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).

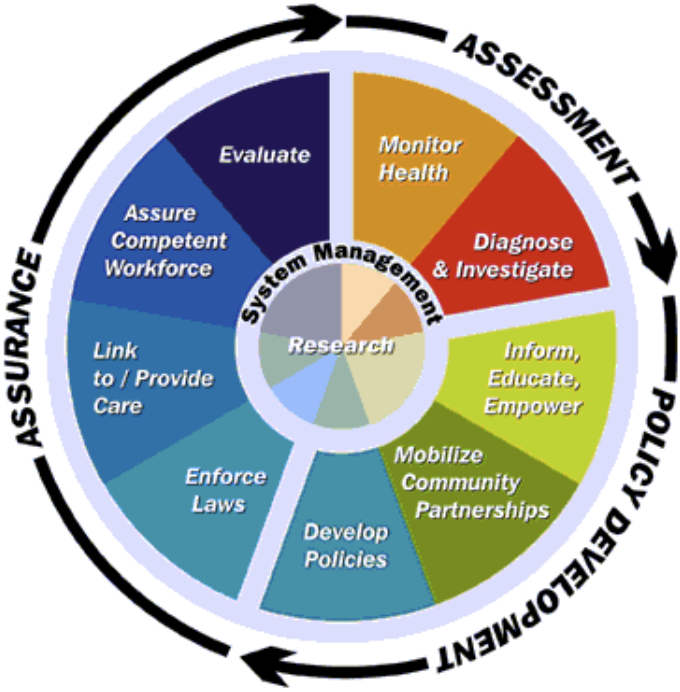

FIGURE 2-1 Essential public health services.
SOURCE: ODPHP, 2008.

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

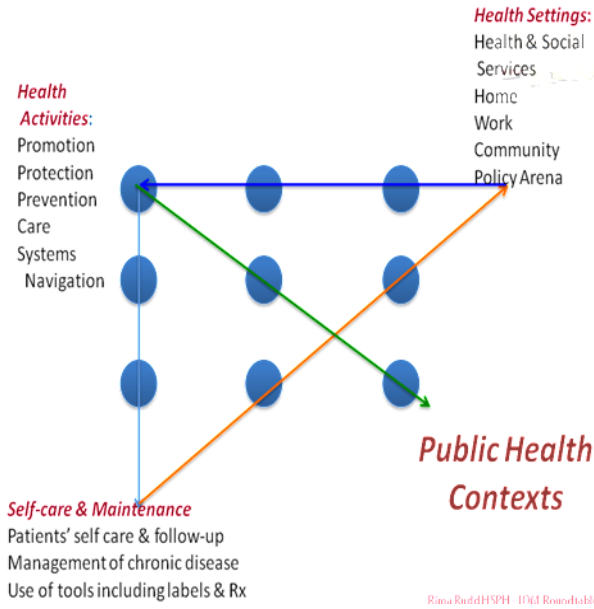

FIGURE 2-2 Thinking outside the box.
SOURCE: Rudd, 2013.

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 choice[2] 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.

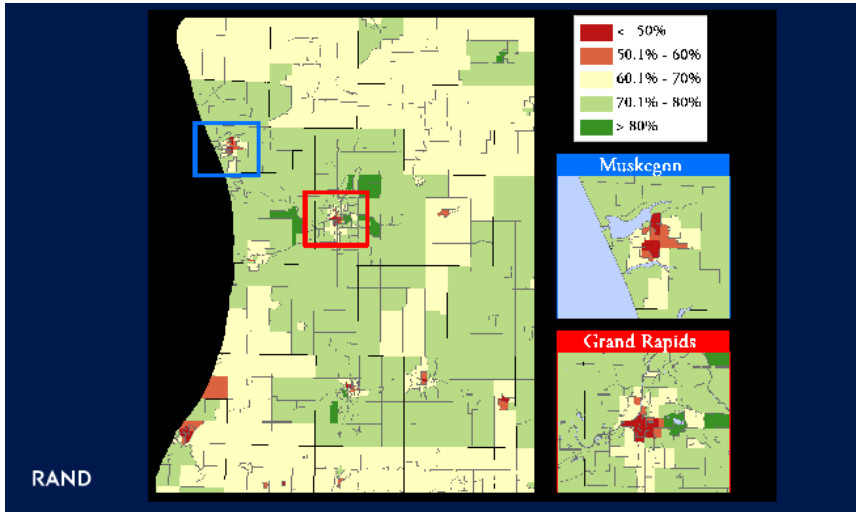

FIGURE 2-3 Percentage of population with "above basic" health literacy.
SOURCE: Martin, 2011.

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-

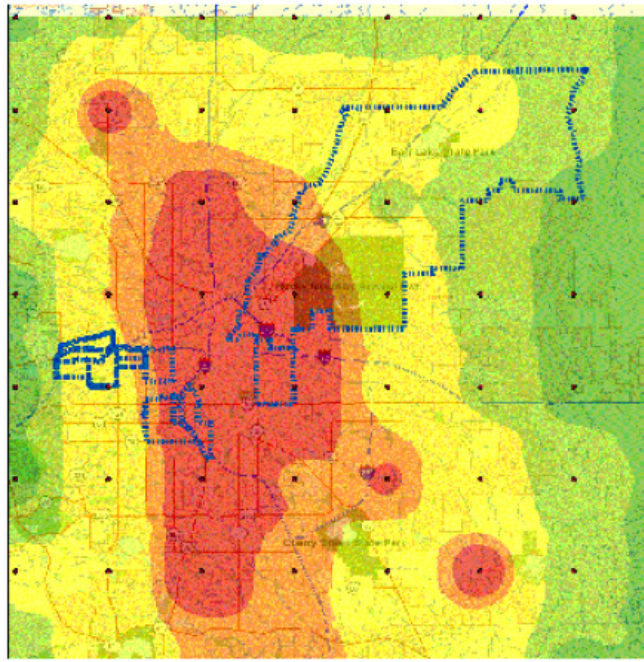

FIGURE 2-4 Missing information can lead you in the wrong direction.
SOURCE: Bird, 2013.

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.

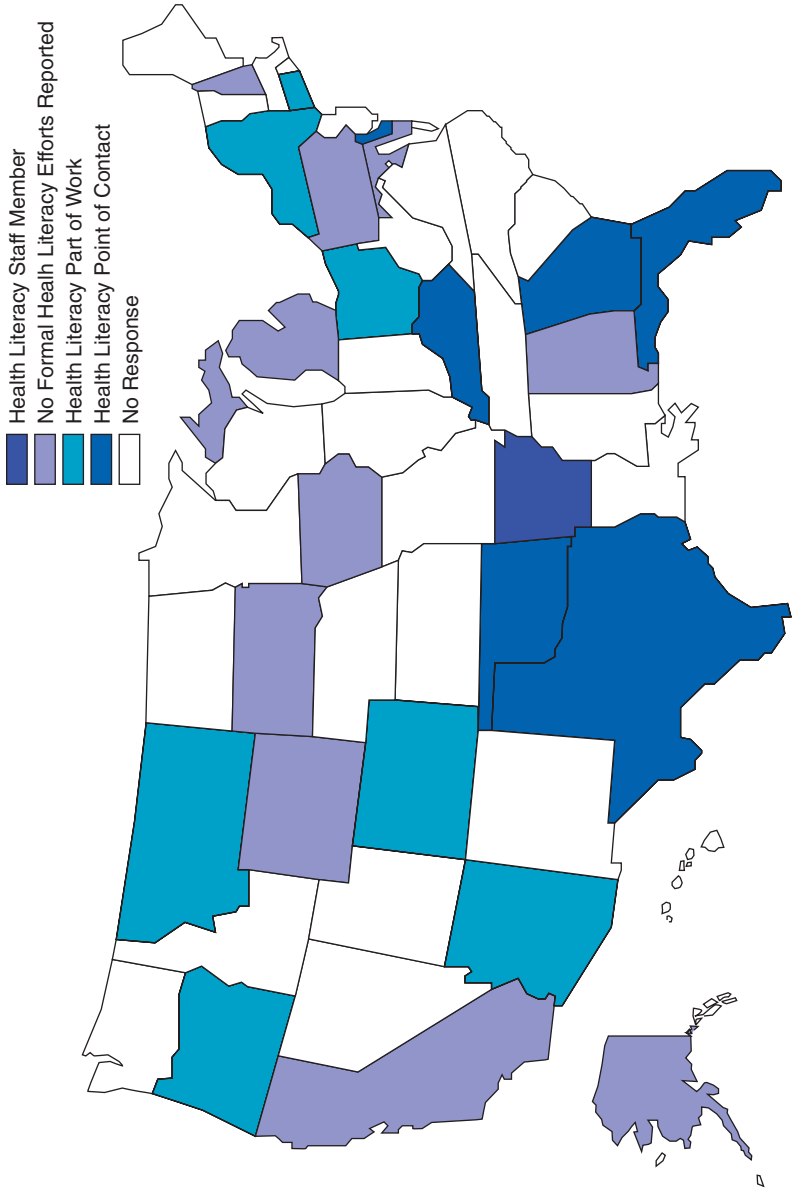

FIGURE 2-5 Health literacy within state departments of public health.
SOURCE: Pleasant, 2013.

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.

Isham 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.

Isham 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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