

LITERACY HARVEST

Health Literacy Fall 2004

Literacy Assistance Center

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LITERACY HARVEST

Fall 2004, Volume 11, Number 1

Health Literacy

Literacy Harvest is the Literacy Assistance Center's annual themed journal by and for literacy practitioners and researchers. It highlights research, trends, and exemplary practices in adult, family, and youth literacy education.

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Literacy Assistance Center

PERSPECTIVES ON HEALTH LITERACY

The statistics and stories presented in these pages on the relationship between literacy and health are sobering indeed, yet they only confirm what adult educators know from their practice: People with low literacy skills in English are at a profound disadvantage in obtaining quality health care and in taking steps to maintain their own health and that of their families. If we didn't know the exact statistics, we'd certainly heard the stories. We knew that poor health and inadequate health care often keep adult literacy students from continuing the very studies that would help them better manage their health.

Medical professionals have long been concerned with the abilities of their patients to understand and follow medical directions. Some have diagnosed low health literacy as a patient problem; some have taken steps to improve their own communication tactics. Only recently, however, have medical professionals and health literacy professionals joined together to improve health literacy, particularly among low-income and immigrant populations.

The LAC is pleased to be part of this movement with the creation last year of the New York City Health Literacy Initiative. In partnership with the Mayor's Office, we have established connections between adult literacy programs and health care institutions in New York. Such relationships are an obvious way to help

improve the health literacy of New Yorkers: Health care professionals understand health content and can provide resources on health and medicine; literacy practitioners understand the needs of low-literate and immigrant populations and can provide resources on effective adult learning and teaching techniques.

The NYC Health Literacy Initiative also offers professional development for literacy practitioners on teaching health literacy skills. Dr. Rima E. Rudd of the Harvard School of Public Health—whose article on hospital navigation appears in this issue of *Literacy Harvest*—has constructed a model of study circles in which literacy educators focus on teaching the *skills* necessary to navigate the health care system, manage chronic diseases, and participate in prevention and screening activities.

This issue of *Literacy Harvest*, supported by the Altman Foundation, is part of the NYC Health Literacy Initiative. It focuses on health literacy needs, resources, and projects across the country.

Anthony Tassi's article provides a sound introduction to the issues surrounding health literacy, as well as a stirring call to action for adult literacy practitioners and public policymakers. As the mayor's health literacy advisor and an important partner in the NYC Health Literacy Initiative, Mr. Tassi is well placed to speak to the importance of health literacy not only in New York but nationwide.

To emphasize the national concern for health literacy, we have also included in this issue an excerpt from the speech by U.S. Surgeon General Richard H. Carmona in which he identified health literacy as one of his top priorities.

From New York and a policy perspective we move to Massachusetts and a perspective that will speak to the hearts of many adult literacy educators: an empowerment model of adult education. Marcia Hohn demonstrates how well suited health topics are to the Freirian approach to adult literacy; her study of a peer leadership health literacy model underscores the effectiveness of health literacy instruction. Across the continent, California Literacy has established an ambitious statewide health literacy initiative, as described in Beccah Rothschild and Molly Bergstrom's article. The California Health Literacy Initiative provides a model for building collaborations in order to improve awareness of health literacy needs and to share resources.

Dr. Rudd's study of the difficulties adult learners *and their teachers* had in navigating large urban hospitals is the centerpiece of this journal. Dr. Rudd's article provides concrete suggestions of ways in which medical institutions could help laypeople find their way around.

The final three articles describe specific projects and initiatives to improve health literacy and access to health information. Kate Singleton's "journey" in developing health literacy curriculum and a health literacy toolkit for literacy practitioners will be of interest to curriculum developers, as well as teachers who are interested in incorporating health literacy into the classroom but don't know where to begin. Sabrina Kurtz-Rossi and colleagues have evaluated an early effort at health literacy curriculum, HEAL: BCC (breast and cervical cancer). Like Hohn's article, their study demonstrates the effectiveness of quality health literacy education. Finally, Stacey Downey and her colleagues describe an innovative combination of technology, literacy education, and health; the Outreach on Wheels project sends a van equipped with Internet-connected computers and staffed with both literacy and health experts to low-income and immigrant neighborhoods to help residents obtain access to a variety of information sources, including plain-language health information websites.

The articles in this journal provide a wide variety of perspectives on the intersections between health and literacy. If you have not already made health literacy a part of your teaching or advocacy efforts, we hope this issue will inspire you to do so.

A great many people have contributed to making this issue a success. In addition to the authors, we would like to thank the members of our editorial board and the LAC staff, particularly Executive Director Elyse Barbell Rudolph, for providing feedback on drafts of the articles. Most importantly, we thank the Altman Foundation and the New York State Education Department for funding the journal's production.

THE EMERGENCE OF HEALTH LITERACY AS A PUBLIC POLICY PRIORITY

From Research to Consensus to Action

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

The emergence of health literacy as a public policy priority has significant implications for the adult education community. Adult education and English for speakers of other languages (ESOL) programs will no doubt be called upon to integrate health literacy skills instruction into existing curricula, a call many programs have already answered in a variety of ways. In addition, heightened awareness of health literacy throughout the health care system may present a new opportunity for adult educators to collaborate with

health care professionals. Pedagogical insights honed through years of adult literacy and ESOL practice could inform new partnerships across health and education sectors to meet the challenge of enhancing health literacy among all Americans.

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

Overview of the Research on Literacy and Health

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

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

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

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

- **Difficulty understanding and using health information.** The 1992 National Adult Literacy Survey found that nearly half of the American public read at the 8th grade level or below and that 40 percent of Americans with chronic medical conditions read at the 5th grade level or below (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Over 300 studies conducted in almost every imaginable health care setting have documented that health care information is routinely written above these reading levels (IOM, 2004).

An Emerging Consensus on Health Literacy

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

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

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

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

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

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

Framework for Action

Finding the Levers of Change in the Health Sector

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

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

Alarming disparities in health status, access to care, and health outcomes along racial and ethnic lines have long plagued the nation's health care system (IOM, 2003). In the past ten years, the health care sector has become increasingly serious about and committed to finding better ways to address these critical shortcomings of the system. Viewing the issues of disparity through the lens of health literacy may offer a powerful complement to existing efforts. Literacy and language skills are not evenly distributed across the population: The National Adult

Literacy Survey of 1992 found African-American and immigrant populations were disadvantaged with respect to literacy levels (Kirsch et al., 1993). It is safe to assume that the distribution of health literacy skills is likewise skewed across the population. Therefore, interventions that seek to enhance low health literacy skills among a patient population will likely address racial and ethnic disparities as well.

A second large-scale challenge currently being tackled throughout the health care system is the imperative to improve patient safety and reduce medical errors. More actively involving patients in their care decisions and communicating more frequently about these decisions can also play a significant role in meeting this challenge. Perhaps the most common medical error is the incorrect administration of prescription medications (Kohn, Corrigan, & Donaldson, 2000). Health literacy could play a central role in implementing successful error-reduction

“Health literacy” goes well beyond the ability to read... and encompasses listening, speaking, writing, and arithmetic skills as well. These skills are needed to fill out patient registration forms, health insurance forms, and other documents and to understand and participate in communications with physicians, nurses, and other health care workers.

programs. Enhancing patients' ability to accurately communicate their symptoms, allergies, medical history, and other vital information could prevent physician errors in prescribing the wrong drug at the wrong dose. Enhancing patients' reading ability and self-advocacy skills—such as the importance of asking questions and the right to informed consent—could help reduce dispensing errors at the bedside. Such interventions may prove to be more cost-effective than information technology solutions or changes in staffing patterns. Likewise, enhancing patient health literacy skills could markedly improve medication management skills outside the clinical setting, improving adherence to therapies and reducing drug errors.

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

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

Implications for Adult Education

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

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

Health care is incredibly complex and given to frequent new developments that are often sensationalized and inaccurately portrayed on the evening news. The so-called best medical advice—on topics such as cholesterol and dietary guidelines—seems to change every few years, and direct-to-consumer phar-

maceutical advertising is a multi-billion dollar business. Adult education and ESOL instructors have neither the time nor the training to keep up with this ever-changing body of knowledge and opinion or to sort through the cacophony of conflicting voices. Basing a health literacy program on specific instructions with respect to specific medical conditions—even if the conditions are relevant to all learners in the class—is unlikely to succeed except under the best of circumstances.

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

Health literacy instructors will need to be guided and trained on how to handle sensitive topics that may come up in the classroom and how to respect the reality that individuals have vastly different health care models that inform many of their daily choices.

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

The Potential for Collaboration

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

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

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

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

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

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

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

years, in a supportive community-based environment. Health care providers should be beating down the doors of adult education programs to gain access to these programs.

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

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CROSS-CULTURAL COMMUNICATION IN HEALTH CARE

Editors' Note: U.S. Surgeon General Richard H. Carmona has identified health literacy as "key to improving Americans' health." In his speech at the Pfizer Sixth National Health Literacy Conference last year, he told this story that illustrates why he thinks health literacy and health communication are so important.

MORE THAN 30 YEARS AGO, I WAS A YOUNG SPECIAL Forces medic in Vietnam... I learned first-hand then that how I communicated with a patient and her family could have direct effects on their outcomes.

These lessons that I learned in a very remote area, working with the Montagnard villagers, were lessons I have never forgotten. This A-Team that I was a part of had a wonderful relationship with the Montagnards, and at one point... we went into the Montagnard village and did what was called a Medical Civil Action Program... When you go into the village as Americans, you just want to... line everybody up and start diagnosing and treating their medical complaints.

Well, the Montagnard village leaders didn't want us meeting anybody or touching anybody until they knew who we were. So we had to sit for a while with the village chief and his family and get to know each other. We talked through an interpreter...

[W]hen it was all over, the village healer started to bring some people in, because we had offered to look at them for conditions that the healer was not able to treat. And the first person who came up was the granddaughter of the village chief. I don't know how old she was, maybe 7 or 8. Mind you, in their language, they don't have words for time or days or years. It's sunrise, sundown. Passage of time is related to the crops and the cattle.

So when I saw her walking toward me, I thought, "I'm going to look brilliant." Her arm was covered with scabs, and I immediately recognized it as impetigo. Even as a 19-year-old Special Forces medic, I was thinking that I was going to look pretty good with this diagnosis and treatment...

I put some... Phisohex in a bottle that the villagers had. They didn't have running water, so we said, "Go down to the river, wash with this, don't pick at the scabs, let them fall off. Oh, and by the way, take these."

... I gave them a little bottle of the PenVK and said, "Take one of these four times a day." There were 28 pills in the bottle, and I said, "I'll be back in a week or 10 days, and I'll check up on you when we come through the village."

So I went away, and then came back in about a week. We went through the whole ceremonial thing again with the food and wine and talking. Then the little girl was introduced as the first patient. She looked wonderful. The scabs were coming off her arm.

... The village chief thanked me for all I was doing for his people. And then he showed me a little box and said, "And we thank you for this gift that you have given us."

He opened the box, and there was a necklace of 28 Pen VK pills.

Then the interpreter told me that now when people are ill, they wear the necklace so that it will ward off the disease.

The thing is that I thought I was a pretty good communicator. Obviously I wasn't, and I learned a lot that day. More than 30 years later I still think of that and what an invaluable lesson I learned about never assuming that someone understands what you're talking about.

The Montagnard villagers had no idea what questions to ask me about the pills. This was the first time that they had ever seen a pill. To them, it looked like a bead. A medicine bead.

So they treated the vial of pills as a bottle of beads. And to take it four times a day, there was really nothing in the language to say that.

I wish I could have anticipated the misunderstanding. As a relative stranger to their culture and their way of life, I didn't even consider that the Montagnard people would see a pill as anything other than a pill.

A PEER LEADERSHIP AND EMPOWERMENT APPROACH TO HEALTH LITERACY EDUCATION

The Massachusetts Experience

MANY ADULT EDUCATION PRACTITIONERS ESPOUSE a philosophy of learner empowerment; however, many also struggle with bringing that philosophy to life. Learner empowerment relates to Paulo Freire’s approach to adult education, which integrates literacy instruction into the context of adults’ lives. For Fingeret (1990), the context of adults’ lives—their issues, problems, aspirations, skills, cultures, and languages—provides both the basis for literacy work and the tools with which to engage in such work. The National Institute for Literacy has incorporated this approach into its Equipped for the Future (EFF) educational reform effort. Developed through a process that included adult learners, EFF promotes literacy education in the context of adult learners’ roles as workers, parents, and community members. According to EFF standards, the purpose of adult education is to equip learners with the knowledge and skills they need to develop their voice, access information, take independent action, and continue to learn throughout their lives (National Institute for Literacy Special Collection, 2004).

Health literacy provides an excellent platform for a Freirian approach to adult literacy education. Health is a critical issue not only for adult students, but for their families and their communities as well. It affects all levels of learners in all types of class-

rooms (Rudd & Comings, 1994). It is also a topic that energizes students (Hohn, 1998). As Bob Bickerton, Massachusetts’s director of adult and community learning services, noted, health “can be jet fuel for programs to begin discussions about how contextualized curriculum and instruction is approached and how curriculum can be reshaped” (Hohn, 2002).

The Massachusetts adult basic education system has been engaging in an empowerment approach to health literacy for over ten years. Based on contextualized, student-centered instruction, these efforts have not only energized the literacy curriculum, but have also influenced the way students think and act about their health.

A Brief History of the Health Work in Massachusetts

In 1991, a group of adult basic education practitioners and health educators began meeting at World Education in Boston to discuss and envision what embedding health instruction in adult basic education programs might look like. The group, which became known as the Literacy and Health Group, found a home at World Education through its work with Massachusetts’s System for Adult Basic Education Support (SABES). At the time, both literacy and

health educators were gripped by recent studies documenting the connection between poor health and low literacy. They agreed that both literacy and health education systems were needed to address the issue. They also agreed that the pedagogical approach must embrace individual and collective empowerment and advocate for community participation in identifying health problems as well as strategies to address those problems.

The first efforts to embed health instruction in literacy education took the form of discrete projects, usually focused on a disease or body part, such as an HIV/AIDS Curriculum Kit and Project HEAL (Health Education in Adult Literacy), which focused on early detection of breast and cervical cancer. In 1994, when tobacco tax dollars were devoted to literacy and health, a broader, more inclusive approach became possible. Advocacy by the Literacy and Health Group with the Massachusetts Department of Education resulted in a series of “Comprehensive Health Projects,” which were based on a peer-leadership and participatory framework. Since 1994, over 50 adult basic education programs in Massachusetts have been funded, receiving \$10,000 to \$20,000 apiece each year to accomplish such projects. Currently, 14 of these 50 programs are funded under Comprehensive Health dollars for a five-year period under regular adult basic education funding. Another venue for the literacy and health work, Student Leadership/Health Mini-grants, has involved an additional 21 programs. The mini-grants, administered through SABES, support short-term projects at \$2,000 to \$4,000 apiece.

How Student Health Teams Function

Based on the guiding principles of individual and collective empowerment and active community participation, student health teams became the means for carrying out the proposed projects. In a student health team, groups of five to ten students work with a team facilitator, who is usually a teacher or staff member from the program with a special skill and interest in the participatory process. The health teams also work with teachers, community health organizations, and health practitioners to engage other students in health activities through peer teaching and mutual learning approaches. Health team activities include:

- Researching health information
- Teaching other students about health, often through creative methods such as drama, art, or music
- Making and distributing health brochures
- Developing and conducting health surveys
- Participating in or running health fairs
- Arranging for medical screening services at the program site
- Documenting and taking action on community health issues

In order to join a health team, interested students (usually with the encouragement of their teachers) must apply. Applicants are then interviewed and selected by the health team

facilitator or the program director. In established teams, experienced members conduct the interviews and select new members. Students join a health team for a variety of reasons. Many are attracted by the stipend of \$8 to \$13 per hour that team members earn; many also want to practice their English, make friends, involve themselves in something new, and develop their skills (Hohn, 1998).

Student health teams meet regularly—usually once a week for several hours—to discuss which health issue they plan to address, to learn about the health issue, and to decide which activities they will use to present the topic, encourage discussion, and disseminate information. During the actual implementation of these activities, team members may work between 10 and 15 hours a week.

Identifying Student Health Interests and Needs

Ascertaining and responding to the health information needs and interests of the other students in the program is a fundamental part of the work in which student health teams engage. Teams choose health topics in a variety of ways: Some provide a list of possible topics and have students select their top choice, some have classrooms vote on their choice, and some conduct individual surveys. In one program, ten major health topics were posted in the common area and everyone in the program—students and staff—placed a colored dot next to his or her top three choices. This enabled the community to actually witness its vote emerge. Having students select the topics not only promotes ownership over the learning, but also generates intense interest in how the team will address the topic.

Peer Teaching

Once the topic has been selected, some teams opt to teach students directly; others facilitate presentations by local experts. Teams that choose to teach students directly typically spend several months researching the topic. They consult local health care professionals, written materials from community health agencies, and resources from prevention centers. They also search the Internet. The health team facilitator plays a crucial role, assisting the team in the development process and acting as a bridge to community health resources. Once the research is complete, teams devote as much time and employ as many activities as necessary to ensure that other students and staff understand the information and can apply it to everyday life. For example, when one team was teaching about depression, they organized a variety of activities, including a drama in which students acted out different levels of depression and treatments, small-group discussions where students could discuss depression as they and their friends and families had experienced it, and follow-up discussions that focused on varying cultural beliefs and attitudes about depression. The team also created and distributed a brochure suggesting places where students could go for help.

When local experts present the topic, health teams generally provide supplemental activities, such as dramas, posters, and small-group discussions. Teams usually work with presenters to ensure they understand the audience they will be addressing. Teams may also provide translations for the presentations.

Whenever possible, teams provide opportunities for students to engage in hands-on, concrete activities—though some topics lend themselves more easily to hands-on learning than others. If the topic is early detection of breast cancer, team members can demonstrate breast self-examination. If the topic is HIV/AIDS, students can practice putting a condom on a banana. Topics such as unprotected sex, domestic violence, or environmental hazards require a more creative approach. Team members may plan concrete activities, such as role-play, social action theater (evocative dramas where actors stay in character so audience members can ask them questions), small-group discussions and strategy sessions, and visits to community organizations.

Toward Better Health and Fuller Participation

Connecting students with community health services is another important function performed by student health teams. Once students understand a health topic, they need to know where they can go to get help or take the next steps. Student health teams might provide written information about community resources or encourage local health service representatives (for instance, a health van) to visit the program.

Health teams do not develop overnight. Using participatory methods, the facilitator must help the team develop and guide the conversations. One student, speaking in a focus group, underlined the importance of the team facilitator's role:

No matter what, we will always be a team because we also became a very unusual family. We had two parent figures [the facilitators] who help us to grow and to become who we are. They were always there to listen and help just like a parent should. Most of us did not have this and I feel the value of this non-judgment atmosphere was a major influencing asset in our growth as individuals and as a team. We had to learn to trust them first, then we were able to trust each other and finally start trusting ourselves.

Enhancing traditional literacy skills is inherent in all health literacy work. Researching community health resources can help students develop their reading, writing, and math skills. Searching the Internet requires students to evaluate the authenticity and reliability of the information they find, presenting another opportunity to develop literacy skills. Drama and role-playing activities not only help students build their oral communication skills but also demonstrate how they can advocate for themselves and their families. Team facilitators can help teachers work with student health teams to build classroom literacy activities around the health topic.

Researching Impacts and Outcomes

So what is happening as a result of a decade of work in Massachusetts on health and literacy using a peer-leadership and empowerment model? What health topics have students learned about? What health knowledge and skills have they gained?

In the fall of 2002, I undertook a series of informal focus groups and individual interviews with adult students, student health team members, teachers, and program support staff about the impacts and outcome of their health work. My questions included:

- What health topics did you learn about?
- What were the most important things you learned about those health topics?
- Did you share what you learned with others? If so, what did you share? With whom?
- Thinking back to a year ago, do you think differently now about your health and your family's health? If so, what is different?
- Thinking back to a year ago, what do you do differently now about your health and your family's health?

Table 1 shows the number and type of participants in the eight informal focus groups and 19 individual interviews. Eleven programs are represented.

Table 1. Research methods and respondents

	Focus groups	Interviews	Total
Student health team members	16	0	16
Other students	16	3	19
Program directors*	3	6	9
Program teachers*	10	5	15
Health team facilitators*	3	5	8
Total	48	19	67

* Program directors, teachers, and health team facilitators were asked to respond to questions based on their discussions with students. They were also asked to comment on the impact of health work on the program's organizational development.

Later on, I gathered additional input from students and health team facilitators who participated in two regional meetings where my findings were presented. Approximately 30 students and 10 facilitators answered three supplementary questions:

- Is there anything you think should be added to these findings?

- Can you give some examples from your own life to further illustrate these findings?
- How would you apply these findings in your life?

A Unique Approach to Health and Literacy

In their responses to focus group and interview questions, teachers and program directors expressed satisfaction with this new approach to health education and literacy learning. One teacher put it this way:

I see this as a very different kind of health education. Lots of ESOL teachers have done health, but it has always been pedestrian. It assumes the health education framework is already there and can be transferred over by language. But the student health teams do not assume any knowledge or experience.

Teachers were also delighted with the way in which health topics energized literacy instruction. In fact, teachers from one program that did not have a health grant or a student health team were nevertheless working with students to develop a curriculum based on the health interests and needs of students. The following comment, made by a teacher, demonstrates the success of working with a topic that encourages students to take ownership of their own learning:

The students were so open and excited, wanting to participate and willing to share. Students really can direct their own learning, and we will never again presume to know what students need, want, and know. This was a learning process for all of us.

A program director agreed that health is a perfect platform for self-directed learning:

Health issues are right there with students' needs. They don't have the information they need and access to services. The health team is reaching students in a new way. It is so incredibly effective. The health team really reached the students and the students got the help they needed. It has heightened consciousness about student leadership and helped make student purposes and goals the centerpiece of the program, [as well as] deepening commitment to providing a variety of learning and growth experience. It infused a different methodology across the program to a critical mass of staff.

Student-Reported Learning on Health Topics

In focus groups, student health team members, as well as students who had participated in the health team activities, reported on the health topics their programs chose to study. The most frequently mentioned topics were:

- Stress and depression
- Diet and exercise
- Cancer, including tobacco education

Topics that were also mentioned, although less frequently, included sexually transmitted diseases, including HIV/AIDS; first aid, including CPR; community and family violence; alcohol and drug abuse; and hand-washing techniques, which was

particularly popular during the SARS scare. By studying these topics, students said they not only learned new information but also, in some cases, new ways to behave.

Learning about Stress and Depression

It's not surprising that many health teams selected stress as a topic to study. Like so many Americans, adult literacy students often find themselves juggling work, school, and family. English-language students may also simultaneously be adjusting to a new culture, a new language, and a new way of life. As one student said, "Everyone has stress. This is a topic everyone can relate to—students, teachers, everyone."

During focus groups, students said that learning about the emotional and physical effects of stress was important to them; they were relieved that others were acknowledging their stress. Many said they had not known that stress could raise blood pres-

Topics such as unprotected sex, domestic violence, or environmental hazards require a more creative approach. Team members may plan concrete activities, such as role-play, social action theater (evocative dramas where actors stay in character so audience members can ask them questions), small-group discussions and strategy sessions, and visits to community organizations.

sure and, over time, play a role in the development of heart disease. Similarly, many said that they had not known that stress could tighten muscles, resulting in headaches and backaches. One health team member related this learning to his own experience:

I didn't know stress and my back pain were related. I was taking drugs for my back pain but what I really needed to do was get my stress under control. I see how things are connected more now and that there are different options.

Students said they had been interested in examining connections between stress and emotional outcomes, such as anger. During the focus groups, they discussed how the health studies activities allowed them to explore the interplay between physical and mental or emotional reactions. In doing so, they were able to identify stressful situations with their families or their work that had spiraled out of control and how they might have better managed these situations if they had acknowledged, and known how to, reduce their levels of stress.

In the focus groups, students said they had fun and were interested in learning about stress-reducing activities. Frequently mentioned activities included deep breathing, stretching, listening to music, exercising, and reading, as well as self-massage and acupressure. Some students introduced stress-relieving techniques from their own cultures, particularly massage and

meditation. Students identified smoking tobacco and drinking alcohol as popular reactions to stress. They noted that reducing stress might make it easier to quit smoking. Some talked openly about the way their cultures—and in some cases their families—use alcohol as a form of self-medication for stress and depression.

Like stress, depression is prevalent among adult education students. ESOL students often experience depression as they adjust to life in the U.S. A variety of experiences can trigger depression including past trauma, the loss of one's familiar culture and language, the overwhelming number of adjustments an immigrant must make, feelings of powerlessness, difficult life circumstances, or any combination of these experiences. Similarly, American-born literacy students may feel hopeless about the prospects of improving their lives. Any conversation of depression reveals a variety of cultural beliefs, societal perspectives, and experiences among both English language learners and English-speaking students about mental illness in general and depression in particular. Some cultures do not acknowledge mental health issues or pursue drug and therapy interventions. Some cultures, including American sub-cultures, interpret depression as a sign of laziness. Moreover, ESOL students are rarely familiar with community health resources for screening and treatment.

The health literacy activities affirmed for many students that depression is, in fact, a medical condition—that those terrible feelings of hopelessness have a name.

In light of these complexities, many students said it was useful to learn about the distinctions between sadness and depression and between stress and depression, as well as how to recognize symptoms and levels of depression. They were relieved to learn that depression has a physical basis and can be treated. Some recent immigrants described feeling “down” and wondered what was wrong with them, why they felt this way. One student explained how studying depression helped her cope with these feelings:

I couldn't understand why I felt so bad. After all, I was in America and this is what I wanted. But my children are still back in my country and it will be many years before I can bring them here. I miss my language and English is so hard and there is so much I do not understand about the culture. I feel so alone. I feel better knowing my feelings have a name and there are things I can do to feel better.

During focus groups, most students reported that understanding the physical and psychological components of stress and depression affected the way they thought about and reacted to the conditions. The health literacy activities affirmed for many

students that depression is, in fact, a medical condition—that those terrible feelings of hopelessness have a name and can be ameliorated through medication or therapy, exercise, and diet. As a result, students said that they were more apt to:

- Talk openly about stress in their own life, as well as the lives of their family members
- Take action to control stress, such as exercising, listening to music, stretching, or using self-massage

Learning about Diet and Exercise

If everyone deals with stress, everyone must also eat. And food, which is about as closely allied to culture and social traditions as a topic can get, generated enormous enthusiasm during the focus groups.

Many students said that prior to health team activities, they had not paid serious attention to what they ate, how much they ate, or how the food they ate was prepared. One student said:

I was appalled when I saw how much [fat] was in Coke, fries, and hamburgers. I did not know this before and I was really shocked. I am trying to eat at home more and use healthy recipes.

“Getting fat in America” was a recurring theme. One student said:

In my country everyone walks. But here, everyone rides in a car or a bus. And when it is cold, you stay inside and watch television and eat. There is food everywhere and sizes are so big. You get fat in America.

Every focus group and interview conducted included a conversation about being overweight and trying to lose weight. The amount of sugar—especially hidden sugar—in foods prompted vigorous discussions. Students said that as a result of the health team activities they were making connections between eating habits and medical conditions such as high blood pressure and diabetes.

Along with learning about diet, students learned about food preparation and cooking. During the focus groups, students said they had learned how to trim the fat from beef and chicken, use recipes that require less oil and salt, and incorporate more fruits and vegetables into their meals. One program conducted a Healthy Eating Fair in which health team members prepared healthy dishes, accompanied by recipes, representing the students' countries of origin. Some health teams sponsored “healthy recipes” contests with prizes for the best recipes. Students, many of whom were in their mid-30s and had school-age children, were particularly interested in learning how to provide nutritious meals and snacks for their families. One health team member noted:

Spanish people fry everything and use a lot of butter and mayonnaise. They need to know how much fat that adds to what they are eating. I told my Mom to try different ways to prepare food and she is trying.

In focus groups, students spoke about diet and exercise together; however, most of the behavioral changes they reported were related to food. Students said that they had:

- Cut down on junk food
- Incorporated fruits and vegetables into recipes, and used fruit as a snack
- Used cooking methods that relied on less fat
- Replaced soda with water, and increased their water intake

Though exercise was discussed in less detail, students did report behavioral changes, primarily in relation to weight control, stress reduction, and general well-being. Students who studied depression recognized the role exercise can have in treating that condition as well. Many students talked about the amount of walking they did in their native countries. Since walking was the primary form of exercise for most students, some health teams prepared posters advertising pleasant places to walk, as well as low-cost gyms in the area. To address the needs of parents, one team also prepared information about playgrounds and YMCA programs for children. Students who reported changes in behavior said they substituted walking for riding whenever possible, or walked in the park or on the beach in warm weather.

Learning about Cancers and Smoking

Various cancers and smoking cessation constituted a third cluster of frequently mentioned health topics. Students said they were concerned about cancer because it affected their families. They wanted to learn about different types of cancers and treatments. Breast cancer was of particular interest, perhaps because of publicity from the earlier breast and cervical cancer health literacy initiatives and because of the large number of women enrolled in the programs. Cervical cancer received less emphasis, though the women students were, as a group, more at risk for cervical than for breast cancer because so many were in their mid-30s.

Most health teams that tackled smoking focused on the physical effects, with an emphasis on how to stop. They talked about smoking as a reaction to stress. They also discussed the role of tobacco smoke in disease, especially cancer. Health teams presented data on the effects of secondhand smoke. This information was new to most students, who were surprised and upset to learn that their smoking could affect their children's health.

In terms of actual behavioral changes, many students said they had tried to stop smoking—although nobody reported that he or she had been able to quit completely. Most students said they were in the process of cutting down; they were interested in stopping completely, as one student put it, “to save money and my health.” Students did, however, report significant behavioral changes relating to secondhand smoke. Upon learning about the effects of secondhand smoke, a substantial number of smokers said they had started to smoke outdoors, away from their children. One health team reported that their program's smokers no longer clustered in the doorway used by children from a day care center.

Student-Reported Learning across Health Areas

Besides learning about specific health topics, students said that they would be able to apply the knowledge and skills they had learned to other health issues, as well as to the health of their families.

Students were particularly enthusiastic about having developed a health vocabulary. It was important for them to understand the exact definitions of terms such as *depression*, *stress*, *blood pressure*, *blood sugar*, and *cholesterol*. Similarly, knowing the names for body parts (such as *cervix*, *uterus*, *prostate*, and *testicle*) and screening tests (such as *Pap*, *mammogram*, and *PSA*) gave students the means to describe and discuss their health.

In fact, the ability to communicate about health may have been one of the most important outcomes for many students. Students reported that they were better equipped to describe what it means to be healthy, as well as the physical symptoms of medical conditions. As a result, their skill and confidence increased. Students said they were less afraid to pose questions to doctors and other health care professionals, and that they were not afraid to speak up when they didn't understand something.

Students also improved their ability to find and evaluate health information. Most health teams provided information on where to find local health information and community health services, especially for prevention and early detection. During the course of studying health topics, students also learned how to search the Internet for health information. Specifically, they learned how to find sites with easy-to-read information and how to distinguish reliable sources from sales pitches.

The concepts of prevention and early detection were new to many recent immigrants. Many English language students had little or no experience with tools such as blood pressure checks, blood sugar and cholesterol screening, mammograms, or Pap tests. Learning that these tests are available and why they are important prepared many students for learning about specific health topics.

Finding out about available community health services was also critical for many students, especially immigrant students being introduced to the concepts of prevention and early detection. Students learned about community health centers and mobile vans that provide a variety of screening tests and services, from tests for blood pressure, blood sugar, cholesterol, HIV/AIDS, or sight and hearing acuity to flu vaccines.

Many students said they learned how to make sense of nutrition labels, allowing them to improve the nutritional quality of meals for themselves and their families, and to control their weight.

The Impact of Health Learning

During focus groups and interviews, students and staff in programs that had used a peer leadership model to promote health learning reported that students not only gained new knowledge

and skills, but also changed their attitudes and even their behaviors in regard to their own health and the health of their families. Self-reported data has its limits, and my findings should be confirmed by studies that incorporate larger focus groups and more varied methods. However, my conversations with program participants lead to several possible conclusions about the impact of the health work in Massachusetts:

- Students and program staff affirmed that it is important to learn about health in adult literacy programs.
- Teachers and program directors said that learning about health contextualized and energized literacy curriculum and instruction.
- Students in this study increased their knowledge about the health topics they studied and their skills across a variety of health areas. They acted on this new knowledge to make changes in their habits and self-care practices that can affect their health and the health of their families. The skills they learned might help them better advocate for their own health as well as the health of their family members.
- Students in this study seemed to believe that they have more control over their own health, as well as the health of their family members, than they did before they participated in the activities.
- Intense engagement with health education using the empowerment model promotes a positive experience of that education, which may set the stage for lifelong learning about health.

For the students in this study, learning about health through a peer leadership empowerment model promoted self-efficacy in health care and promoted positive changes in thinking and acting about health. These tentative conclusions suggest that the health work in Massachusetts has already had a significant impact on students who have participated in the programs. The peer-leadership empowerment model of health literacy education is working and should be expanded to include more programs and more students.

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About the Author

Marcia Drew Hohn, Ed.D., has worked with literacy and health in Massachusetts since 1991. From 1995 to 1997, she conducted a two-year participatory action research project with the Operation Bootstrap Student Action Health Team, culminating in the NIFL report “Empowerment Health Education in Adult Literacy” (1998). She has published many articles and presented at conferences on literacy and health issues and on embedding health education in adult literacy. She continues to facilitate the Bootstrap health team and oversees the statewide literacy and health interest group in Massachusetts.

NAVIGATING HOSPITALS

Literacy Barriers

MANY PEOPLE, INCLUDING THOSE WHO SUCCESSFULLY make their way about the streets, transportation routes, and malls of small and large cities, find themselves ill at ease within specialized institutions, such as government buildings and medical facilities. These institutions offer important services to the public, but they are also the places where bureaucrats and professionals work. Consequently, the environments within these service centers are shaped by the nature of the assistance provided, as well as by the needs of those working within. The written word—in the form of signs, postings, and paper work—is used to welcome, direct, and sometimes screen visitors. These signs and postings often reflect the specialized language of the professionals who work there. Overall, the language, density, and complexity of these materials establish a literacy environment that makes demands on all who enter. This exploratory study focuses on the literacy environment of hospitals and on the factors that hinder, as well as support, the ability of individuals to make their way to, and within, a hospital.

The hospital is a place of work for people from various fields, including medicine, nursing, pharmacy, laboratory sciences, and the service industry. The culture and language of medicine permeate the buildings, and can be found in written materials, observed in the clothing and uniforms of the various personnel, and overheard in conversations among health workers. The written word, used in the various postings and materials, and the spoken language, used by the professionals working within the institution, are often not the words of everyday speech. In addition, the layout and the design elements of the physical environment

tend to have been shaped by a scientific and medical logic—a logic that is not necessarily intuitive to those not trained in the field. Some places are open to the public; others have restricted access; and others are not accessible at all. A service area, a clinic, or an office may be located on a certain floor based on the nature of an illness, a specific body part, or even the presence of a certain machine. Anyone unfamiliar with the common parlance of medicine and the traditional groupings of diseases and disorders might not follow this logic and therefore have problems navigating the floors, hallways, and offices.

With a group of research assistants, I conducted a small exploratory examination of hospital navigation issues in order to garner insight into the literacy environment of hospitals and into those factors that may hinder or support the ability of individuals to make their way about that environment. Interviewers walked with informants around the public areas of ten municipal hospitals. The walking interviews involved graduate students, research staff, adult education teachers, and students enrolled in adult education programs.

Background

Modern society and its institutions rely heavily on the written word. However, findings from the National Adult Literacy Survey (NALS) indicated that about half of U.S. adults do not have the literacy skills required for tasks in the workplace and for full participation in the activities of everyday civic life (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993; Tuijnman, 2000; Kirsch, 2001; Sum, Kirsch, & Taggart, 2002; Comings, Reder, & Sum, 2001). A 2004 analysis, *Literacy and Health in America* (Rudd,

Kirsch, & Yamamoto, 2004), focused on adults' ability to use health-related materials and to accomplish health-related tasks drawn from the NALS and other large-scale surveys using the same measures and understanding of functional literacy. Findings, mirroring those from the NALS, offer evidence that adults have difficulty accomplishing tasks using health-related materials. For example, as is illustrated in the report, three-quarters of U.S. adults would have difficulty using a chart from an over-the-counter pediatric medicine to determine the correct dosage for a child.

In addition, hundreds of studies that have focused on the assessment of health materials and been published in medical and public health journals indicate that the reading level of most health materials exceeds the reading ability of the people for whom they were designed (Rudd, Colton, & Schacht, 2000). Although a good deal of attention has been focused on assessing health-related materials in sentence and paragraph format, little attention has been given to the many signs and documents used in health care settings and to the overall literacy environment within hospitals. Based on these analyses, the Institute of Medicine (2004) called for change in institutional demands. When ninety million U.S. adults are unable to use much of the print materials provided in health and medical settings, words clearly get in the way. Unnecessary barriers such as those posed by these demands can hinder access to needed care and services.

Methods

An interviewer recorded the activities and the perceptions of an informant entering a hospital and subsequently locating three places within the hospital. The process began in the lobby of the main entrance, where the interviewer and informant met for an initial discussion session. The pair then made their way from the information desk to the hospital cafeteria and to a pharmacy (designated as the place where people could buy medicine). The interviewer and the informant then chose the third destination together from an array of options, including a specific service area, such as ambulatory care, or a specialty department, such as an asthma unit, a women's health clinic, or physical therapy. Interviewers were instructed to ask the informants to talk about the process as they tried to locate each destination. At the end of the walking interviews, the interviewers were asked to engage the informants in a review of the overall experience.

Assessments and Tools

Before meeting with the informant, the interviewer visited the hospital to collect and assess a sample of available materials using the SMOG reading level assessment tool. SMOG readability formulas are designed to link the literacy demands of written materials to a specific grade level, or, in some cases, to rank the materials on a discrete score of reading difficulty. One of the most

commonly referenced formulas, SMOG requires no reference to charts and is easy to use in field assessments. SMOG is based on calculations of the number of polysyllabic words in a set number of sentences. The formula focuses on sentence and word length, both of which are associated with reading ease or difficulty (McLaughlin, 1969).

In addition, interviewers examined signs and postings using insights from the PMOSE/IKIRSCH document readability formula (Kirsch & Mosenthal, 1998), which assigns scores based on a document's organizational pattern and density, as well as how much information is contained within, or outside of, the document. All interviewers studied the PMOSE/IKIRSCH document readability formula and were particularly alert to the use of complex and nested signs.

Study Informants

Ten of 15 adult basic education (ABE) and English for speakers of other languages (ESOL) teachers who were contacted agreed to an interview, to participate in a tour, and to set aside time for an announcement in their classes. Fifteen students agreed to participate in a tour. About half of these students were drawn from adult education classes visited by graduate students from the Harvard School of Public Health. Just under half were drawn from classes in an adult education center that was engaged in discussions with

The culture and language of medicine permeate the buildings, and can be found in written materials, observed in the clothing and uniforms of the various personnel, and overheard in conversations among health workers.

the School of Public Health's health literacy research team. The informants in this exploratory study constitute a convenience—not a representative—sample. However, because the study drew teachers and students from adult education classes of varying levels, the sample does include people with both high and limited educational attainment and literacy skills.

The adult education students who agreed to participate in the interview exercise identified the hospital they would most likely use for their own care. Adult education teachers toured facilities closest to the adult education center where they worked. Each interview took approximately one hour. Teachers and students were paid for their time. In addition, teachers were offered a follow-up class session, an outlined lesson plan, or both. The research protocol was reviewed and accepted by an institutional review board. All participants offered informed consent.

Analysis

Findings, which were assembled from interview forms, reflect four different perspectives. Both teachers and students served as informants. However, teachers commented on their own experience in an unfamiliar setting and, in addition, commented on their students' probable reaction to the setting. Students commented on their own experience. Along with noting informants' comments and activities, interviewers added their own observations. Even when the informants did not offer commentary, the interviewers collected information about the overall literacy environment, as well as the specific characteristics of signs and other print materials.

We assembled commentary from the field records and noted the source of each comment: teacher, student, and interviewer. Comments were then grouped under the categories of the interview protocol: entering the hospital, the lobby, tools (information desk, maps, and signs), general process notes, and concluding commentary. We grouped together those comments under common themes. Findings are presented as observations attributed to teachers, students, or interviewers and are not tabulated in the form of counts. When only one informant offered a unique observation, the comment is attributed to the source; for example, "one teacher commented on use of people's names in signs." When more than two informants offered the same general commentary, the comment is attributed to "several teachers and students" or "several teachers."

Findings

The interview protocol began at the entrance to the hospital because visitors are most likely to find an "Information" or "Help" desk at this site. However, informants first needed to get to the hospital and locate the main entrance. In an urban area, visitors and outpatients are most likely to use public transportation, and informants did make use of bus and subway systems. Thus, the analysis included comments related to finding the meeting place.

Access and Entry

Several informants reported difficulty finding the facility. In two cases where a transportation stop is named for the hospital, the informants found no signs on the street directing them to the actual institution. Not surprisingly, given that hospitals have multiple entry points, many informants had difficulty locating the official main entrance. One teacher noted that several of the hospital's entrances were prominent and well trafficked. Some entrances were named with terms such as admitting, receiving, ambulatory care, emergency entrance. The teacher found this confusing for her own appointment and noted that it could be very difficult for students looking for a main entrance. In addition, she noted that a poor reader, or even a good reader with an average vocabulary, might confuse "ambulatory" with "ambulance."

Literacy Environment

First impressions often set a tone or mood. Informants offered a wide range of first impressions. Comments ranged from "appalling" to "chaotic and overwhelming" to "pleasant and welcoming" to "unthreatening." The large facilities tended to elicit the widest range of comments. For instance, the same hospital lobby was variously described as "luxurious," "scary," "depressing," "intimidating," and "clean and beautiful." One of the teaching hospitals was likened to a hotel lobby or a corporate headquarters, while another was compared to a mall because of the franchise restaurants in the lobby. One student pointed out that many of the people in the hospital lobby were professional looking and well dressed. One teacher noted the presence of uniformed guards.

More than one teacher noted that settings with numerous signs and postings had a "high literacy demand"—meaning that people with low literacy skills entering such settings might feel overwhelmed by print. Interviewers noted that several hospitals had signs written in languages other than English. Spanish was the most frequently used second language, but one hospital that serves a large immigrant population also had signs in Portuguese and Haitian Creole. Two hospitals included in this project featured large signs in their lobbies with "Welcome" written in several languages.

The interviewers asked informants to request directions from the information desk to the cafeteria in order to begin the walk. For the most part, both teachers and students reported that the information desks were prominent and easy to access; many of the desks were labeled with the word "Information" or a question mark. One teacher suggested that foreign students in ESOL classes might feel intimidated by uniformed guards, particularly if a student's immigration status was in question. Overall, informants—both teachers and students—said that the staff members they spoke with were friendly and knowledgeable. Interviewers noted that two of the larger hospitals had volunteers waiting at the desks ready to escort visitors and patients to their destinations.

Maps

Because the interview protocol instructed informants to get a map (if available) at the start of the walk, almost all of the students attempted to use this tool to help them find their way around the hospital. Most could not. In one case, a student did have success using an "enhanced map"; a hospital staff member had traced a route in pen onto the map, highlighting the easiest way for the informant to find the desired location.

Interviewers reported that some of the lobbies contained maps—either posted on walls and in displays, or available in racks for hand held use—while others did not. In some instances, hand-held maps were also available for the asking from the staff at the information desk. Interviewers listed several problems with the maps, including:

- The size of drawings
- The use of small print
- The use of medical jargon and abbreviations for names of locations
- The lack of consistent vocabulary between the map and the names actually used in the hospital
- The complex color-coding and symbol schemes in the map that were not linked to hospital signs

Signs and Postings

One teacher and several students pointed out words on signs that were hard to understand. Several teachers noted that many of their students would have problems reading the signs because of medical jargon and abbreviations. Examples of medical jargon and abbreviations were numerous and included Pulmonary Diseases, Nuclear Medicine, EEG, EKG, EMG, and Rheumatology.

More than one teacher noted that settings with numerous signs and postings had a “high literacy demand” —meaning that people with low literacy skills entering such settings might feel overwhelmed by print.

The format and placement of signs and directories were problematic as well. Many teachers reported that the print was too small to be read easily, that the signs were inconsistently placed around the hospital, that they contained too much information to process at one time, and that the vocabulary was inconsistent. One teacher highlighted a difficulty with donor names. Signs often included, in headline banners, the donor name of the floor or wing. One teacher suggested that her students would have difficulty differentiating between proper names and medical terms. She indicated that the use of proper names to identify particular wings, rooms, and clinics was confusing.

One teacher involved in ESOL education also commented on the presence or absence of signs in languages other than English, an important consideration in a multi-ethnic city. However, another teacher noted that some people with very low-level reading skills might be confused by signs in more than one language because of the different words (and, in some cases, alphabets) used.

Informants also took note of where signs were placed. A teacher pointed out that signs were often placed inconsistently around the hospital. For instance, in one case, signs for a specific destination, which for the most part had been placed at eye level, hung from the ceiling at infrequent intervals. In some cases, the vocabulary was inconsistent as well. For instance, a teacher

pointed out that the word “cafeteria” was used in signs but “café” was used at the actual location—a small change, but one that might confuse someone who does not read very well.

Most of the students said that they had problems reading text when the font size was small and that the language was confusing. Interviewers indicated that the size of the print on posters was often too small to be read with ease.

Hospital Workers as Resources

Several teachers said that people with limited literacy skills often ignored the written word and made use of other tools to find their way around. Interviewers observed that many of the students ignored the signs and other written materials from the onset. Interviewers reported that many of the students did not note or comment on signs until they were asked to do so. One student explained that whenever she has a medical appointment, she always arrives early so she has enough time to ask questions and feel her way around. She anticipates that she will get lost and builds it into her plan. During the walking interviews, some teachers and students stopped hospital personnel in the hallways to ask for directions. In several cases, hospital staff offered unsolicited help to informants who appeared to have lost their way.

Generally, students asked for directions as they moved from one location to another. During one walking interview, a student returned to the information desk when faced with a confusing choice of corridors. Interviewers observed that the most frequently used resource was the individual people informants encountered along the way. Although asking for assistance was popular and, in most cases, effective, this strategy also had its limits. For instance, in a few cases, students asked for directions from hospital workers, who, though friendly and eager to help, had not been oriented to the overall layout of the hospital. One interviewer, speaking to a hospital volunteer, discovered that while the volunteer was expected to assist patients and visitors entering the hospital, she herself had not been oriented to the hospital and was still learning her way around. One interviewer, who conducted a pre-interview walking tour of a community hospital on a weekend, reported that the front desk was not staffed.

Assessments of Materials and Signs

Some hospitals were described as dense literacy environments because they contain numerous signs and posting, while others were reported as sparse. Interviewers noted that individual directories, signs, and postings varied in complexity as well. Most directories were complex, containing nested information. Some signs contained different size fonts and multiple layers of information, such as those found on a newspaper front page: banner, headline, subhead, and text. Some signs were color- and letter-coded and required access to explanatory materials. Interviewers had highlighted and labeled these documents as complex and difficult to read according to the PMOSE/IKIRSCH document

readability formula during the pre-interview assessment of materials (Mosenthal & Kirsch, 1998).

Interviewers also assessed a sampling of postings, brochures, and pamphlets that were made available for patients and visitors. According to reading level assessments based on the SMOG readability formula mentioned above (McLaughlin, 1969), the reading demand of the materials ranged from grade 8 to grade 21

Findings from this exploratory study indicate that when people need assistance, they currently rely more heavily on other people than they do on signs and maps. This preliminary study indicates that a dense and demanding literacy environment can be intimidating, that most people find complex signs difficult to read.

(advanced doctoral level). Several teachers indicated that longer sentences, which are more likely to contain clauses, are harder to follow, and that longer words are more difficult for new readers to sound out and read. Overall, while some materials scored at levels accessible to average adults (8th grade level), most of the materials scored at higher, more demanding levels. Ironically, the research assistants reported that the postings of patient rights and responsibilities often contained complex sentences and difficult vocabulary.

Informants' Suggestions

Each interview concluded with a summary discussion between the interviewer and informant. A number of very concrete suggestions for easing the navigation process came out of these discussions.

Teachers suggested that hospital personnel—especially staff members who work at the information desks—should be trained to give precise directions in common terms and in a friendly and respectful manner. Interviewers noted that hospital workers—some of whom may have difficulty understanding medical language and reading signs and maps themselves—need to be familiarized with the layout of the hospital. For example, one interviewer cited an instance when a student approached a friendly janitorial aide. With expressed regret, the aide was unable to provide information about the hospital layout.

Teachers and students suggested that hospitals adopt consistent design elements. For example, maps should be simplified and correspond to the colors and words used in signs and hallways. Directories and maps should be placed in multiple locations, and signs for common destinations—such as the cafeteria, pharmacy, medical records, ambulatory care facilities, physical therapy, and patient rooms—should be prominently displayed, be consistently labeled, and include a “* You Are Here” notation.

Furthermore, teachers stressed the importance of maintaining a consistent vocabulary for all signs within the institution. For example, in one hospital, directions for the same clinic used the terms *asthma* and *pulmonary* interchangeably. Teachers also suggested that the signs employ common language instead of medical jargon. One teacher noted that since the doctors and nurses generally know their way around, signs should be oriented toward those not familiar with medical institutions or medical language. Some teachers suggested that both a medical term and a lay term could be used together.

Nearly all of the informants, regardless of their reading ability, experienced some difficulty navigating from place to place. Teachers (who had strong literacy skills) tended to rely more heavily on the written word in the form of maps and signs than did students. They seemed to assume that the maps from the front desk or the signs on the walls would be logical and that their reading skills would make the information decipherable, even when the maps were poorly designed and the signs contained inconsistent, highly technical vocabulary. The students, on the other hand, did not operate under this assumption. They started out by asking for directions, a strategy that was not only effective but was, in fact, eventually employed by almost all of the informants.

Discussion and Implications

Overall, the participating teachers and students offered a great deal of insight into the barriers hospital visitors face. Findings from this exploratory study indicate that when people need assistance, they currently rely more heavily on other people than they do on signs and maps. This preliminary study indicates that a dense and demanding literacy environment can be intimidating, that most people find complex signs difficult to read, and that a person with average literacy skills is not familiar with many of the medical terms used on signs and in forms.

This limited exploratory study is based on a small convenience sample of informants and institutions. These findings, which are in the form of insights, need to be further explored and confirmed through more rigorous studies. However, they do indicate that the language and vocabulary in signs and postings, while familiar to health professionals, is not easily decipherable to the lay public. In addition, the format and content of signs and forms are complex and do not correspond to the average skill level reported in the NALS (Kirsch et al., 1993). Thus, the tools intended to help the public gain entry into, and make their way around, a hospital are of little use to the visitors and non-professional staff for whom they have (at least in part) been designed. In other words, words do get in the way.

Overall, the participating teachers and students provided useful suggestions for those interested in reducing the barriers. Their observations and comments indicate that the communications and outreach departments of the hospitals would do well to

test all written materials with adults who are served by the institution. In addition, hospital administrators might explore the use of a glossary of terms and an explanation of organizing principles to help those who are new to their institution.

Because these findings indicate that when people need assistance, they rely on other people more heavily than they do on signs and maps, hospital administrators might consider the representative role that all employees have and expand worker training and orientation programs. The individual sweeping the floor is sometimes more likely to be approached for help than the busy professional hurrying along a hallway.

To help identify these barriers, hospital administrators might conduct relatively simple walking tours with local informants, and then assess signs and maps, orientation materials, postings of patient rights, educational materials, descriptions of procedures, directives, informed consent documents, and medical history and insurance forms. Overall, policy boards within hospitals, as well as external boards of accreditation, need to consider the literacy environment of hospitals and develop formal literacy-related audit procedures to make sure that words do not get in the way.

Author's Note: Thanks and recognition are offered to Kelly Bruce, TinVan Diep, and Susan Koch-Weser for their insights and assistance. Participants in the Health Literacy course at the Harvard School of Public Health were invaluable contributors to this study.

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THE CALIFORNIA HEALTH LITERACY INITIATIVE

A Statewide Response to an Invisible Problem

“Follow up instructions from the emergency room were not comprehended. The patient’s condition deteriorated, and she did not understand that the deterioration was addressed in the discharge instructions. Had the patient recognized the situation, she would have sought care earlier. As a result the patient died.”

A HOSPITAL ADMINISTRATOR WHO PARTICIPATED in California Literacy’s 2003 pilot study, *Low Literacy, High Risk: The Hidden Challenge Facing Health Care in California*, told this chilling story. Because no efforts were made to ensure that the patient understood the information provided, the entire system failed with devastating consequences.

As this story demonstrates, inadequate literacy skills can cost not only money—but also lives. Findings from *Low Literacy, High Risk* reveal the following statistics about pilot study respondents with limited literacy skills:

- Seventy-seven percent claimed to have difficulty reading medical information such as brochures, pamphlets, and instructions from medical staff.
- Sixty-five percent reported that they avoided going to the doctor because of difficulties associated with completing paperwork.
- Forty-five percent identified medical paperwork as one of their greatest health literacy challenges.
- Seventy-three percent stated that they have had difficulties understanding what medical professionals have told them about their health due to the use of medical terminology.

As these findings demonstrate, the ability to obtain quality health care is a major obstacle for adults with limited literacy skills. To address this crisis, California Literacy, a non-profit organization with 200 member organizations and over 50 years of experience, launched the first statewide effort in the country to improve the health and well-being of individuals with low literacy skills, the California Health Literacy Initiative.

Initiative Model

The first step in creating the California Health Literacy Initiative (CHLI) was to identify the key figures working in the field of health literacy. From this research, California Literacy came across the health literacy champion Dean Schillinger, M.D., associate professor of clinical medicine at San Francisco General Hospital, University of California at San Francisco. An expert in the relationship between health and literacy, Dr. Schillinger has provided the CHLI with tremendous guidance, as well as credibility within the medical field.

The next step was to organize a task force. California Literacy made a conscious decision to invite representatives from fields whose clients, staff, and participants would directly benefit from CHLI’s effort and who would be actively engaged in the project.

The task force was comprised of health care providers, health educators, public health directors, language access advocates, adult literacy directors and practitioners, adult education directors, and representatives from community-based organizations.

Once the task force was established, California Literacy invited all of the members to a two-day meeting to create a strategic plan for the CHLI. During the meeting, members identified the topics they felt were most critical for the CHLI to address. They also identified which projects could realistically be accomplished within the first two years of funding, and which projects should be outlined in the strategic plan for future years.

As a result of the task force meeting, California Literacy established a clear goal and mission for CHLI: “To inform and partner with individuals and organizations to positively impact the health and well-being of individuals with low literacy skills, their families, and their communities.” This mission serves as a groundbreaking national model for health literacy.

With a strategic plan and an explicit mission in mind, California Literacy secured funding for the CHLI from The

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California Endowment, Pfizer Inc., Kaiser Permanente, and the Institute for Healthcare Advancement. The American Medical Association Foundation has since provided additional financial support. California Literacy assumes responsibility for facilitating, convening, and prioritizing all CHLI efforts, which include the following five foundational projects:

- To partner with major health care organizations to make health literacy a priority, using committed health literacy champions as conveners
- To develop an online health literacy resource center
- To create and conduct an awareness campaign directed at health care professionals and low literate adults
- To contribute to the development of quality standards for low health literacy populations that are accepted by the medical community
- To convene working groups around ten strategic projects identified by the task force

Partnerships

Health literacy is an enormous issue. In order to make an impact, CHLI needed to join forces with other stakeholders. Partners for CHLI included the American Medical Foundation Association, the California Medical Association, the California Medical Association Foundation, the California Endowment, the CHLI task force, a student advisory committee, the Institute for Healthcare Advancement, Pfizer Inc., the Partnership for Clear Health Communication and Vision Literacy, and Dr. Dean Schillinger. Each partnership has been unique and essential to CHLI, and each partner has contributed with publicity and promotions, evaluations, expertise in the field, and funding.

Health Literacy Resource Center

The development and upkeep of an online health literacy resource center is CHLI’s second foundational project. Launched in May 2004, the Health Literacy Resource Center provides comprehensive online health literacy resources for adult educators, health care professionals, adult learners, researchers, and policymakers, as well as individuals in search of clear and comprehensible health information. While there are numerous online sources that offer valuable health literacy information, the CHLI’s resource center is the first all-inclusive health literacy website.

The Health Literacy Resource Center is made up of ten categories. Designed to raise public awareness about health literacy and to assist adult literacy and health professionals in developing lasting solutions to the issue of health literacy, the General Health Literacy Information category provides data from public, private, and non-profit organizations and associations. The Health Literacy Directory refers visitors to academic researchers and literacy professionals working to advance the health literacy movement. The Plain Language Health Resources provides easy-to-read resources on general health issues as well as 35 specific diseases, such as asthma, diabetes, mental health, and many types of cancer. The Health Literacy Resource Center also features the U.S. policy on health literacy and models of health literacy, as well as a publications category, which includes emerging state, federal, and community responses to health literacy. Finally, the website offers a collection of health literacy clip art that can be used in the creation of patient education, outreach materials, and plain language health information.

Awareness

The awareness campaign has been a vital element of the CHLI’s success. In year one of the initiative, CHLI wanted to focus awareness efforts on providing educational presentations to adults with limited literacy skills, adult literacy tutors, adult literacy professionals, and health care professionals. The presentations have been designed to help bridge the gap in health care communication. Over the course of the first year, CHLI reached

CALIFORNIA LITERACY, INC.

California Literacy, Inc., the oldest and largest statewide non-profit adult literacy organization in the U.S., is dedicated to helping adults improve their reading skills so that they can achieve personal goals, participate more fully in the upbringing of their children, and become more productive members of society.

Established in 1956, California Literacy provides leadership for new and existing California-based adult literacy programs by lending support and help in areas such as marketing and public relations, technical assistance, training, advocacy, and more. California Literacy serves more than 200 local literacy programs associated with churches, YMCAs, libraries, prisons, drug and alcohol rehabilitation centers, homeless shelters, and adult schools. Through its affiliated programs, over 14,000 volunteers dedicate more than one million hours a year, tutoring 46,000 adult Californians in literacy and English language skills necessary for them to more fully participate in society.

For more information on how to create a program similar to the California Health Literacy Initiative go to www.cahealthliteracy.org, and for more information about California Literacy go to www.caliteracy.org.

2,152 adult literacy students and representatives from adult literacy and health care fields, receiving enthusiastic responses. After one presentation for adults with limited literacy skills, a participant said, "It was a good workshop for me. I'm going to feel more comfortable now going to [the] doctor!"

The presentations for adults with limited skills are based on the Partnership for Clear Health Communication's *Ask Me 3* campaign, which promotes self advocacy by helping patients with low literacy skills communicate with their health care providers. In the presentation for adult literacy tutors, participants learn how to help students improve their health literacy and become better advocates for their own health. In the presentation for health care providers, attendees learn about the realities of adult literacy and how low literacy can impede their ability to provide optimal health care. Presenters include Dr. Dean Schillinger, as well as California Literacy staff members who have been trained to use the American Medical Association Foundation's (2003) curriculum, *Help Your Patients Understand*.

As part of the awareness campaign, the CHLI has also produced a wallet card, designed for adults with limited literacy skills, that explains how to make the most out of a visit to the doctor. The tri-fold wallet card, which was reviewed and revised by the health literacy student advisory committee, provides useful information on what to do before, during, and after a visit to the doctor. It also includes information on how to find a California-based adult literacy or ESOL program. Samples of the wallet card have been distributed to each of California Literacy's 200 member organizations. The card will also be available on the CHLI website.

The 2003 pilot study, *Low Literacy, High Risk: The Hidden Challenge Facing Health Care in California*, was another component of the awareness campaign. CHLI conducted the study to:

- Investigate how literacy has an impact on the health care experiences of California's adult patients with limited literacy skills
- Assess how physicians and administrators are addressing health literacy as limited literacy patients seek health care services
- Create a foundation for future research

The study mixed quantitative and qualitative methodologies to survey 102 adults with limited literacy skills, 64 physicians, and 16 hospital and clinic administrators throughout California. The results of the study offer a harsh look at the reality of the health care system. The findings reveal that adults with limited literacy skills in California are marginalized by the health care system because their literacy levels affect their ability to receive quality health care.

The full report has five sections that address flaws in the health delivery system (as it relates to health literacy), as well as suggestions for best practices. These sections include:

- Paperwork
- Medical jargon
- Patients' feelings of shame
- Effective communication between adults with limited literacy skills and their health care team
- Hospital and clinic administrators' awareness of the issue of health literacy

The statistics from the study are sobering: over 80 percent of pilot study participants with limited literacy skills reported that they had trouble completing medical paperwork; 67 reported that their doctor did not know about their struggles with reading and writing; 49 percent reported having difficulty explaining their conditions to their doctors.

Health care providers also experience difficulties in effectively communicating with their patients. An overwhelming 94 percent of health care providers surveyed believed that patients with limited literacy skills received a lower quality of care, and 83 percent believed that health literacy received low priority in the provision of health care in California. One family medicine physician that participated in the pilot study wrote:

[Low literate or non-English speaking patients receive lower quality of care because] of poor communication with health care providers, providers making assumptions about what patients want rather than asking, [and] assumptions that disenfranchised patients do not want or will not comply with preventative care.

Hospital and clinic administrators are aware of the issue of health literacy, but they do not fully understand the effects of health literacy on medical professionals and their patients. Sixty-three percent of administrators surveyed reported having heard about medical errors that were related to the literacy skills of their patients, yet only 25 percent of administrators said they had provided health literacy training to their staff.

Quality Standards

For the quality standards project, CHLI is planning to develop and implement measurable quality standards of access to health care for recipients of the Medicaid program, Medi-Cal Managed Care. Health literacy standards include regulatory mandates (required actions) and recommendations (voluntary actions). Currently, there exist few quality standards guiding medical providers, health plans, and health care organizations on how to address health literacy issues among patient populations. There are more standards for language access, culturally and linguistically appropriate materials, and cultural competency training than for health literacy. There are also standards that require all patient-related materials and signage be written in the languages spoken by the patient population represented in the service area (U.S. Department of Health and Human Services, Office of Minority Health, 2001). Examples of potential quality standards include a recommendation that hospitals and clinics partner with, and refer patients with limited literacy skills to, local literacy programs; a mandate to require a maximum grade level for all patient forms and materials; and a mandate ensuring that health literacy is included as part of health care professional training.

Strategic Planning and Projects

For the fifth foundational project, the CHLI plans to convene working groups around ten strategic projects identified by the health literacy task force. The first four foundational projects are the focus of the first two years of CHLI; after that time, CHLI will have the framework in place and will be able to direct its attention to the strategic projects.

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The ten strategic projects can be broken down into two main themes: a community awareness campaign and a direct services component for adult literacy students.

For the awareness campaign, CHLI plans to:

- Promote community education by creating a media partnership that will develop effective multimedia materials on health literacy and air them on appropriate media outlets
- Promote community education by using innovative, interactive teaching tools in non-health, non-literacy venues (such as senior centers) and by using awareness trainings based on the experiences of adults with low health literacy
- Create plain language, culturally appropriate materials on chronic diseases, including a generic model that others can use in developing materials on health-related topics
- Create and deliver health literacy information, training and literacy conferences, in-service trainings, and workshops
- Work with California State's literacy efforts to ensure that health is a priority

In terms of the direct service component, CHLI plans to:

- Provide grants and stipends for learner-developed health materials to be used in adult education settings
- Establish a training program to teach adults with limited literacy skills to moderate community forums on health issues and to mobilize neighborhoods and communities
- Develop a speakers' bureau of adults with limited literacy skills to conduct sensitivity and awareness training based on the experiences of adults with low health literacy
- Engage adults with limited literacy skills and community members in advocacy efforts through training, plain language versions of health legislation, and advocacy partnerships
- Provide forums for health care providers and community members to discuss issues and develop solutions to problems of low health literacy

Some of the strategic projects have, in fact, already been initiated during the CHLI's first year. In the up-coming years, the CHLI will be able to solidify plans to move forward with each project.

Lessons Learned and Looking Ahead

During the CHLI's first year, California Literacy has learned many valuable lessons. A key element to CHLI's success has been its ability to work with, rely on, and learn from its partners. Additionally, a large portion of its success has come from having Dr. Dean Schillinger act as a guide for the projects. Other partners have been extremely helpful in promoting CHLI's efforts as well.

The health literacy student advisory committee has played a crucial role in structuring CHLI. They have provided feedback from the perspectives of adult learners on a variety of projects, including the plain language section of the Health Literacy Resource Center, the health literacy presentation for adults with limited literacy skills, and the health literacy wallet card. The student advisory committee's current leader is an adult literacy student who is in the process of re-structuring the committee. During the first year, CHLI learned that it is essential for all committee members to be adult literacy students who have (or have had) health problems, who are articulate, who are interested in literacy and health, and who are willing to share their experiences publicly.

Many of the lessons CHLI learned over the course of the first year have involved the creation, distribution, and collection of evaluation forms. CHLI hired an external evaluator to determine the effectiveness of the self-advocacy presentations for adult literacy students and the awareness presentations for health care practitioners. The formal evaluation was conducted in January 2004. However, CHLI did not plan ahead to collect program evaluations during the initial presentations, which made the professional evaluator's job more difficult than it had to be.

Creating an evaluation form that adult literacy students, given their limited literacy skills, would be able to fill out—and that would extract the critical information—presented another challenge, as did the distribution and collection of the forms. In order to ensure the completion of evaluation forms, CHLI has started to incorporate evaluations into the allotted program time; it has implemented this policy in the presentations for adults with limited literacy skills as well in those for health care providers. Through these evaluations, CHLI has been able to collect the necessary information to identify the strengths of the presentations, as well as learn about gaps in the information provided.

In its second year, CHLI looks forward to continuing to raise awareness about the importance of health literacy, collaborate with more partners from the health and literacy fields, and find solutions to the issue of health literacy.

The Key Findings as well as the full report *Low Literacy, High Risk: The Hidden Challenge Facing Health Care in California* can be found on the California Health Literacy Initiative website at www.cahealthliteracy.org/.

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Molly Bergstrom was the health literacy coordinator in the Emeryville office of California Literacy, Inc. Prior to joining California Literacy, she spent three years with the Arthritis Foundation, serving primarily as the community programs coordinator, where she was responsible for educational programs, community outreach, physician education, and Latino outreach. Bergstrom has also taught ESOL and volunteered as an immigration and naturalization counselor. She received her B.A. from Lewis and Clark College.

AN ADULT EDUCATORS'S JOURNEY INTO HEALTH LITERACY

Developing Health Literacy Curriculum for ESOL Learners

Ana is a 35-year-old uninsured woman from El Salvador who has been hospitalized several times for complications relating to adult onset diabetes. The nurses and doctors refer to her as “noncompliant” because Ana doesn’t monitor her blood glucose levels and take her medication correctly, so she keeps ending up in the hospital with worsening symptoms. A nurse explained how to do these things properly in Spanish, but Ana still doesn’t understand.

In a rapidly expanding Virginia town there is a growing immigrant population, a large portion of which is uninsured and limited English speaking. The local free clinic seems the likely place for these people to seek primary health care, but most lack a photo identification card, which is required for clinic registration. Consequently, many go without any medical care.

Delmy, a young Guatemalan woman who delivered her third baby the previous day, is lying in her hospital bed in a panicked state. She speaks very excitedly in Spanish to her nurse. The nurse only speaks a few words of Spanish, but feels she can handle things without an interpreter. Delmy is very upset. She tells the nurse that she is terrified that she is pregnant again. The nurse tells her that is impossible. Delmy explains that she had never had headaches before her pregnancy, that she had a headache the whole time she was pregnant, and that when she had delivered the baby the headache went away. Now, the headache is back, so it must mean she is pregnant again.

Almaz is a 29-year-old married high school graduate from Ethiopia. She was relatively healthy until she developed a seizure disorder in her second pregnancy. The pregnancy was successful and her seizures were managed with medication throughout the pregnancy. After giving birth, however, she stopped getting regular medical attention because she lacked health insurance. Whenever she was having a seizure, her husband rushed her to the emergency room. The ER doctors gave her some medicine with a couple refills. Over time Almaz became fatigued and depressed, and lost a lot of weight. She felt unfit to take care of her two children by herself because of her health problems, so she sent them to be raised by relatives in Ethiopia. No one had explained to Almaz that the medication she was taking could cause side effects of fatigue, depression, and weight loss if it wasn't monitored correctly by a doctor, nor had anyone told her that she could get such medication management at a local free clinic.

STORIES LIKE THESE, SHARED BY ESOL LEARNERS and hospital patients with whom I worked in Virginia, are in large part what prompted me to develop health literacy materials for adult ESOL students. These materials include *Picture Stories for Adult ESL Health Literacy*, *Virginia Adult Education Health Literacy Toolkit*, and a multi-level ESOL health awareness curriculum. In the process of developing these materials, I encountered numerous educators across the U.S. who shared my concerns about the health literacy needs of adult learners, and who, like me, had been searching for more pertinent, ready-to-use materials and teaching ideas than those that have traditionally been available for health instruction.

Developing Health Literacy Resources

Starting with the Basics: Picture Stories

The traditional health content of beginning-level ESOL textbooks, while well intentioned, seldom meets adult learners' immediate needs. Body part vocabulary and descriptions of what hurts may be linguistically appropriate for beginning-level ESOL learners; however, such basic vocabulary is woefully insufficient preparation for an emergency situation. These types of materials need to be supplemented with information that is more immediately helpful.

Basic topics that are especially useful to beginners or new arrivals to the U.S. include:

- How to access local affordable care
- What care options exist in addition to the emergency room
- Basic information about patients' rights, such as the right to an interpreter, the right to ask questions of the health care provider, the right to a second opinion, and the right to ask for a reduced hospital bill or payment plan
- Basic information on patients' responsibilities, such as showing up on time for appointments, knowing family medical histories, practicing preventive care, and paying for health care (Singleton, 2003, p. 94)

To give myself and other educators a way to address these issues with learners who have minimal English skills, I developed *Picture Stories for Adult ESL Health Literacy* (2001).

Picture Stories offers eight illustrated vignettes on topics such as access to care, communication with health care providers, domestic violence, mental health, and diabetes prevention. The simple stories are accompanied by background information—including explanations for instructors on the health literacy issues raised in each story and the implications of each issue for adult ESOL learners—statistics illustrating the extent of the problem, and resources for more information or assistance. I have also included lesson plans that incorporate the Language Experience Approach (see Taylor, 2000). The illustrated stories allow learners to connect with and communicate on challenging

topics. The LEA format presented in the lesson plans maximizes language use, allowing students to practice all four language skills—reading, writing, listening, and speaking—as they think critically and solve problems.

“A Doctor’s Appointment,” which is made up of eight frames, tells the following story:

A man feels a pain and goes to the doctor. The doctor examines him, asks questions about the symptoms and gives him a lot of information. The man pretends he understands, but he doesn’t speak much English and doesn’t know what the doctor is saying. The doctor gives him a chance to ask questions, but the man doesn’t ask any. He gets some new prescriptions but doesn’t understand how to take them. At home one of his family members asks what the doctor said, and the man reports that he doesn’t know. He is frustrated and confused. (Singleton, 2001, p. 5)



Prompting questions that accompany the story include, “Do you think the man understands the doctor? Why does he say ‘OK’? What is the problem with taking the prescriptions?” (p. 5). Using the picture story as a launching point, teachers can address important health literacy issues—in this case, patient self-advocacy, avoiding medication errors, and the right to an interpreter—as they teach the four major skills.

Part of what makes *Picture Stories* useful is that students are often able to recognize themselves or their loved ones in the vignettes. Teachers report that in the first moments of looking at the stories, especially those on access to care and health care communication, someone in the class frequently exclaims, “Teacher,

that’s me!” At the same time, the stories allow students who do not wish to publicize their health and health care experiences to comfortably discuss the situation in terms of the fictitious characters in the story. Teachers also report that lessons with these stories often end with learners thanking them for talking about the topic and giving them helpful information on what resources are available.

Next Step: A Health Literacy Toolkit for Adult Educators

While I was developing *Picture Stories*, I was also working on a master’s degree in social work, which increased my awareness of the intricacies of the U.S. health care system, the depth and breadth of the skills needed for individuals to advocate on their own behalf in situations relating to health, and the resources available to help those in need. Having worked as an ESOL instructor for ten years, I was already well aware of how difficult it can be to truly comprehend the implications of low health literacy, not to mention how daunting it can be to address the topic with adult learners. With these concerns in mind, I developed the *Virginia Adult Education Health Literacy Toolkit* (2003).

The *Toolkit* offers a detailed definition of health literacy that makes sense for adult literacy instruction. This definition takes into account self-advocacy skills, cultural knowledge needed to function in the U.S. health care system, and patient and provider expectations and responsibilities. The *Toolkit* also provides a glossary of health care and health insurance terms, such as *ambulatory care*, *co-payment*, *out-of-service provider*, and *pre-existing condition*. These definitions are written in simple English so that teachers can easily explain the terms to their students. In addition, the *Toolkit* lists affordable health care and legal aid resources in Virginia, potential funders and collaborators for health literacy initiatives, numerous online and print resources, and ideas for teaching health in adult literacy programs. It examines aspects of health literacy curriculum development, and suggests how educators might address the more sensitive aspects of teaching health topics.

I developed the *Toolkit* with input and support from many sources. Susan Joyner, now-retired director of the Virginia Adult Learning Resource Center, initiated the project. She secured funding and provided tremendous advice from the perspective of an adult education instructor as well as an administrator. Public health nurses also provided valuable information, such as descriptions of the health care safety net for the uninsured in Virginia and elsewhere, and the particular health care needs and communication snags experienced by low-literacy and limited English speaking adults. To learn more about the unique needs of individual population groups, as well as the extent and limitations of services available, I also consulted many organizations in my state that advocate for the needs of minority population

groups. My fellow social work graduate students at Virginia Commonwealth University also informed my work on the *Toolkit*, as did my own observations working as a case manager at

Teachers report that in the first moments of looking at the stories, especially those on access to care and health care communication, someone in the class frequently exclaims, “Teacher, that’s me!”

Whitman Walker Clinic of Northern Virginia, a provider of medical care and other supports for people living with HIV and AIDS. Adult education teachers and students in Virginia and other states also provided priceless contributions by sharing their stories, concerns, and ideas.

For the Classroom: A Health Curriculum

Concurrent with developing the *Toolkit*, I was working on a multi-level health awareness curriculum as part of the Fairfax County, VA, adult ESOL program’s English Literacy/Civics curriculum project. This endeavor provided considerable insight for the *Toolkit* as well. In developing the curriculum, I had to assess not only the health literacy needs of the Fairfax County program, but practical issues as well. For instance, the program was in the process of integrating computer-based instruction into the classroom; however, not all sites had yet acquired the computers. Similarly, the instructors who would be using the curriculum had varied levels of teaching experience, from none to several decades. In the end, I had to develop a curriculum that was flexible enough to adapt to an assortment of elements, including varying educational levels, teaching styles, and classroom environments.

Much of my initial decision-making on the curriculum project served as the impetus for the *Toolkit*’s “Section D: Teaching Health Topics.” This section presents a series of questions designed to simplify the process of creating a health literacy curriculum. Some examples include:

- How much time can you realistically give to health classes in one term and still cover other necessary life skill topics and program requirements?
- Will your health curriculum stand alone, or will you create it as part of a larger lifeskills curriculum? Will you focus on one health topic in depth, or will you offer a broad selection of health and health care issues in the curriculum?
- How will learners’ needs be assessed at the different levels in your program to ensure that the health curriculum is relevant and appropriate?
- If the curriculum is to provide specific health information, how will writers obtain and verify the information?

- What teaching approach best fits your learner population?
- What introduction to health instruction do teachers in your program need?
- What other instructional supports do you want to provide in the curriculum? (pp. 92–93)

In terms of applying a pedagogical approach to the Fairfax curriculum, the selection process was easy. To promote learner interaction and critical-thinking skills, I incorporated problem-solving exercises into content-based instruction, including options for practicing all skill areas and using word processing or Internet research to satisfy program requirements. Aspects of project-based instruction were incorporated into higher levels, where I thought learners would benefit from the more participatory approach.

Selecting topics for the curriculum, however, was more of a challenge. For beginning levels, I knew I wanted to focus on the basic topics, such as accessing health care. For higher levels, however, there seemed to be a variety of directions to take the curriculum, each of which could provide various opportunities for language development. I knew that communication with health care providers would be an important subject for all levels, as would cultural values of U.S. health care, such as preventive care. I con-

Having students calculate the difference between insurance plan costs is an opportunity for them to develop their numeracy and mathematics skills. Having students weigh the benefits versus the drawbacks of a medication's side effects presents an opportunity for them to develop their critical thinking skills.

tinued to research information on health disparities from sources such as the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, the Office of Minority Health, and the Kaiser Family Foundation to see what health conditions and obstacles were most problematic for different ethnicities in the ESOL student population. Based on this research, I chose to include lessons on medication safety, payment for care, understanding health insurance, nutrition and exercise (as prevention or management of conditions such as diabetes and cardiovascular disease), and stress management, among others.

This exploration of health topic selection prompted the inclusion of two features in the *Toolkit*: a three-page list of suggested health topics (pp. 94–97), and a breakdown of health instruction opportunities by ESOL and ABE skill areas, including reading, writing, speaking, and listening; numeracy and

mathematics; critical thinking; science; social studies; and computer literacy (pp. 33–35). The list of suggested health topics begins with basic issues, such as defining health, using medication, understanding preventive care, examining health disparities, and navigating managed care. It then moves to more specialized interests, such as women's health, alternative medicine, and safety in various situations. The breakdown of teaching opportunities can help instructors decide where and how to incorporate the basic skills into health education. For instance, having students calculate the difference between insurance plan costs is an opportunity for them to develop their numeracy and mathematics skills. Having students weigh the benefits versus the drawbacks of a medication's side effects presents an opportunity for them to develop their critical thinking skills. And having students identify stakeholders in health care and analyze their viewpoints is one example of how instructors might integrate social studies skills into health lessons. In all of these activities, students have rich opportunities to exercise English speaking, reading, and writing skills.

Using Health Literacy Resources in the Classroom

Introducing health content into the classroom has the potential to evoke anxiety in adult ESOL educators. For many, health and health care topics are seen as unfamiliar or highly personal terrain for the classroom. Does the ESOL instructor need a medical degree or counseling certification? No. Instructors do not have to be “experts” in health and health care to teach about these topics in their ESOL classes. The following are some tips that I have learned through my own explorations and from experiences other teachers have shared:

- Know your boundaries. Part of your job is to be a conduit of information to help your learners make good decisions on their own—not to be the maker of decisions for them. The other part of your job is to give learners as many opportunities as possible to express themselves in English, which means that you need to present health content in such a way that you can hand the communication over to the learners as soon as possible. Let them do the problem solving and information gathering as much as their level of English allows.
- Resources abound! The Internet contains a wealth of health and health care information. The *Toolkit* lists many useful websites on health and health care topics and teaching health to adult literacy learners (pp. 66–82). One of the Internet staples for ESOL teachers who want simple and clear explanations (simple and clear for teachers, that is, not for learners!) of medical conditions and prescription drugs is Medlineplus, <http://medlineplus.gov>.
- Learn a little about your learners' cultural beliefs around health and health care. The best and easiest way to do this is,

in most cases, to ask the learners themselves. Websites with helpful cultural information on health include Ethnomed, <http://ethnomed.org/>, and Queensland, Australia's Cultural Diversity: A Guide for Health Professionals website, www.health.qld.gov.au/multicultural/cultdiv/default.asp.

- Be open-minded and respectful of learners' beliefs and practices. These beliefs have worked for them thus far. It is not reasonable to expect people to drop past practices and replace them with U.S. health care values. Nor is it our place to tout the mainstream U.S. health care system as the best way to understand and treat health.
- Sensitize yourself to what the limited English speaker is up against in trying to interact with the health care system in the U.S. An excellent place to start is *The Spirit Catches You and You Fall Down* by Anne Fadiman (1997).
- Collaborate! Many professions are currently interested in addressing adult health literacy problems—and interest is growing. Get to know organizations and resources in your community and state that can help serve your learners' health care needs. While agencies are often busy and may not have time to come to you, they might welcome a visit from a concerned ESOL educator who can help convey important information to adult learners. A first contact could lead to future projects to serve your learners.

Weighing the Benefits of Health Literacy Instruction

Addressing health literacy in an adult ESOL class requires time and effort; the instructor must assess learner needs and devise ways to convey complicated and confusing cultural and linguistic information to learners. Is it worth it? Over the past few years, I have encountered some instructors who feel discouraged when teaching health content. They have told me that they feel almost cruel telling learners about free clinics with long waiting lists, or about strategies for requesting a reduction of a medical bill, when the teachers strongly suspect the care provider will not agree to a bill reduction if the student asks. Certainly, the scope of the health literacy problem is enormous. However, many more instructors have told me that their students not only appreciate learning about health and health care in the classroom, but are happy for the opportunity to practice their health literacy communication skills and to discuss the frustrations and concerns they encounter in their efforts to keep themselves and their families healthy. Instructors have also been enthusiastic when telling me about new health literacy ideas and projects in their programs and communities. Can ESOL educators make a positive impact on health literacy in the United States? They can. In fact, they already have.

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HEALTH LITERACY RESOURCES

- *Picture Stories for Adult ESL Health Literacy* is available online at www.cal.org/nclc/health/
- The Virginia Adult Education Health Literacy Toolkit is available online at www.aelweb.vcu.edu/publications/healthlit/
- The Fairfax County Health Awareness Curriculum is located online within the Virginia Adult Education Health Literacy Toolkit at www.aelweb.vcu.edu/publications/healthlit/sections/d/secD-p5.pdf. (Links to pdf files for the various curriculum levels can be found on p. 107.)

About the Author

Kate Singleton, M.S.W., has worked in adult ESOL education for 15 years in Virginia and Maryland. Currently, she works as an emergency room social worker for the Inova Health System, where she assists limited English-speaking patients and their families. She also gives workshops on health literacy concerns of limited English speakers to adult educators, students, social workers, and public health workers. In her work on the Health Initiatives Task Force for the Virginia Commonwealth University School of Social Work, she is also exploring health literacy in relation to social work education and practice

USING RESEARCH TO INFORM HEALTH AND LITERACY PROGRAM DEVELOPMENT

Results from the HEAL: BCC Evaluation Study

THE RELATIONSHIP BETWEEN LITERACY AND HEALTH

is increasingly evident; low income and minority populations are less likely than those with higher incomes to get the health information and care they need (U.S. Department of Health and Human Services, 2000). As a result, many adult education programs across the country have begun to integrate health content into literacy instruction. How do we know if these efforts are working? With the current emphasis on research-based methods and materials, evaluating the introduction of health content into adult education using valid and reliable evidence has become a vital step in the development process (Truman, 2000; Whitehurst, 2003).

World Education recently evaluated its Health Education and Adult Literacy: Breast and Cervical Cancer (HEAL:BCC) project, a health literacy initiative that disseminates information about breast and cervical cancer early detection and screening through adult basic education (ABE) and English for speakers of other languages (ESOL) programs. Results from the evaluation are encouraging: Introducing health content into adult education programs can—and, in fact, does—help students and their families live healthier lives.

Project Description

The earlier cancer is found, the easier it is to treat. However, women with low educational levels are less likely to be screened for breast and cervical cancer (U.S. Department of Health and Human Services, 1998). The HEAL:BCC project was developed by World Education, a non-profit organization supporting non-formal adult education in the U.S. and abroad; evaluated by Dr. Cathy Coyne, West Virginia University Medical School; and funded through a cooperative agreement with the Centers for Disease Control and Prevention. Designed to fit within the ABE context and meet the health information needs as well as literacy goals of ABE learners, the curriculum includes activities to improve reading, writing, and oral presentation skills. Components of the project include a center-wide orientation, a training for teachers implementing the curriculum, a resource box of materials, the HEAL:BCC Curriculum, student materials, technical assistance and support, linkages to local breast and cervical cancer screening providers, and a final project event.

The HEAL:BCC Curriculum was originally developed for use in intermediate to advanced ABE and ESOL classes. Unit

One, “Staying Healthy,” engages learners in discussions about good health and preventive health care. Unit Two, “What Is Cancer?” introduces the topic of cancer and the concept of early detection and screening. Unit Three, “Breast and Cervical Cancer,” describes mammograms and Pap tests in detail. Unit Four, “Taking Action,” prepares learners not only to take healthful action for themselves but to help others do so as well. Unit Four also includes a class project. Each unit includes activities that promote critical thinking and problem solving about important issues in students’ lives. Accompanying the curriculum are learner materials, such as the HEAL:BCC *Word List*, a mini-dictionary containing the definitions to over 120 medical terms, and the *Passport to Health*, a health education booklet with information on cancer prevention, screening, and self-exams. The HEAL:BCC Curriculum usually takes about three months to complete.

Evaluation Design

There are a variety of ways to determine program effectiveness. On the one hand, effectiveness is tied to outcomes. In designing an evaluation of HEAL:BCC outcomes, we wanted to know whether the project increased women’s knowledge, attitudes, and behaviors in regard to mammograms and Pap tests. On the other hand, effectiveness is tied to process. Therefore, we also wanted to know what both teachers and learners thought of the program, how the curriculum was applied, and what kinds of support were needed for implementation. In addition, we wanted to determine what learners thought of the materials, how they used them, and whether they shared the information with others in their families and communities.

Specifically, the HEAL:BCC evaluation was designed to measure how effectively the project:

- Increased breast and cervical cancer screening among women who have less than a high school education
- Encouraged healthful action related to breast and cervical cancer
- Promoted healthful action within the community

To do this, we looked at two specific behavioral outcomes:

- The proportion of women learners over 18 who went for a Pap test
- The proportion of women learners 40 years of age and older who went for a mammogram

We used a quasi-experimental comparison group design to assess program effectiveness. To collect data, we used both quantitative measures (pre- and post-intervention questionnaires) and qualitative measures (teacher and learner focus groups, classroom observations, curriculum feedback forms). Because we did not randomly assign or match implementation and control centers, the evaluation design was considered “quasi-experimental.” In

this sense, the HEAL:BCC evaluation study did meet not all of the requirements of a randomized control study—the gold standard for evidence. However, the fact that the evaluation was conducted in “real” adult learning centers and was implemented by “real” teachers increases the chances that our findings can be applied to other settings.

In designing an evaluation of HEAL:BCC outcomes, we wanted to know whether the project increased women’s knowledge, attitudes, and behaviors in regard to mammograms and Pap tests.

Between October 2000 and June 2001, a total of 17 adult learning centers (13 implementation centers and four control centers) in five states (Florida, Virginia, New York, Rhode Island, and Massachusetts) participated in the evaluation of the HEAL:BCC project. Each program offered classroom instruction that focused on skill development—ABE, per-GED, or Intermediate/ Advanced ESOL—and women made up at least 50 percent of the student populations. Four centers in New York City participated in the study, each serving a diverse, urban population. Four counties in Virginia participated in the evaluation: two serving rural communities, and two serving urban and new immigrant communities. In Florida, all of the centers were located in Hillsborough County; two of these centers served Spanish-speaking migrant farm workers. In Providence, Rhode Island, and Southeast Massachusetts, the centers served primarily urban and new immigrant communities. The four control centers, which did not implement the HEAL:BCC Curriculum, were similar to the implementation centers in size and student population. A majority of the classrooms participating in the evaluation study were ESOL, and two-thirds of the over 600 adult learners who participated in HEAL:BCC instructional activities during the evaluation period were ESOL students.

In order to determine whether teachers were implementing the curriculum as it had been designed, evaluators conducted classroom observations midway through the program period. Using a classroom observation checklist, evaluators described what they saw in 11 implementation centers. In addition, teachers were asked to complete curriculum feedback forms to report the specific materials used in their classes and to document any changes made to the program.

What Teachers Said

HEAL:BCC evaluators asked teachers to complete curriculum feedback forms. Following each lesson, teachers were asked to write down their impressions. They reported the changes they

VISIT THE HEALTH & LITERACY SPECIAL COLLECTION

<http://www.worlded.org/us/health/lincs>

The Health & Literacy Special Collection website is for teachers, students, health educators, and health care consumers. The site can direct you to free and low-cost materials, including:

- Health curricula for ABE and ESOL classes
- Guides for integrating health and literacy education
- Health brochures in plain English, or in languages other than English
- Health information tutorials with sound, text, and illustrations in English and Spanish
- Information about the link between literacy and health status
- Links to organizations dedicated to health and literacy education

The site is maintained by World Education, with support from the National Institute for Literacy's LINCS project. LINCS is a national effort to provide web-based access to information for adult literacy practitioners. The Health & Literacy Special Collection is one of several collections of resources relating to specific areas of interest to the adult literacy field.

For more information, or to provide feedback about the site, contact Sabrina Kurtz-Rossi, World Education, 44 Farnsworth Street, Boston, MA 02210; phone 617.482.9485; or email sabrina_kurtz-rossi@worlded.org.

made, the skills their students developed, the time it took to complete the lesson, and suggestions for improvement. They also reported their perceptions of students' reactions to each lesson. We developed a focus group guide and facilitated four teacher focus groups following implementation of the curriculum. Focus group questions elicited feedback regarding the implementation of the curriculum and recommendations for how the program could be improved.

Of the 45 participating teachers, 30 completed and returned curriculum feedback forms. Over half of the teachers reported making some modifications to the curriculum during implementation. For example, one teacher added vocabulary and rewrote the "What Is Cancer" unit for her beginning readers. Half of the teachers also indicated that they had arranged for outside support from a health educator, medical provider, or HEAL:BCC staff person during implementation. Because of the relatively short duration of instruction, a rigorous assessment of

students' literacy skills was not a part of this study; however, all of the teachers who returned the curriculum feedback form did report that their students' literacy skills had improved. A majority of teachers noted that the curriculum helped students develop skills in reading and writing. Teachers also noted improvements in organization, categorization, alphabetization, speaking, listening, dictionary skills, comprehension, test taking, computer skills, group work, and abstract thinking.

During the focus groups, teachers said they found the curriculum well organized and easy to use. One teacher said, "I think it was just really well done. Easy for an ESOL teacher to do any adjustments if that was necessary." Many teachers voiced a need for more information on cultural issues. This prompted us to add cultural notes and suggestions for how to adapt lessons for different class levels to the final version of the curriculum. Teachers said that having a relationship with a local health agency was helpful. The San Jose Mission in Hillsborough County Florida, for example, had a health clinic and parish nurse on site. The nurse helped carry out a community-wide screening event as part of the project.

What Learners Said

After teachers and learners had completed the curriculum, implementation centers participated in a final event in their area, where learners could celebrate their accomplishments and participate in focus groups. Ten participating students from each learning center attended their local event, totaling approximately 30 students per event. There were four events overall. Through displays and presentations, the students demonstrated not only impressive amounts of knowledge of breast and cervical cancer, but that they could teach others about the subject as well. Some students gave factual presentations using overheads, others read from their journals, and others performed skits. In some cases, students and teachers did presentations together; they reported on their community outreach projects, as well as the impact the projects had on individuals' lives. Each presentation was unique and powerful.

During the afternoon of the final events, we conducted student focus groups using a discussion guide designed to elicit specific feedback: reaction to the curriculum and student materials, what students felt they had learned, and the actions they had taken relating to their own health and/or the health of others. Learners in every focus group offered positive comments about the project. They liked reading the student materials. One learner said, "This is basically the only program [where] I've ever sat down and read the books." Learners said the materials taught them about breast and cervical cancer, served as an excellent reference, and helped them improve their reading skills. Learners also said that preparing materials for the final event and completing curriculum journal pages helped them with their writing

skills. While the HEAL:BCC Curriculum was originally designed for students in intermediate ESOL and pre-GED classrooms, ESOL students from all levels were especially enthusiastic about the program and said their literacy skills had improved as a result of their participation.

During the focus groups, male students reported that they found the information very useful and that they shared what they had learned about breast and cervical cancer with their mothers and wives. From classroom observations, evaluators noted that both male and female students appeared engaged and comfortable with discussing HEAL:BCC topics. Most programs did not have a problem with the sensitive nature of the material. In one class, however, the men and women chose to cover the self-exam lesson separately.

Reporting Outcomes

To determine changes in knowledge, attitudes, and behaviors regarding breast and cervical cancer, we asked HEAL:BCC students to complete a pre- and post-intervention questionnaire. Teachers administered the questionnaires during class time. We also distributed postcards for health care providers to initial and return after students had received a screening; however, too few were returned to draw any conclusions.

Over 1,300 adult learners completed the pre-intervention questionnaire: 607 were learners in HEAL:BCC classrooms at implementation centers; 419 were learners in non-HEAL:BCC classrooms at implementation centers; and 300 were learners in the control centers. Of the 607 learners in HEAL:BCC classrooms

The proportion of women learners over 18 who reported having had a Pap test increased from 58 percent prior to participating in HEAL:BCC classes to 72 percent after the class had finished the curriculum.

who completed pre-intervention questionnaires, 271 also completed the post-questionnaires. We used the data from these 271 learners to assess changes in knowledge and behavior. Of the learners in this subgroup, 72 percent were women, 34 percent were over 40 years of age, 33 percent had no insurance, 63 percent had an income of less than \$14,000 per year, 45 percent were Hispanic, 26 percent were Asian, 13 percent were African American, 13 percent were white, and 1 percent were Native American.

The pre- and post-intervention questionnaire contained a total of 32 questions. These questions examined the following factors: learner demographics, content knowledge, screening behavior, and information sharing. We found statistically significant increases in the number of learners who answered the

content knowledge questions correctly on the post-intervention questionnaire as compared to the pre-intervention questionnaire. For example, only 49 percent of learners responded correctly on the pre-intervention questionnaire to the true-or-false question, “A mammogram is only needed when a women feels a lump in her breast.” Eighty percent of the learners gave the correct response on the post-intervention questionnaire. We found similar increases in the amount of correct answers for all content knowledge questions.

In terms of the behavioral objectives—that is, obtaining mammograms and Pap tests—the proportion of women learners over 18 who reported having had a Pap test increased from 58 percent prior to participating in HEAL:BCC classes to 72 percent after the class had finished the curriculum, again a significant increase. The number of women learners age 40 and over who reported having had a mammogram also increased, from 72 percent to 78 percent, although this was a not statistically significant increase. To assess whether learners helped others, we asked them whether they had suggested screening to a friend or relative. The number of learners who reported suggesting mammograms increased from 53 percent to 73 percent, and the number who suggested going for Pap tests increased from 47 percent to 71 percent—both significant findings.

Conclusion

The HEAL:BCC evaluation study is good news for adult education programs and staff members who are looking for research-based results to convince administrators and funders to support the integration of health content into literacy classrooms. The results may also reassure teachers that this type of curriculum can be done successfully while meeting both the literacy and health information needs of their students. The HEAL:BCC project effectively brought information about breast and cervical cancer early detection and screening to adult basic education learners and the communities served by adult learning centers. More importantly, we have strong, positive feedback from adult basic education teachers and learners suggesting that integrating health content and literacy skills development not only is feasible, but also meets adult learners’ needs.

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Cathy Coyne, Ph.D., has over 15 years of experience in health education intervention research and evaluation. She is an assistant professor in the Department of Community Medicine at West Virginia University. She also serves as the research coordinator for the north central region of the Appalachia Cancer Network. She conducted the evaluation of the HEAL:BCC Project.

Judy Titzel has worked in adult education since 1984. As a leader and manager of adult basic education centers, she has extensive experience in curriculum development, teaching, assessment, and evaluation. She is the primary author of the Adult Literacy and Health Vision and Action Agenda. She served as co-principal investigator on the HEAL:BCC Project.

OUTREACH ON WHEELS

Trans•form•ing Health and Literacy Outreach

INTEREST IN HEALTH LITERACY IS INCREASING AS research, such as the Institute of Medicine's 2004 report, *Health Literacy: A Prescription to End Confusion*, continues to validate the connection between low literacy and health outcomes. With this increased interest comes increased funding, which in turn leads to increased resources. One popular kind of resource is online centers designed to provide accessible information on health and health care options to adults with limited literacy skills.

Unfortunately, as most literacy educators are all too aware, resources alone do not change people's behaviors or improve health outcomes—especially when many of the people most in need of the resources have limited access to, and experience with, the Internet. To address this discrepancy, in the fall of 2003, several partners in Washington, DC launched Outreach on Wheels, a technology-based initiative that not only provides communities with access to online health resources but also offers training on how to use and evaluate the resources as well. The partners include:

- The University of the District of Columbia, State Education Agency, Adult Education (SEA), a funding body that awards grants to community-based adult education organizations to enhance the literacy skills of DC residents by providing training in reading, writing, computer skills, ESOL, GED, and workplace education
- George Washington University School of Public Health and Health Services' Partners for Health Information (Partners), an organization that teaches electronic health information resources and skills to the patients and staff members of community health centers

- Family and Medical Counseling Service, Inc. (FMCS), a social service and medical care center for people with HIV and AIDS
- Unity Health Care's Upper Cardozo Health Center (Upper Cardozo), a federally qualified health center

Defining the Issue

The Institute of Medicine (2004) reported that low levels of literacy and poor health literacy disproportionately affect people with limited education and English skills. Washington, DC, has one of the lowest literacy rates in the country. According to Reder (1996), 37 percent of District residents performed at level one on the literacy scale; 61 percent fell into the two lowest levels of reading proficiency. In addition, the Brookings Institution reported that the Washington metropolitan area has one of the nation's fastest growing rates of new immigrants, a population that is in need of ESOL services (Singer, 2004). According to the SEA's 2003 annual report, 46 percent of the District inhabitants served in SEA-funded programs are African American; 48 percent are Latino.

At the same time, Washington metropolitan area residents exhibit some of the worst health status indicators in the U.S. According to the Kaiser Family Foundation (2004), in 2002, over 8 percent of District residents had diabetes as compared to 6.7 percent nationwide. Moreover, in 2001, 50 percent of DC residents were considered overweight or obese (Kaiser Family Foundation, 2002). Additional statistics reveal a sharp disparity in the health status of DC residents along racial and ethnic lines. In 2001, over 85 percent of new cases of AIDS in Washington were among African-American adults and teens, compared to

HEALTH INFORMATION PARTNERS

The Outreach on Wheels partners listed on page 40 are also working together in a newly formed regional coalition that collaborates on health fairs, surveys, and data collection in an effort to increase health information and improve health status among low-income and low-literate residents of the Washington metropolitan area. By working together and leveraging resources, the coalition members believe that they can be more effective in serving DC residents. Fifteen different community-based organizations and agencies have joined to form Health Information Partners (HIPS).

Building on goals similar to those of Outreach on Wheels, HIPS plans to:

- Enhance health literacy through promoting reliable resources and teaching skills in using technology and evaluating information
- Develop advocates for health information in order to help members of low-income, low-literate communities achieve better health

To do this, HIPS plans to organize health fairs, arrange for the Trans•form•er to visit additional health centers, create bilingual outreach materials to promote the use of online health resources, and hold trainings and workshops.

just over 49 percent of African Americans nationwide for the same year (Kaiser Family Foundation, 2004, July). Five times more African Americans than white DC residents died as a result of diabetes (Kaiser Family Foundation, 2004). Similar mortality rate trends exist for cancers and heart disease (Kaiser Family Foundation, 2004). Finally, while the District's infant mortality rate was reduced to 10.6 percent in 2001, that number is still higher than the national rate, which is 6.8 percent (*Kids Count Data Book*, 2004).

One way that the health community has addressed this issue is through digital libraries that offer online health information and resources. For example, the National Library of Medicine not only produces MedlinePlus, a gateway to reliable online health information for the public, but also funds numerous information outreach programs to provide health professionals, researchers, librarians, and clients with high-quality digital health information resources and information services. In fiscal year 2002, the National Library of Medicine awarded 52 grants totaling four million dollars through its Internet Access to Digital Libraries (IADL) grant program (National Institutes for Health, 2004). The public can now find volumes of health material and data online.

Unfortunately, most of these resources are not reaching low-literate and low-income users. In a survey of low-income residents in Washington who use community health centers, only 18 percent of respondents said they use the Internet for health information; a mere 6 percent said that they search regularly for health information. However, all respondents indicated that they would like to retrieve health information from the Internet (Partners for Health Information, 2002).

Outreach on Wheels

Outreach on Wheels was designed to bring the benefits of the national online health information initiatives to low-income DC residents. A joint partnership between the SEA, Partners, Upper Cardozo, and FMCS, the Outreach on Wheels objectives are to:

- Raise awareness and knowledge among those delivering health information and literacy services
- Show adult learners how to find easy-to-read health information on the Internet
- Increase the awareness of MedlinePlus health information resources by 200 percent among visitors in one year
- Refer 50 percent of visitors to adult education programs, literacy classes, and/or ESOL services in one year, and enroll 25 percent of those referred into an appropriate program
- Participate in health fairs throughout the community

Outreach on Wheels uses the SEA Trans•form•er, a van that is equipped with 12 networked computers, a high-definition television screen, Internet access, webcams, assistive technology, a scanner, a printer, and educational software for adult basic education, GED, and ESOL learners. The Trans•form•er's visits to two neighborhoods served by Partner organizations illustrate its effectiveness in meeting these goals.

Many visitors reported that the information they found through Outreach on Wheels has not only increased their understanding of health-related issues but has also led them to new opportunities.

The Upper Cardozo Health Center

The Outreach on Wheels effort began in Columbia Heights, a heavily populated Latino community in northwest Washington, DC. Columbia Heights is home to many new immigrants from South and Central America, as well as to the Upper Cardozo Health Center, which is situated at the corner of a bustling intersection near a Metro subway and several busy bus stops.

Community-based organizations in Columbia Heights include the Latin American Youth Center, a multicultural community organization focused on youth and family development, and La Clinica del Pueblo, a multi-service, multi-specialty health clinic.

Upper Cardozo offers a variety of medical services, including adult medicine, pediatrics, obstetrics, gynecology, and dental care. The center also offers a number of social services, including HIV support groups, Medicaid applications, and the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). Upper Cardozo offers medical exams to District residents by appointment or on a walk-in basis. The majority of visits are for routine tests and immunizations, for conditions such as hypertension, and for general health complaints. In 2002, Upper Cardozo provided primary care health services to 12,698 adults and children, totaling nearly 50,000 medical visits (Rodante, 2002).

In September 2003, the Trans•form•er began visiting the Upper Cardozo Health Center twice a month. Each visit lasts approximately four hours. The SEA provides the mobile unit, driver, and one staff person. Partners provides two staff members, both of whom speak Spanish. Staff members aboard the Trans•form•er help clients find appropriate health information and community resources on the Internet. They also make adult education referrals.

In the first year of operation, Outreach on Wheels served over 100 visitors from the Columbia Heights community onboard the Trans•form•er. Visitors included the Upper Cardozo staff members, health center patients, neighborhood residents looking for referrals to literacy classes and community resources,

Staff members on board the Trans•form•er have helped visitors search for health information, GED and literacy programs, financial aid for higher education, and resources for children.

and teachers who work in the nearby Latin American Youth Center. Visitors performed a range of activities. They searched the Internet for GED and literacy classes, immigration services, jobs, and treatment options for medical conditions such as fibroids and diabetes. They also wrote résumés and established email accounts. Many visitors reported that the information they found through Outreach on Wheels has not only increased their understanding of health-related issues but has also led them to new opportunities. For instance, a woman investigating topics on women’s health exclaimed during a visit how helpful it was to get clear information and “understand that my problem was not in my imagination!”

UPPER CARDOZO HEALTH CENTER IN 2002

Number Served	12, 698 in Year 2002	
Adult Ethnicity	53% Hispanic	35% African American
Pediatric Ethnicity	78% Hispanic	15% African American
Gender	62% Female	38% Male
Recorded Educational Level	27% None	29% High School

Rodante, 2002

For teachers, Outreach on Wheels offers technology-based trainings, such as “Integrating Technology into the ABE Classes,” as well as instruction in common office software. Teachers, along with caseworkers, social workers, and physicians, also use the Trans•form•er to gather information about adult education programs and network with the SEA.

Family and Medical Counseling Services

On the other side of town, in Anacostia, the Family and Medical Counseling Services, Inc. (FMCS) provides social services, substance use counseling, and medical care for people with HIV and AIDS. For the last four years, FMCS has championed online health education for its patients. The Trans•form•er began visiting FMCS in the summer of 2004. The visits have been extremely popular among residents and staff members from neighboring social service and health care providers.

The Trans•form•er generally receives 25 or more visitors during each two-hour session in Anacostia. As with the Columbia Heights outreach, staff members on board the Trans•form•er help visitors search for health information, GED and literacy programs, financial aid for higher education, and resources for their children. One of the SEA staff members who visits Anacostia is a former adult education student who received her high school diploma at the age of 45. As an advocate for adult education, she provides valuable support at the FMCS location, helping visitors identify their goals, as well as the barriers they may face.

Feedback and the Future

Early feedback from adult learners and health center clients has been promising. Staff members have kept a log of each outreach visit, recording the number of people served and the type of service provided—for instance, health information dissemination, adult education referral, remedial Internet instruction. Thus, the Outreach on Wheels effort has been able to track initial outcomes:

- Trans•form•er visits with health and literacy staff members increased the awareness of MedlinePlus among visitors. Very few reported that they were previously familiar with it or other reliable online health information.
- Approximately 25 percent of visitors asked for referrals to ABE, literacy, and ESOL classes.

- A majority of visitors needed introductory or remedial instruction in Internet and computer skills. Over half of the visitors with health or community resource questions required introductory instruction or support in using the web and software. Many people were taught how to establish email accounts, write résumés, and search for job opportunities online.

Plans for more rigorous evaluation strategies, including a multiple-choice survey, will be developed over the next year.

While the Transform•er is a unique and exceptional tool, adult education centers can replicate this type of health literacy outreach without it. Patients in health centers, particularly walk-in clinics, spend a considerable amount of time waiting to be seen by a practitioner. This is a perfect opportunity to engage them in meaningful activities, such as computer training and sharing community resources. Adult education centers can also work with local health organizations to help improve the content and organization of health materials and websites. Health professionals are eager to have adult learner focus groups review health information. This type of feedback is invaluable to the health community in making sure information is comprehensible.

Ultimately, without increased access to these resources—as well as increased literacy and computer skills training—adult learners may find themselves even more marginalized by a medium intended to bring all health consumers into the fold. Making health information available in different settings—for instance, at a health center, an adult education center, or a house of worship—is an essential step in supporting adult learners to become advocates for their own health as well as the health of their families.

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