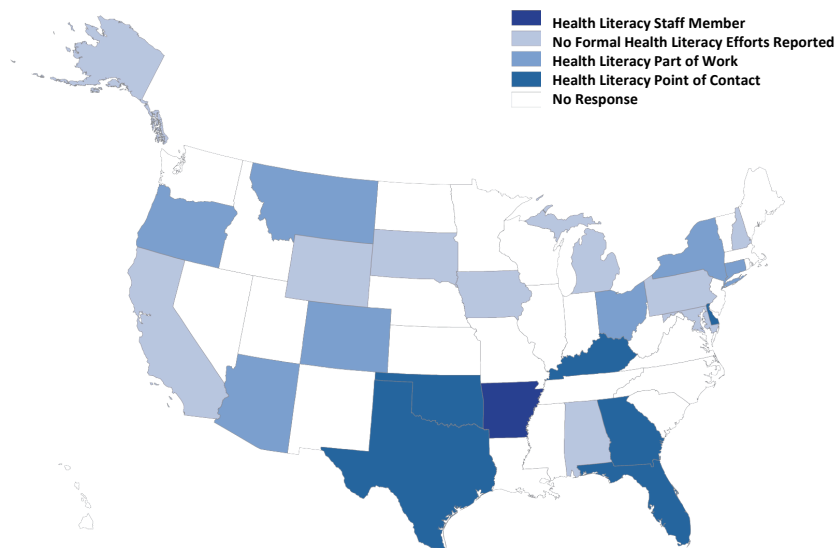


FIGURE 3 Health literacy within state departments of public health.

previous descriptions and did not report any formal efforts to address health literacy. These states are Alabama, Alaska, California, Iowa, Maryland, Michigan, New Hampshire, Pennsylvania, South Dakota, and Wyoming.

The nature of those responses, of course, made us more curious. So we created an online inquiry using Survey Monkey that targeted professionals who worked within a local, state, tribal, or territorial department of public health. Using Internet-based methods, we widely broadcast an invitation to participate in this effort.

We distributed this request to respond to a brief online inquiry via the following electronic listservs:

- LINCS Health Literacy
- Social Determinants of Health listserv
- Health Education listserv in Los Angeles County
- Public Health Nursing listserv organized by the National Institutes of Health (NIH)
- Healthcare Information For All listserv
- Healthcare Working Group at the American Public Health Association (APHA) listserv
- Environmental Health listserv from the Centers for Disease Control and Prevention (CDC)
- Public Health Education and Health Promotion listserv of the APHA

We also sent the invitation to participate directly to individuals at the following organizations:

- The National Association of County and City Health Officials (NACCHO)
- The Association of State and Territorial Health Officials (ASTHO)
- The National Association of Local Boards of Health (NALBOH)
- The Office for State, Tribal, Local, and Territorial Support at the CDC
- The Arkansas Health Literacy Working Group

In addition, we sent the invitation to participate to more than 400 individuals identified via the APHA member directory online whose titles and affiliations indicate they work at a state, local, tribal, or territorial public health organization. Finally, using social media platforms, we distributed the invitation to participate in the online inquiry through the following:

LinkedIn Groups:

- Health Communications, Social Marketing, and Social Scientists Group
- Health Literacy Exchange
- IHA Health Literacy Conference
- Medical Information Services & Communication
- APHA
- Health Literacy (a subgroup of Plain Language Advocates)
- Health Literacy Nebraska
- Healthcare for Vulnerable Populations to Eliminate Disparities in Health

Google+ Communities:

- Public Health
- Health Communication
- Carpool Health Community
- Wellbound Storytellers

Twitter:

- The week of August 19, 2013, one author (Dr. Rikard) sent out six Twitter tweets related to the online information-gathering effort, with few retweets.
- The week of August 26, 2013, Dr. Rikard sent 20 tweets as well as tweets to 16 specific public health organizations/agencies.

All invitations to participate also encouraged the recipients to broadly share the invitation with their network of public health professionals. The use of social media, electronic listservs, and a snowballing methodology means it is impossible to determine a response rate because we do not know exactly how many individuals ultimately received the invitation. The overall response rate, nonetheless, is clearly exceedingly low, as we received 63 responses. Two responses had to be removed from the sample because individuals who worked at federal-level public health organizations responded to the inquiry, although our invitation specified that the effort was specifically targeted to public health officials at state, local, tribal, or territorial public health organizations.

Findings from a Brief Inquiry of Public Health Professionals at State, Local, Tribal, and Territorial Public Health Departments

The 61 valid responses to the online inquiry represent 25 states and 56 state, local, tribal, or territorial public health organizations. On average, they reported being employed at their current public health organization for 10.2 years and within the field of public health for 16.2 years.

Excluding duplicate reports from multiple individuals employed at the same public health organization, participants are employed at organizations that serve an average population size of more than 3 million people (3,122,638) and an aggregate population of 95,437,540, or roughly 30 percent of the U.S. population. The population profile of those communities served by participants are reported to be, on average, 59.7 percent white, 14.4 percent African American, 8.7 percent American Indian or Alaskan Native, 1.8 percent South Asian (India/Pakistan), 6 percent Asian (e.g., China, Japan, Korea, etc.), and 2.2 percent Native Hawaiian or other Pacific Islander. The population served by participants' organizations is also reported, on average, to be 17.1 percent Hispanic or Latino in ethnicity. Twenty-five participants reported that their public health organization serves rural areas, 28 reported serving urban areas, and 16 reported serving suburban areas. Thus, the small number of responses does represent a large and diverse array of public health organizations.

Participants were asked how the public health organization where they are employed defines health literacy. In response, seven (12.5 percent) participants reported using the definition from the IOM publication on health literacy commonly used by the U.S. Department of Health and Human Services (HHS). The source of that definition was often attributed as the reason the public health organization put forth that definition.

More than half (53.6 percent) of participants reported using one of a variety of other definitions. Two participants (3.6 percent) reported their public health organization is currently in the progress of developing a definition. Five participants (8.9 percent) reported not knowing if their public health organization had a definition of health literacy and 12 participants (21.4 percent) said the public health organization where they work did not have a preferred definition of health literacy.

In more practical terms, 13 participants reported that health literacy was viewed as an issue for only patients and the public; 2 participants reported that health literacy was viewed at their public health organization as an issue for only health care professionals and health systems; and a vast majority of 38 participants said health literacy was viewed as an issue for both sides of that relationship equally.

Participants were also asked to respond to the individual attributes of a health-literate organization developed recently by members of the

IOM Roundtable on Health Literacy (Brach et al., 2012). The question employed a four-point Likert scale with labels of strongly disagree (1), disagree (2), agree (3), and strongly agree (4), and an option to indicate that the proposed attribute of a health-literate organization was not relevant to the mission of the public health organization where participants are currently employed. The scale mean is 2.5, so an average response higher than 2.5 indicates more agreement than disagreement that the public health organization is conducting business in a way that reflects the attribute (see Table 1).

The proposed attributes deemed most irrelevant to the mission of the participants' public health organization mission (Statements 9 and 10) are the two that focus most on the clinical care context. Overall, each proposed attribute of a health-literate organization received more agreeing responses than disagreeing responses, indicating that participating public health professionals do perceive that their public health organization's mission aligns with the attributes of a health-literate organization.

Participants were also asked to estimate the percentage of overall effort at their public health organization that is invested in addressing health literacy in some way. Examples given included reviewing publications for plain language or establishing health literacy as an outcome of a program or effort. On average, participants reported that 30.7 percent of the overall effort at the public health organization where they are employed is spent addressing health literacy in some fashion. The lowest response received was 0 percent and the highest was 100 percent, indicating a broad range of perceptions of not only the amount of effort directed at health literacy within public health organizations, but also likely indicating a broad range of understanding of health literacy.

When asked about any trend in the awareness of health literacy during the past 12 months within their public health organization, one participant reported awareness was decreasing, 24 reported awareness had stayed the same, and 23 reported an increasing level of interest in health literacy. The mean response on this three-point scale was 2.5, indicating that health literacy awareness was slightly increasing across the participants' public health organizations.

We also asked participants to respond to a three-point scale indicating their level of agreement that their public health organization was conducting specific examples of health literacy activities. This scale consisted of the statements, "We have not considered or discussed this health literacy activity," "We have considered but not implemented this health literacy activity," and "We have initiated this health literacy activity." An average response higher than the scale mean of 2 indicates more participants have initiated each health literacy activity than have not (see Table 2).

Both quantitatively, as displayed in Table 2, and qualitatively, par-

TABLE 1 Perceived Relevance of the 10 Attributes of a Health-Literate Organization

Institute of Medicine Roundtable on Health Literacy: 10 Attributes of a Health-Literate Organization			
	n	Average Response	Number of Participants Indicating Not Relevant to the Organization's Mission
1. Has leadership that makes health literacy integral to its mission, structure, and operations.	61	2.9	0
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.	61	3.0	0
3. Prepares the workforce to be health literate and monitors progress.	61	3.0	2
4. Includes populations served in the design, implementation, and evaluation of health information and services.	61	2.9	0
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.	60	2.9	0
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.	59	2.7	2
7. Provides easy access to health information and services and navigation assistance.	59	3.0	0
8. Designs and distributes print, audiovisual, and social media content that is easy to act on and understand.	58	3.1	1
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.	59	2.9	7
10. Communicates clearly what health plans cover and what individuals will have to pay for services.	59	2.8	19

Participants reported that rewriting plain-language materials was the most frequently adopted health literacy activity. Many expressed a view that this was also a very effective strategy for public health organizations to employ. For example, one participant wrote, "Our department web pages have been rewritten to make the information clearer and easier to navigate and understandable by customers. Each division involved a panel of diverse advisors

TABLE 2 Health Literacy Activities Within Public Health Departments

Which Health Literacy Activities Has Your Public Health Organization Considered or Initiated?					
	n	Mean of Responses	Number of Participants Selecting (percentage of total)		
			Currently Conducting	Considered But Not Conducting	Not Considered
1. Rewriting materials to make them easier to read and understand.	48	2.6	34 (70.8%)	8 (16.7%)	6 (12.5%)
2. Developing an awareness of cultural competencies.	47	2.6	33 (70.2%)	9 (19.1%)	5 (10.6%)
3. Training staff to communicate with clients in simple, clear language.	47	2.4	26 (55.3%)	16 (34.0%)	5 (10.6%)
4. Training translators to communicate with clients in simple, clear language.	46	2.2	20 (43.5%)	14 (30.4%)	12 (26.1%)
5. Rewriting signage so that it is visible and easy to understand.	46	2.2	20 (43.5%)	14 (30.4%)	12 (26.1%)
6. Piloting new materials with members of intended audience.	48	2.0	16 (33.3%)	18 (37.5%)	14 (29.2%)
7. Using health topics to teach literacy skills.	46	1.9	13 (28.3%)	15 (32.6%)	18 (39.1%)
8. Adopting an organization-wide plain-language policy that promotes clear communication between provider and health care consumer.	45	1.8	11 (24.4%)	15 (33.3%)	19 (42.2%)

to assist with the rewriting of their websites. A centralized language services program was adopted by the department to increase meaningful access to programs and services for individuals with limited English proficiency.”

Another participant reported that the public health organization where the person works has made addressing plain language an agency wide policy. “The plain-language policy affects all aspects of the health department. Not only those working with health-related materials, but also our Health Communications and Marketing must abide by this policy and ensure all information that goes out to the public is an appropriate literacy level.” That policy was reported to state that “All health communication activities must adhere to Agency policy or practice regarding confidentiality and disclosure of information and will use the principles of effective health literacy.” The participant did not offer further elaboration of what the public health organization defined as principles of effective health literacy.

Other health literacy activities reported as being conducted by more than half of the participants are developing an awareness of cultural competencies and training staff to communicate with clients in simple, clear language.

Most of the health literacy activities we inquired about, however, were reported as being conducted by fewer than half of the participants’ public health organizations. These activities include the following

- Training translators to communicate with clients in simple, clear language
- Rewriting signage so that it is visible and easy to understand
- Piloting new materials with members of intended audience
- Using health topics to teach literacy skills
- Adopting an organizationwide plain-language policy that promotes clear communication between provider and health care consumer

While there is certainly evidence to support the effectiveness of each of those health literacy activities, most participants reported their public health organization was not undertaking those efforts.

Perhaps most revealing was the activity that received the least recognition of having occurred—adopting an organizationwide plain-language policy. Plain language is perhaps the easiest approach to addressing health literacy. While it does not reflect the totality of current understanding of health literacy, the complexity of language is the “front door” to health literacy. For some reason, however, this core activity has not been adopted widely by the public health organizations where this study’s participants are employed.

Inquiring further as to how participants’ public health organizations were responding to health literacy as a potential tool to improve public

health, we asked if the agencies have provided training on health literacy to either health professionals or the public. Twelve participants reported that their public health organization has provided trainings to health professionals while 26 said no and 10 reported not knowing. Nine participants reported that their public health organization has provided training to the public or patients while 26 said no and 12 reported not knowing.

Only one participant reported that the public health organization in question had terminated a health literacy initiative in the past year. The multiple reasons reported for this effort being terminated were a lack of funding, a lack of trained staff, and a lack of interest by constituency.

Seven participants responded that their public health organization has at least one person with primary responsibility to address health literacy. Four participants reported that there is at least one person on staff with health literacy as a part of their formal position title. However, 33 participants reported that their public health organization does not have either a person with health literacy as a primary responsibility or with health literacy in his or her position title.

In parallel, 12 participants reported that their public health organization has one person (3 participants) or multiple people (9 participants) who have primary responsibility to ensure health literacy is addressed by the public health organization's efforts. Twenty-nine participants reported that within their public health organization, no one has primary responsibility to address health literacy, but many people do address the issue (23 participants), or that no one has primary responsibility, but one person does address health literacy issues (6 participants). Three participants reported that they did not know how health literacy was addressed by their public health organization.

Finally, we qualitatively explored the health literacy activities and perceptions of health literacy at the public health organization where participants are employed.

Themes in the responses indicate that when health literacy is addressed within public health organizations, it is being approached in a piecemeal fashion often limited to one individual or a small group versus instituted in an organizationwide and coordinated fashion. For instance, one participant wrote that "there are pockets of activity—I have done a media project directed at health literacy, but have little collaboration from others in the agency. There may be efforts in other divisions, but there has been no communication about them across the agency."

Another participant wrote, "We have made some attempts at this in some selected program areas, but generally we are pretty weak in working on this topic." Similarly, another participant described the approach to health literacy as, "Our Department has a strategic plan, but health literacy is not part of it. I have never seen any proposal to help provide guidelines

to staff or reviewers. This seems a shame since so many tools and guides are readily available.” Yet another wrote, “We have pockets of expertise, but they are not easily identifiable and are not available to help other programs. They work within their own programs.”

When health literacy is put to use within a participant’s public health organization, the participant generally described those efforts as focusing only on plain-language aspects of health literacy, but also as generally effective in reaching the organization’s goals.

For example, one participant wrote, “We focus tested a number of our materials and some draft new materials to get input from parents and physicians. We also tested some of the more scientifically oriented and text-heavy pieces that were favored by our colleagues. We were not surprised that the easier-to-read versions—even for medical professionals—were favored. This is a very difficult concept for public health professionals who are not ‘communicators’ to understand. We learned that well-chosen HPV [human papillomavirus] disease facts coupled with a personal story proved very compelling, leaving most parents who read this material with the intention of seeking more information or a shot appointment right away.”

A participant from Minnesota described one of the more robust efforts to integrate health literacy into a public health organization. This approach, as multiple other states have also done, used an initial workshop or conference to create a launching point for health literacy awareness and activities.

In Minnesota, this process was described by a participant as follows:

The Health Literacy workshop had four main components: (1) Morning presentations providing an overview of health literacy concepts, perspectives on information processing and on applying theory to tailor health messages, and background on implementing health literacy in a state health department. (2) A lunchtime screening of health message videos. (3) A presentation and moderated breakout session allowing participants to apply health literacy principles to their work. (4) A panel presentation on communicating with a diverse audience, followed by a moderated question-and-answer session and workshop wrap-up. The next step is creation of a Health Literacy Work Plan to further develop a health literacy initiative at the Minnesota Department of Health. Items to include in the work plan are: develop a health literacy committee to sustain the initiative; leverage existing partnerships and opportunities; investigate grants such as [those from the] CDC and NIH to support health literacy work; conduct a departmentwide assessment on health literacy activities and practices; work with partners to offer more training in health communications and health literacy; develop policies, procedures, and guidance for including health literacy principles into all written and oral communications for the public, hiring applications, grants, and evaluations; encourage all divisions/units to develop their own health literacy plans; encourage staff to

participate in further health literacy training; continue to advertise health literacy events, activities, and resources to maintain staff awareness of health literacy; and review current communications policies and resources to identify areas that currently support health literacy and to understand gaps where improvements can be made.

Multiple participants indicated they found utility in the document *Say It Right the First Time: Using Plain Language to Address Health Literacy* (http://www.publichealth.lacounty.gov/hea/docs/2012.08.31_SayItRightManual_WEB.pdf). No participants reported a health literacy effort that had been evaluated to the point of understanding if the effort improved the status of public health.

When asked about the best next steps they would recommend in order to advance the role of health literacy within public health organizations, participants reported a variety of possibilities. (We are reporting the recommendations offered here, not endorsing those recommendations.)

- Communicate about public health as if everyone has problems with health literacy (universal precautions) and then provide additional information at higher and lower literacy levels for people who have the need or interest.
- Create appropriate buy-in and support for health literacy to be adopted within public health organizations starting at the leadership level. ASTHO, NACCHO, and NALBOH should get involved to help promote health literacy efforts.
- Launch an educational campaign to health professionals emphasizing the need for improvement in addressing health literacy to improve public health outcomes.
- Launch an educational campaign to the public to empower them to demand clear, concise, and understandable information from public health organizations and professionals.
- Create standard health-literate approaches to addressing complex health-related topics; for example, CDC or elements of HHS could produce and distribute them to public health organizations.
- Adopt health literacy policy to elevate the issue within the organization so that health literacy must be addressed and integrated into all publicly funded public health activities.
- Take advantage of the Patient Protection and Affordable Care Act and the resulting increase in health care coverage as an opportunity to use health literacy within both public health and clinical health care systems.
- Make health literacy and plain-language training widely available to the public health workforce.

- Develop evidence-based toolkits, including short online self-training programs, and make them required annually (updating them regularly) as are the Health Insurance Portability and Accountability Act and other online annual self-managed courses. Tailor the materials to focus on health literacy applications to prevention and public health.
- Develop more evidence-based best practices of health literacy focusing on public health contexts, especially in Health in All Policies contexts.
- Integrate health literacy performance improvement efforts to enhance the efficiency and effectiveness of the delivery of public health services.
- Prioritize funding to support employee position(s) within public health departments to specifically address health literacy of the population the organization serves.
- Make departments and staff accountable to a requirement to address health literacy effectively.
- Employ community health workers to address health literacy and ensure that they have the necessary training and resources.
- Integrate health literacy into public health and health systems research.
- Conduct further research into how best to communicate public health concepts and data to audiences with low health literacy. Research needs to address real-world conditions, and produce practical and useful evaluation strategies.
- Conduct appropriate formative research and evaluation in health communication campaigns and promotional activities to address key communication issues to enhance effectiveness, especially within the reality of financial constraints.
- Include objective health outcomes in all research and evaluations of health literacy efforts.
- Identify the key factors in designing and delivering successful communications. Identify a “checklist” that should be used in developing all communications, and update that checklist as knowledge develops and experience is gained.
- Embrace the definition of public health literacy: “The degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community” (Freedman et al., 2009).

One participant offered an observation that seems to wrap up the overall experience of many participants working within public health.

I have been frustrated with the approaches and discussion of health literacy in my agency and in general. There seem to be a lot of misconceptions about how it impacts what we do—like we should be doing separate initiatives to address health literacy and then continuing to also do what we usually do rather than incorporating (health literacy) as an ongoing consideration as we work day to day. There are also those who want to make addressing health literacy in day-to-day work very onerous (and expensive) and requiring someone with special knowledge . . . (this position is) “that there is no simple way to do this and everything we communicate should be constructed, reviewed, tested, evaluated, reworked, retested, etc., etc., before it can be used.” This is not practical and so because public health staff cannot do this major undertaking—they just do things the way they always have. Much of the research done is contradictory, far removed from day-to-day public health practice and often uses approaches that are not realistic for the practice world. I think there needs to be work done to frame health literacy as the usual way of doing business, a core public health skill and not an addition or an exception for certain groups.

The Potential Utility of Health Literacy to Public Health

Health literacy can provide great benefits to the research and practice of public health. In particular, health literacy can serve as an everyday basis for the design and implementation of public health interventions. Additionally, health literacy can provide a critical perspective from which to analyze the successes and failures of public health interventions. These areas of utility have yet to fully overtake the perception that health literacy is just about plain language. Plain language, like the teach-back technique, is one of many health literacy tools and strategies that can be used to help people help themselves, their family, and their community to improve health. Plain language is not the outcome of a health-literate approach. The outcome of a health literacy intervention should be, in fact, a change in health status.

To date, there has not been significant, or sufficient, uptake of health literacy within efforts to improve public health. An open question is whether the current situation is due to a lack of understanding among public health professionals of the potential value of incorporating health literacy into their activities or is due to limitations (both perceived and real) on what is feasible within the timelines and resources of public health organizations.

The Calgary Charter on Health Literacy, mentioned earlier in this article, may present a useful framework for public health agencies. The Calgary Charter’s logic model of health literacy provides an analytic framework that leads to informed behavior change (Coleman et al., 2009). Given that public health agencies are by and large looking to promote positive behavior change related to health, the Calgary Charter can serve as a basis to inform the design and implementation of public health interventions as

well as a way to provide insight into the successes and failures of public health interventions.

The five-step logic model of the Calgary Charter on Health Literacy proposes that people can (and can be helped to) use their skills to (1) find, (2) understand, (3) evaluate, (4) communicate, and (5) use information to make informed decisions. That logic model can be used to design effective programs, critically evaluate, and inform both sides of the health literacy equation—the supply from individuals and the demand from health systems and professionals.⁴

To hopefully help illustrate the potential benefits of health literacy to public health, we will employ the Calgary Charter's logic model of health literacy as a path to behavior change as an analytic framework (Coleman et al., 2009). That model clearly distinguishes health literacy from literacy by positing health literacy as a model for how people can use their skills, rather than a list of what skills people may possess.

The Calgary Charter on Health Literacy's logic model begins with finding (or helping to find) and understanding (or helping to understand) information. These two areas essentially reflect the principles of plain language. The model advances further, however, and identifies the more complex and linked actions of evaluate, communicate, and use information (or help people to accomplish those steps).

From a public health perspective, we can easily theorize a broad set of short-term and long-term outcomes associated with each of those steps in the Calgary Charter on Health Literacy's logic model. Finding information, for example, would relate to outcomes regarding navigating the system, access, and levels of equity in access. Understanding clearly produces outcomes related to knowledge gain. The act of evaluating information produces outcomes regarding perceived relevance, self-efficacy, and formation of attitudes and beliefs. Outcomes resulting from the communicate step could include the use of the teach-back technique, creation of social support, and the diffusion of ideas and innovations. Finally, using information to make an informed decision can produce behavior changes that, in turn, would lead to changes in objective health status. That brief description just begins to paint a picture of the complex, multifactorial functions of health literacy in public health.

To illustrate, we will next describe how the Calgary Charter's approach

⁴ From a supply and demand perspective, environmental economics depicts a scenario in which demand outstrips supply of open-access resources—the so-called *Tragedy of the Commons* (Hardin, 1968). People experiencing the negative health outcomes of low health literacy may be experiencing something quite parallel to the tragedy scenario. Their supply of health literacy—their skill level and ability to direct the skills they do have toward making informed decisions—essentially can be depleted by the demands created by complex communication coming from a health professional or health system.

to health literacy can be used by public health agencies. We will use three real-world examples. First, we turn to a situation of great importance to public health—vaccinations. In the United States, vaccinations are mandated, or an exemption is required, by the state before children can enter public schools. Overall, immunization rates remain at 90 percent and higher, but in some locations vaccination rates have fallen over the past decade. This has led to calls for educational programs or stronger regulations.

Applying the Calgary Charter on Health Literacy's logic model as an analytical framework, the first question is about finding information. This is not a significant problem in this case as, by and large, access to vaccinations is relatively straightforward and equally available to all. The second question the Calgary Charter approach poses is about understanding. Currently, there are few robust educational efforts to ensure broad understanding of vaccination. The driving assumption has been that top-down regulation is sufficient. Over time, that approach has created the possibility of a lack of understanding about vaccinations that, in some, seems to lead to a lack of perceived relevance. The third question this approach to health literacy poses is how an understanding is evaluated in the context of a person's life. Vaccines have made an accurate evaluation challenging through their own success. People literally do not see the need for a vaccination in their lives when the diseases that vaccination targets are increasingly less common. That not fully informed evaluation has also created space for uninformed communication of science and risk to and within the public—communicate is the fifth question posed by the Calgary Charter's model of health literacy. As a result, some people are making uninformed or misinformed decisions about their behavior and thus opt to not have their child receive warranted vaccinations.

That brief analysis illustrates how poor public health outcomes can occur due to a lack of thorough attention being paid to all of the important steps toward informed behavior change that is posited by the Calgary Charter on Health Literacy logic model. (Many other definitions agree in whole or in part with that logic model; it is the author's preference based on experience to use the Calgary Charter model for this analysis.)

By employing health literacy as an analytical tool, public health departments could identify where and how to alter the design of programs and interventions to increase effectiveness. Greater effectiveness in public health, especially over the long term, promises increased cost-effectiveness as well. When the demand for health literacy exceeds the supply, the result is lower individual and public health. Poorer health will increase costs through increased need for care and treatment. Especially when focused on prevention, health literacy promises a more efficient and effective public health system.

Another illustrative case of how health literacy can be used as an ana-

BOX 1
**A Public Health Opportunity:
Advancing Health Literacy in Jails and Prisons**

Andrew Pleasant, Ph.D.

The United States has the highest incarceration rate in the world. In 2012, more than 10 million people will spend some time in jail, and in 2011 there were over 1.6 million adults in state and federal prisons (Carson and Sabol, 2012).

The 2003 National Assessment of Adult Literacy (NAAL), as did its predecessor 10 years earlier, included a specific focus on the literacy of adults in prisons. The assessment was administered to approximately 1,200 inmates (ages 16 and older) in state and federal prisons. Compared to the overall sample for the U.S. population, prisoners in the 2003 NAAL study were more likely to be male, Black, and/or Hispanic, and to have been diagnosed with a learning disability. Fewer prisoners, as compared to the overall population, were 40 or over and fewer spoke a language other than English as children. Overall, prison inmates had lower average prose, document, and quantitative literacy than the U.S. population sample. The assessment allowed comparisons among prison inmates who had participated in an educational or vocational training program while in prison, and in general those who did participate had higher average literacy than inmates who did not participate. Twenty-nine percent of the prison inmate sample reported participating in such a program, but more inmates reported being on a waiting list to participate.

Research has indicated that inmates in jails and prisons have lower health literacy, are poorer financially, are in greater need of health services than the non-prison U.S. population, and have disproportionately higher incidence of chronic health conditions and poorer health outcomes compared to the general popula-

lytical framework to evaluate public health efforts is possible through the campaign titled “This Is Public Health.” This campaign is sponsored by the Association of Schools of Public Health to “let people know that public health affects them on a daily basis and that we are only as healthy as the world we live in.” In brief, the core activity of this campaign consists of providing stickers (see Figure 4) to students to place on items and locations in their community that they think “are” public health.

How would a public health organization use health literacy to evaluate this campaign? First, the question is about finding or accessing the campaign. One could ask a community, for example, how many, if any, stickers residents have seen. Has the campaign been rolled out effectively in a sufficient number of communities to create broader or national awareness?

The second question the logic model of health literacy asks is about understanding. When people see a sticker, do they understand what it

tion. For inmates, low health literacy has been shown in one study to predict the risk of cardiovascular disease (Miller et al., 2012), which is the leading cause of death in inmates in the United States. The public health issues that inmates face are significant—and largely preventable. For example, it is reported that up to 19 percent of all HIV, 30 percent of hepatitis C, and 15 percent of hepatitis B cases in the United States occur within the jail and prison population; more than 30 percent of the prison population suffer from a mental health condition; and 53 percent of individuals who enter jail struggle with some form of addiction (Regenstein and Christie-Maples, 2012). A recent study in a county jail using a threefold intervention designed to improve health literacy, self-care management skills, and personal health care decision making was well received by inmates (Young and Weinert, 2013).

Financially, the opportunity to save money while advancing health by improving the health literacy of jail and prison inmates is perfectly clear. Most inmates (approximately 90 percent) are uninsured and the estimate is that inmates will make up approximately one-third of the newly insured Medicaid population under the Patient Protection and Affordable Care Act of 2010 (Regenstein and Christie-Maples, 2012). It offers an excellent opportunity to help reduce high recidivism rates by providing access to much-needed mental and substance abuse treatments upon release into communities (Smith, 2012).

The U.S. inmate population presents an unprecedented opportunity to advance health literacy, reduce health disparities, achieve health equity, and improve public health. While many prison inmates may have access to fundamental literacy programs, there is a true opportunity to introduce a focus on health literacy in order to improve health and lower health care costs. This area of opportunity could perhaps provide the basis for future Institute of Medicine Roundtable on Health Literacy efforts.

means and why the sticker is located where it was seen? Especially for people with low health literacy, the answer to those questions is likely negative. The campaign provides no informational content in the stickers themselves. Public health is left undefined.

That lack of understanding, of course, makes it much more difficult for individuals with low, or high, health literacy to effectively evaluate the information provided by the campaign. The relationship between public health and where a sticker was placed is left undefined.

Furthermore, without access to the Internet, there is no way for people to begin to understand or evaluate why they encountered a sticker. In addition, as there is no repository of information explaining where stickers were placed and why stickers were placed where they were, people may easily be left with little or no understanding of public health or the ability to evaluate what public health means in their lives.



FIGURE 4 “THIS IS PUBLIC HEALTH” campaign sticker.

Communication, the next step in the Calgary Charter on Health Literacy’s logic model, is a two-way process by definition. The “This Is Public Health” campaign does not afford that opportunity. An undefined and potentially irrelevant message is sent in one direction, but there is no communication per se. No feedback is made easily possible.

Finally, no behaviors are targeted by the campaign. There is no support to help people use the information provided—that someone placed a sticker somewhere in the world—in order to inform a decision. In fact, we find it quite difficult to identify any change that this program actually intended to make in the world.

Overall, it seems clear that a good injection of health literacy into the “This Is Public Health” campaign could help redesign the effort by building a structure into the campaign to help individuals find, understand, evaluate, communicate, and use the information provided to make an informed decision about public health and about the particular characteristics of their lived environment that influence public health. We note that this sort of a public health campaign—a fairly shallow effort to draw attention to an issue, but not helping people make an informed decision about public health behaviors—is unfortunately quite common. We could, for example, have conducted much the same analysis of the American Lung Association’s “Faces of Influenza” campaign.

We close this section with a look at a now-classic case study of public health in the United States: the anthrax letters that were mailed to news organizations and two U.S. Senators between September 18 and October 9, 2001. The outcomes of this public health threat included the deaths of 5 people and 22 people being exposed to anthrax. Some reports claim that up to 68 people were directly harmed by the anthrax. The Federal Bureau of Investigation efforts have been called “one of the largest and most complex in history,” but there has yet to be a prosecution.

Applying the Calgary Charter on Health Literacy's logic model of health literacy, again the first question is about finding information. Clearly, the public discourse in the United States was replete with information and misinformation about anthrax. All media outlets and social media of the day were focused on the anthrax threat. Finding information, and gaining access to information, about the anthrax threat was not problematic.

Understanding information is often an outcome of the complexity of information. What the public understood is the next question proposed in the logic model. During the anthrax threat, gaining an accurate understanding was a problem for many. There are multiple examples of inaccurate and exceedingly complex information coming from the government. A telling example of that complexity is in the definition of anthrax that was on the CDC website at the time. That definition read "Bacillus anthracis, the etiologic agent of anthrax, is a large, gram-positive, non-motile, spore-forming bacterial rod. The three virulence factors of *B. anthracis* are edema toxin, lethal toxin and a capsular antigen. Human anthrax has three major clinical forms: cutaneous, inhalation, and gastrointestinal. If left untreated, anthrax in all forms can lead to septicemia and death."

Many clinicians, many public health experts, many elected officials, many journalists, and certainly individuals with low health literacy were challenged to understand that definition. When the demand for health literacy exceeds the supply of health literacy, the result is a low public understanding that puts public health at further risk—that was certainly the case during the anthrax threat (Zarcadoolas et al., 2006).

As a result, the public at large was poorly equipped to correctly evaluate the information that they did possess. The incorrect evaluation that drove much public behavior at the time was a perception that everyone was at an equal risk. Evidence supporting this lies not only in the postal workers' union complaining of bias against its members, but also in the broad public demand for antibiotics and a host of commercial products alleged to offer protection against anthrax by advertisers. Much of the communication, the next step in the logic model, about anthrax—both the top-down directives from government and the multidirectional flood of words in the public space—was often misinformed and misaligned with public health goals. Individuals were therefore terribly hard-pressed to make an informed decision about their behaviors.

The outcome of this mismatch between the supply of health literacy and the demand for health literacy resulted in a failure to follow the logic model proposed by the Calgary Charter on Health Literacy as the path to informed decision making. People made uninformed or misinformed decisions based on the little information or misinformation they possessed. As a result, for example, only 44 percent of those at high risk for exposure to anthrax completed the recommended course of antibiotics (Stein et al.,

2004). Thus, poor public health communication efforts potentially contributed to what may well be the larger risk for all—the incorrect use of antibiotics, leading to antibiotic resistance.

CONCLUSIONS AND RECOMMENDATIONS

Successfully integrating the best practices and knowledge of health literacy into the field of public health is likely the most significant opportunity that currently exists to improve individual, community, and public health. Those benefits are not yet fully manifested, as it seems public health organizations in the United States are not sufficiently interested in—at least not engaged in—embedding health literacy into their efforts.

Of course, we must offer necessary caveats. The case studies offered are isolated examples of public health departments that have integrated health literacy into their work. Yet, they are clearly not representative of efforts within all public health departments in the United States. In addition, we tried multiple times to obtain responses from each state's department of public health, yet did not succeed in reaching that goal. This effort widely communicated the opportunity to participate in the online inquiry to many thousands more individuals than participated. That low response rate may indicate we received a biased response or it may demonstrate overall lack of interest in health literacy among public health professionals employed in the state health departments. The analysis of public health efforts from a health literacy perspective employs a broad conceptualization of health literacy, but relies on just one conceptualization of health literacy.

We have illustrated throughout this article the many potential uses of health literacy in public health and the possible benefits of fully engaging the fields of public health and health literacy, and offered illustrative case studies where public health departments have worked to successfully incorporate health literacy into efforts to fulfill their mission. We have, in what may be a first, started to paint a picture of how health literacy is—and is not—perceived and used within local, state, tribal, and territorial public health contexts in the United States.

If health literacy were truly and broadly incorporated into public health efforts, we most likely would have received a larger response to our inquiry of public health professionals. The most likely conclusion we can draw from this experience seems to be that the relationship between health literacy as a field of practice, research, and action and the efforts of local, state, tribal, and territorial public health organizations remains in its infancy.

On the positive side, this situation indicates that the field of health literacy faces a great opportunity to improve public health practice, research, and health outcomes. The challenges are not insignificant. The fields of health communication and health education have certainly made contri-

butions to public health over many decades of effort, but they have been unable to turn the tide in public health.

On the negative side, that means many entirely preventable issues were not prevented. People and communities have suffered unnecessarily. Health disparity gaps continue to widen, and both the public health system and health care system in the United States have been burdened with further unnecessary costs.

The potential benefits of embedding health literacy into public health organizations in the United States apparently have not been made sufficiently evident to the key public health decision makers within those organizations. That is the only acceptable explanation for why the research, critical perspective, and best practices of health literacy have not fully informed efforts to improve public health in this country.

At the end of the day, if there is a “golden rule” to health literacy, it should be to involve people early and often. Doing so inherently means that public health professionals, and clinical professionals as well, would address the entire person—not just a diagnosed disease. Such an integrative approach to public health, combined with engaging with the public early and often, should inevitably lead to a shift in focus to preventing disease. In a nutshell, this is one way health literacy can help redesign the public health and health care system to produce overall gains in public health at a lower cost.

On a positive note, a few clear exceptions do exist as the case studies in this article clearly indicate.

The onus to adopt health literacy across the spectrum of activities that occurs within a public health organization is partially on the leadership and staff employed at such organizations. However, a responsibility also squarely falls on the growing number of individuals engaged in the study and practice of health literacy. The failure to embrace the public health community within health literacy efforts must be ours.

Even in the earliest days of organized public health, as exemplified by the foundational public health story of the Broad Street water pump in cholera-stricken London, it is easily possible to envision a role for health literacy. Why it has taken well over 120 years for the concept of health literacy to emerge in scholarly and applied settings is a true mystery.

Perhaps it is a mistake that most, if not all, textbooks about public health include that story of the “founding” of public health and epidemiology that focuses on a technological intervention in which the public is depicted as having no role other than as hapless victims and fortunate recipients of a top-down edict. Perhaps, that founding story simply needs to be recast to illustrate the role the public played in developing the regulatory solution. Perhaps as a result, we can continue to produce generations of public health professionals who focus on identifying top-down

and technological solutions versus bottom-up and health-literate solutions that truly engage the public. Further research on the question of how public health training and professionals view the role of health literacy and public engagement should be of interest and seems clearly warranted.

The story of the utility of health literacy within public health efforts remains very unfinished. To complete that story, the field of health literacy needs to continue to advance as well. Research and practice have demonstrated that health literacy is a significant determinant of health.

A critically important strategy that the field of health literacy should fully understand and embrace in practice is to ensure that the evaluation of all health literacy interventions includes measurement of an objective health indicator. The explicit promise of the field of health literacy is to improve health status, and all interventions should embrace this promise, no matter what risk or challenge it poses. If a program does not have the capacity to improve participant's health status, a fair question is whether the program is truly an effort to improve health literacy. Practitioners and researchers of health literacy need to raise the bar for themselves or the field may suffer a not uncommon fate of initially raising awareness and then slowly sliding into history while the world remains substantially unchanged.

Every indication is that now is an ideal time to fully realize the potential of health literacy to lower costs while improving the overall health and well-being of the U.S. population. To fulfill that vision, public health organizations must work to ensure that either individuals have the necessary health literacy to navigate the public health and health care systems or that those same systems successfully reach out to accommodate those people who have less than proficient health literacy. A large-scale outreach effort engaging all departments of public health seems necessary as the last national assessment of health literacy found that at least 88 percent (excluding 3 percent who could not complete the methodology) were below the "proficient" level of health literacy in the U.S. adult population.

While it remains true that the "U.S. public health system is more fragmented than those in other countries," health literacy does have the conceptual potential to address that fragmentation if taken in its most robust definition (Coleman et al., 2009; NRC and IOM, 2013).

To reach the robust, ambitious, yet incredibly worthy goal of advancing health literacy to improve public health, we recommend that researchers, practitioners, administrators, elected and appointed officials, members of the fields of health literacy and profession of public health, and—most importantly—members of the public at large support and adopt the following recommendations. These recommendations are very much in line with those included in the National Action Plan to Improve Health Literacy (http://www.health.gov/communication/hlactionplan/pdf/Health_Literacy_Action_Plan.pdf).

- Develop and implement a locally relevant, specific, measurable, actionable, realistic, and time-bound plan to increase the capacity to address health literacy across each public health organization.
- Require public health agencies to report on the health literacy status of the populations they serve on an annual basis.
- Create incentives through policy, funding, and regulations for public health organizations at all levels to engage with and demonstrate gains in public health through the explicit incorporation of health literacy into the entire spectrum of efforts to improve public health.
- Mandate that health literacy be included in curriculums for all public health and allied health professions.
- Engage with public health organizations such as APHA, ASTHO, NACCHO, NALBOH, and The Society of Public Health Educators to mandate training and evaluation of the health literacy awareness and skills of all public health professionals.
- Build and actively promote an open-access and evidence-based repository of the best practices of health literacy that have been proven to improve public health.
- Ensure that all future legislation addressing the organization and funding of public health efforts in the United States explicitly addresses the opportunities that health literacy presents to public health organizations.
- Launch and fund significant and nationwide efforts to explicitly improve the health literacy and literacy skills of all U.S. residents.
- Draft and adopt health literacy policies within all public health organizations.

For too long, the field of health literacy has focused on the “have nots” and the deficits of health literacy. Now is the time to further define a community as driven to poor health by poverty, social exclusion, implicit and explicit biases, and perceived low self-worth. Now is the time to see such communities as opportunities to advance health literacy and, as an outcome, improve public health.

To conclude this article deliberately titled, “A Prescription Is Not Enough: Health Literacy in Public Health,” we highlight two main themes that run throughout the findings and our conclusion and recommendations for next steps.

First, traditional approaches to diagnosing and treating diseases, while necessary, are truly not enough to adequately address public health and eliminate health inequities. The public health status of the United States should be sufficient evidence. Health literacy efforts in public health must necessarily expand beyond traditional clinical and medical approaches to sick care—be they clinical or community-based efforts. Public health

must proactively engage with and incorporate efforts focusing on primary, secondary, and tertiary prevention and embrace an integrative approach to health. All efforts—universal precautions—must be focused on using existing best practices of health literacy and developing and testing new best practices.

Second, the field of health literacy needs to revisit the early report from the IOM, *Health Literacy: A Prescription to End Confusion*. While that work has received, and is due, significant credit for helping to advance health literacy, the world has changed significantly since that initial publication nearly a decade ago. The 10-year anniversary of that report is an opportune moment to secure support and funding in order to revisit and update the volume. The proposed revision, or perhaps an entirely new volume, should comprehensively discuss the many advances in health literacy and, especially, explore and advance the application of health literacy to public health.

Overall, we propose two significant, and necessary, shifts in research, practice, and policy. The first is a move away from sick care and toward a true health care system based on the best practices of health literacy. The second is a reenergization of the field of health literacy through a renewed analytical perspective based on the potential of health literacy to eliminate health disparities and address public health.

Nearly 30 years ago, the Ottawa Charter for Health Promotion proposed health as “a resource for everyday life, not the objective of living” (First International Conference on Health Promotion, 1986). Embracing health literacy in the practice of public health, as we have suggested above, is how the world can finally reach the worthy goal of a healthy public serving as a resource for future growth and development rather than the status quo of public health being a continuing drain on private and public resources.

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Appendix D

Revised Questions for Nebraska Survey

State Added 3: Health Literacy – Path A & B

Now I would like to ask you some questions about health forms that you fill out and health information that you read.

SA.3.1 Health forms include insurance forms, questionnaires, doctor's office forms, and other forms related to health and healthcare. In general, how confident are you in your ability to fill out health forms yourself? Would you say...

Please read:

1. Extremely Confident
2. Somewhat Confident
3. Not at all Confident

Do not read:

7. Don't know / Not sure
8. Do not fill out health forms
9. Refused

SA.3.2 You can find written health information on the internet, in newspapers and magazines, on medications, at the doctor's office, in clinics, and many other places. How often is health information written in a way that is easy for you to understand? Would you say...

Please read:

1. Always
2. Nearly Always
3. Sometimes
4. Seldom
5. Never

Do not read:

7. Don't know / Not sure
8. Have not gotten health information to read
9. Refused

SA.3.3 People who might help you read health information include family members, friends, caregivers, doctors, nurses, or other health professionals. How often do you have someone help you read health information? Would you say...

Please read:

1. Always
2. Nearly Always
3. Sometimes
4. Seldom
5. Never

Do not read:

7. Don't know / Not sure
8. Have not gotten health information to read
9. Refused