Focus on Basics

CONNECTING RESEARCH & PRACTICE

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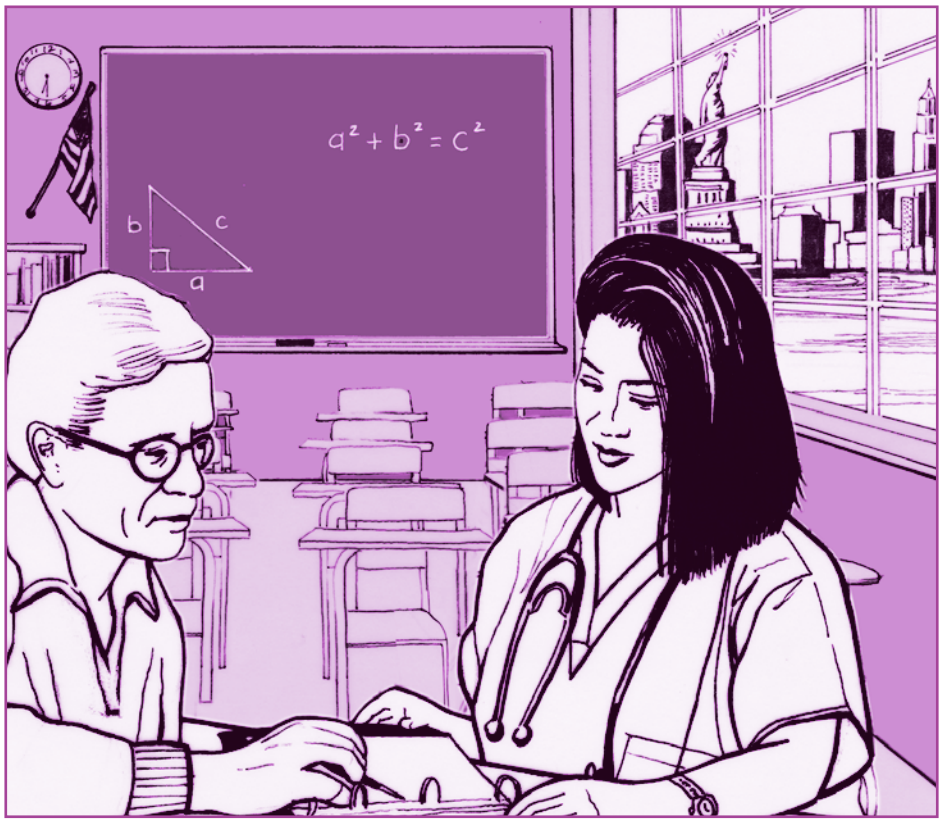
Health & Literacy Partnerships



Health Literate Doctors and Patients:

The New York City Health Literacy Fellowship for First Year Medical Students

by Anthony Tassi & Fatima Ashraf

For the past five years, the New York City Mayor's Office has been working on health literacy issues with a broad coalition of adult educators and health care professionals. Together, we created a summer fellowship program for medical students to deepen their understanding of health literacy and improve their communications skills. Now in its third year, this innovative program has proven an effective model for non-traditional

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Focus on Basics is a publication of the U.S. Division of World Education, Inc. It presents best practices, current research on adult learning and literacy, and how research is used by adult basic education teachers, counselors, program administrators, and policymakers. *Focus on Basics* is dedicated to connecting research with practice, to connecting teachers with research and researchers with the reality of the classroom, and by doing so, making adult basic education research more relevant to the field.

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Welcome to the Partnership Issue!

For this issue of *Focus on Basics* we assembled a team of editors who represent both sides of the health and literacy partnership, including a doctor, a medical librarian, a professor of adult education who works in health and literacy, and a literacy specialist new to health and literacy. As a group we experienced many of the same challenges you face as you forge health and literacy partnerships. We asked each other: "What does this mean?" "What does this stand for?" "Would this be of interest to your colleagues?" "Does this ring true?" We started with the view that health literacy is the responsibility of everyone — the medical establishment, literacy providers, and individuals with limited or not so limited literacy — and we found that theme conveyed in all the articles we edited.

For a review of the link between poor health outcomes and low health literacy, turn to Lilian H. Hill's article on page 8. Then explore the partnerships being carried out around the country. Their sheer variety is exciting. In our cover article, authors Anthony Tassi and Fatima Ashraf describe a project of the Mayor's Office of New York City that brings medical students into adult literacy classrooms. In Cambridge, Massachusetts, the Cambridge Health Alliance works with the Cambridge Literacy Center to train adult literacy students to present health information in literacy programs and in community settings (see page 10).

Ian Bennett, Pamela Pinder, Regina Szesniak, and Jennifer Culhane write about the evolution of their Philadelphia-based collaboration, now a home-based model that connects teachers from the Center for Literacy with new mothers to help them gain literacy and health navigation skills and knowledge (see page 14).

In California, Maricel Santos and Lynette Landry of San Francisco State University have teamed up to create a graduate level course that deliberately prepares literacy teachers and nurses in training to contribute to collaborations between the health and literacy fields. Read about their course in the article that starts on page 21, then travel down the coast to learn about a partnership between two umbrella organizations, one for health and one for literacy, that came together to devise a health literacy agenda for San Diego County. Kelli Sandman-Hurley and Chris McFadden write about the process these organizations went through to develop the agenda and the steps being taken to implement it (page 30).

Susan Levy and colleagues share findings from five years of research conducted in Illinois in the article that starts on page 33. They tested whether adult literacy students' literacy skills and health knowledge would improve if teachers used a curriculum that incorporated health content. Julie McKinney reports on three partnerships—in North Carolina, in Wisconsin, and in New York — and the lessons that can be learned from them (page 26).

Researcher Andrew Pleasant challenges us to rethink the way we conceptualize health literacy and demonstrates how data from the National Assessment of Adult Literacy can be interpreted to tell a variety of stories. Turn to page 46 for his insights.

Literacy and health practitioners charged with developing health communication materials will be thrilled to have Lilian H. Hill's review of the role of visuals in health communication materials (see page 40). She distills key lessons from a multitude of studies and provides just the right visuals to show us what she has learned.

Thanks to the Josiah Macy, Jr. Foundation for funding for this special issue of *Focus on Basics*. To discuss the articles, join the National Institute for Literacy's health literacy discussion list at www.nifl.gov/lincs/discussions/discussions.html.

Sincerely,

Barbara Garner

Barbara Garner
Editor

Health Literate Doctors & Patients

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medical education with important benefits for adult literacy programs. And we have learned some valuable lessons for creating and sustaining mutually beneficial partnerships across the medical and adult education worlds.

The New York City Mayor's Office started from the premise that the concept of health literacy has two distinct components: 1) the ability of individuals to read, understand, and act upon health related information and 2) the capacity of professionals and institutions to communicate effectively so that community members can make informed decisions and take appropriate actions to protect and promote their health. We enlisted the help of adult education programs to think about how to enhance the health literacy skills of adults and worked with health care providers and the City's health department to explore strengthening institutional and professional capacity.[1] Our key partner in much of this work has been the Literacy Assistance Center (www.lacnyc.org), the professional development hub for New York's adult education system.

This is the story of how adult educators came to play a leading role in an innovative medical education program involving medical students from eight schools. The story begins with the framing of health literacy as a responsibility of institutions and a matter of professionalism, as much as a reflection of the abilities and skills of individuals. The story also begins with a generous grant from the New York Community Trust and support from the Mayor's Fund to Advance New York City.

[1] We are appreciative of the participants on the NIFL health literacy electronic discussion list for making this point eloquently on more than one occasion.

2007 Fellow Julie Gonzalez teaching ESOL students at the West Farms Career and Technology Center, part of the Phipps Community Development Corporation in New York City. Julie is a student at the Columbia University College of Physicians and Surgeons. She has been an advocate for health literacy since her fellowship, and assisted with recruitment of the 2008 class of fellows.

Health Literacy Agenda for the Health Care System

We started working with local health care providers on three strategies:

1. **Raising awareness of the importance of health literacy** (through medical grand rounds, conferences, and other activities);

2. **Training providers on specific health literacy interventions** (such as the use of multi-lingual patient navigators and dissemination of high-quality, easy-to-read outreach and education materials); and

3. **Facilitating partnerships with the adult education sector** (for technical assistance in plain language, to have adult learners review draft patient information documents, and to help health educators reach low literate and limited English speaking populations).

Over the past five years, with the hard work of many participating agencies, we have made considerable progress. Today, many hospitals in New York City — led by our public hospital system — have implemented health literacy staff trainings and other interventions. The City Department of Health and Mental Hygiene has revamped its approach to public education on chronic disease prevention and management based on health literacy principles and routinely consults literacy experts when developing materials and training providers. Several health plans have training programs in place for their staff and their affiliated physicians. Foundations, such as the United Hospital Fund, the Commonwealth Fund, and the New York Community Trust, have prioritized health literacy projects in their funding. A number of important research and demonstration projects are underway.

Throughout much of this work, we have heard the same advice many times: if you want to help physicians improve their health literacy skills, get to them early. By the time physicians are practicing medicine, it may be too late. Physicians have many competing priorities. Many physicians do not think health literacy insights apply to their patients. They assume they know how to communicate well.

The Potential Role for Adult Educators

Based on this advice, we started thinking about ways to reach physicians while they are still in

training. We came up with a simple idea: bring medical students into adult education classrooms to work with students and teachers of literacy and English for speakers of other languages. If future physicians could experience what it is like for low literate and limited English proficient adults to try to make sense of the U.S. health care system, they would really "get it." If they could gain insight into how adults learn and practice teaching strategies with help from trained instructors, they would be more likely to develop the ability to overcome literacy and language barriers in their clinical practice. And, if the experience was rich enough, the medical students would become advocates for change within the health care system: champions of health literacy.

Therefore, we envisioned a fellowship that immerses medical students in the adult education classroom, combined with site visits to clinical settings where health care providers are working on health literacy issues, and day-long seminars to learn from experts and debrief from their fieldwork. The big advantage this experience would have over other academic or clinical training opportunities for medical students is that in the classroom, the "patients" don't leave after 15 minutes. The medical students see them for three hours twice or three times a week over a period of several months.

We also built in a research component and the expectation of a paper of publishable quality by the end of the program. We committed to sponsoring a conference for the fellows to present their work. Without a research component, the opportunity for a conference presentation, and a good chance at publishing, we worried that a fellowship in health literacy would not be competitive with other opportunities available to medical students. Nor would it gain the respect of medical school faculty and deans.

> *"Medical students loved the classroom experience, had their eyes opened by getting to know adult learners, and told us that the fellowship had an important impact on their growth and development as physicians."*

The Pilot

Initial conversations with medical schools and adult education programs were encouraging: our stakeholders thought that the partnership made sense. Given the academic schedules of medical students, we focused on a summer program between the first and second years of medical school. We worked with deans at two local medical schools to identify three students and we hand picked three adult education programs to test the concept, launching this small pilot in 2006.

While our primary goal was to train future physicians, we hoped the fellowship would benefit participating adult education programs as well. Medical students could be of immediate service to adult learners interested in health-related knowledge and skills. Adult educators can often use an extra set of hands, especially those of smart and motivated medical students who are yearning to be helpful and learn how to teach.

From a broader perspective, we wanted the "New York City Health Literacy Fellowship" (as we started calling it) to position the adult education field as a source of expertise and technical assistance to the medical profession. Adult learners would not be viewed as patients with a deficiency that needs fixing, but rather as full humans with agency. They could tell their own life stories, marked by struggles and triumphs, rather than have their experiences collapsed into a description of the "presenting problem" that clinicians would read on a medical chart. Teachers would tutor the future doctors on how to assess and address learners' real concerns, break down complex information into manageable chunks, and check for comprehension.

The results from the pilot year were promising. Medical students loved the classroom experience, had their eyes opened by getting to know adult learners, and told us that the fellowship had an important impact on their growth and development as physicians. They were impressed and engaged by clinicians they met during the site visits to local hospitals. Teachers and adult education program managers were equally pleased with the experience and reported that each fellow made important contributions to their program. They told us the learners appreciated having the fellows in the classroom and made good use of their time.

Encouraged by these results, we expanded the fellowship in 2007 to its current size of 10 fellows, established an application process for medical students and for adult education programs, and formalized a curriculum. We also received grant funds from the New York Community trust to commission a program assessment and to produce an informational video (available on-line at www.nyc.gov/html/adulted/html/health/fellowship.shtml. Scroll down and click on "Watch the Making of the Fellowship documentary").

Recruitment and Matching

We organized information sessions at the eight medical schools in New York City during the fall of 2006 to recruit the class of 2007. We received applications from 13 medical students from six schools, a number of whom were referred by the three fellows from the pilot year. We selected 10 applicants from five schools based on academic record, desire to learn about clear health communication, and a demonstrated ability to work outside their comfort zones and the medical school environment. They were placed at 10 adult education programs selected from a pool of 16 applicants. Program applications consisted of a letter of interest and details about class offerings submitted by program managers in response to a call for applications from the Mayor's Office e-mailed to all City-funded programs.

Fellows were matched to programs according to their interests in teaching adult basic education (ABE) or English for speakers of other languages (ESOL), as expressed during their admissions interview. Travel time and geographic preference were also taken into account. Fellows and program coordinators met each other for the first time a week prior to the official start of the fellowship to get to know one another and begin discussing plans for the summer.

The class of 2008 was recruited in a similar fashion as the class of 2007. Information sessions were organized with each medical school. This time, however, we had a documentary film to tell the story of the fellowship and bring the concept of health literacy to life. We re-designed the application for fellows to include more essay questions and a letter of support from a faculty member and received 32 applications from all eight medical schools for the 10 slots. The application to host a fellow was also re-designed to require more up-front planning and an explicit commitment from teachers, together with an endorsement from the program manager. Both applications were posted (and still remain) on the Mayor's Office Web site (to see the form, go to nyc.gov/html/adulted/html/health/fellowship2008.shtml).

Feedback from 2007 also indicated that programs and fellows wanted more input into the matching process. Therefore, we organized a "match-day" dinner during which everyone got a (very brief) chance to get to know one another and then fellows and programs each ranked their top three choices. Most programs and fellows got one of their top three choices and all participants expressed satisfaction with the new matching process.

Program Design

Fellows in the class of 2007 worked at their adult education site four days a week. Paired with one or two teachers, some fellows co-taught health literacy classes while others were given the entire class time to implement health lessons. Fellows decided on health topics typically by conducting a needs assessment with their students. Topics included nutrition, diabetes management, and patient-doctor communication. Most fellows taught non-health related adult education lessons as well.

In 2008, we changed the program design based on feedback from the class of 2007. Fellows now spend three days a week at the program site, one day a week conducting research, and one day a week in seminars and on field trips. This modified design gives fellows more structured time to work on their research projects and write their papers. The range of classroom activities in 2008 is similar to 2007.

In addition to teaching, 2007 fellows spent time designing health literacy research projects. We charged them with designing and implementing a small project and writing up the results along with a literature review. We expected that these papers would be ready for presentation, if not publication, by the end of the eight-

This is Kate Goheen teaching adult learners at the Queens Library. Kate was a 2007 Health Literacy Fellow and presented her summer research project at the Public Health Association of New York's annual conference. Her paper was entitled "The Development of a Pictorial Health-Related Quality of Life Survey for Adults with Limited Literacy." Kate attends the Weil Cornell College of Medicine.

week summer program. The independent nature of the 2007 projects was unrealistic. Fellows found that eight weeks was not enough time to design, implement, and write a publishable quality paper. Furthermore, summer attendance in adult education classrooms is often inconsistent, making it difficult to collect a significant amount of data. The Institutional Review Board (IRB) approval process for conducting human subject research also delayed several fellows' research start dates. Therefore, in 2008, fellows were invited to work on one of four research projects that we pre-selected before the start of the program. Each existing project is led by a senior principal investigator: three health literacy researchers at New York City medical schools, and one senior staff member with the City's public hospital system, the New York City Health and Hospitals Corporation. These projects are pre-designed, IRB approved, and likely to have findings published in a peer-reviewed journal. Participating researchers are expected to mentor the fellows and expose them to all aspects of their research, from literature review to data collection and analysis.

Seminar Series and Field Trips

Fellows also participate in a day-long seminar once a week. This is a chance to visit the City's leading public hospitals and discuss health literacy with clinicians and other health professionals. We arrange for health literacy experts and practitioners to meet with them in our offices for seminars and roundtable discussions. Fellows are given reading assignments in preparation for each seminar.

The 2008 seminar series focuses more on policy issues and is supported by a more structured curriculum. Fellows have the opportunity to meet with the president of the New York City public hospital system, the Deputy Mayor for Education, and several urban health policy experts. Clinical site visits continue. In addition, starting in 2008, fellows have three writing assignments to complete based on the required readings (see box) and seminar topics. We also began the 2008 seminar series during the spring, with two classroom site visits and one roundtable discussion before the summer field work. This gave the participating fellows more grounding in adult literacy before they began the fellowship.

Results from 2007

The fellowship appears to have accomplished its main educational objective. According to our program assessment, fellows increased their understanding of health literacy and improved their communication skills. By the end of the eight-week program, fellows reported a more nuanced understanding of literacy that went beyond just notions of reading and writing to include skills (health-related, computer, numeracy, and others) needed to function in society. They understood the principles of plain language and the factors that influence the readability of documents (grade level equivalence, formatting, jargon, active *vs.* passive voice, for example). They realized the importance of translation and using pictures to illustrate written points. They also gained a much greater understanding of the association between literacy skills and access to medical care.

We administered pre- and post-tests to measure changes in knowledge of concepts related to effective communication and found substantial growth among the fellows. In contrast to the pre-test, in which only two or three of the fellows could name one or two effective communication concepts, on their post-tests most of the 10 fellows named a number of key concepts, such as:

- **Focusing on the patient:** body language, active listening, eyes off translator
- **Watching your language:** plain language, jargon free, appropriate

> *"A long-term goal of ours is for every medical student to gain insight and training on health literacy as part of his or her medical education."*

Required Reading for the 2008 Health Literacy Fellows

- *Advancing Health Literacy: A Framework for Understanding and Action*. Christina Zarcadoolas, Andrew Pleasant, David S. Greer.
- *Understanding Health Literacy: Implications For Medicine And Public Health.* Joanne G. Schwartzberg, Jonathan B. Vangeest, Claire Wang.
- *Teaching Patients With Low Literacy Skills*. Cecilia C. Doak, Leonard G. Doak, Jane H. Root.
- *When the Spirit Catches You and You Fall Down*. Anne Fadiman.❖

to the patient's level of comprehension
- **Confirming understanding:** teach back, asking how/why questions of the patient
- **Changing attitudes:** awareness, patience, dropping assumptions.

One of the 2006 fellows won second prize in the New York City Public Health Association 2007 Goldmann Student Merit Awards for her research paper. A 2007 fellow presented on her fellowship experience at a conference sponsored by the U.S. Department of Health and Human Services (see www.health.gov/communication/literacy/TownHall/ny.htm). Other fellows presented their summer research to faculty and other students on their respective campuses.

In 2008, we expanded our monitoring and evaluation procedures to include site visits to watch the fellows in the classroom and track their progress in teaching skills and communication techniques. In addition to interviewing teachers and program coordinators, adult learners will also be asked about their experience with the Health Literacy Fellows at the end of the summer. The 2008 fellows will also participate in one-on-one exit interviews with Mayor's Office staff.

Lessons Learned, Longer Term Impact

We had hoped to form lasting institutional partnerships between medical schools and adult education programs. However, these on-going relationships have yet to form. The fellow is the sole contact that adult education programs have with the medical school world. This may change in the coming years, as the number of medical school faculty and staff involved in the fellowship continues to grow. We will continue to sponsor an annual fellowship conference to bring the two worlds together.

As fellows returned to medical school for their second year and began to meet with patients and shadow physicians, they reported that their new-found understanding of health literacy and communication skills improved interactions with patients. For example, one 2006 Health Literacy Fellow reminds her professors to take literacy level into account when discussing a patient's diagnosis and treatment with them during their rounds. Her professors have been impressed with her ability to bring an issue like literacy, non traditional to the medical field, to the forefront of her clinical work. Other fellows reported raising the issue of health literacy on numerous occasions during lectures and in conversations with professors and attending physicians. As the number of health literacy fellowship alumni grow, we expect health literacy slowly, but surely, to become more visible in New York's teaching hospitals.

We also learned a number of ways in which the 2007 fellowship helped adult education programs improve the lives of adult learners. Having a future physician in the classroom helps demystify the health care system. In the words of an adult learner, "Sarah was so sweet, so nice. I am not scared of doctors anymore, if doctors can be like Sarah." Another program manager reported the same reaction: her fellow became the face of the medical establishment, humanizing this abstract concept the learners had about doctors as "great authority" figures remote from their daily lives and concerns. While small in scale, breaking down barriers by simply allowing for human interaction outside of an intimidating setting is an important accomplishment.

Program managers also reported that fellows helped their students engage in more advanced learning activities and more sophisticated class projects. The students were often enthusiastic about sharing what they had learned with their fellow classmates and their families.

"...bringing adult education and adult learners to the center of health literacy opens new possibilities for public health promotion and disease prevention."

Professionalism and Institutional Responsibility

A long-term goal of ours is for every medical student to gain insight and training on health literacy as part of his or her medical education. We remain optimistic that medical schools will rise to the challenge. The fellowship has started some conversations in this regard, but has yet to convince any school to make significant changes. Most campuses can point to at least one or two lectures on health literacy included in first- or second-year courses. It will take more than this fellowship for medical school deans and key faculty members to embrace the importance of integrating health literacy into the curriculum in a more systematic fashion, but the fellowship is playing a role in raising awareness and demonstrating student enthusiasm for the topic and related skills.

Finally, bringing adult education and adult learners to the center of health literacy as resources to enhance the capacity and professionalism of future physicians opens new possibilities for public health promotion and disease prevention. As learners become more health literate and more comfortable interacting with doctors, they will spread their knowledge

and sense of self-efficacy to their families, friends, and communities. Adult education programs — together with their clinical counterparts — have a vital role in supporting adults in taking these steps.

About the Authors

Anthony Tassi is the Executive Director of the New York City Mayor's Office of Adult Education, an office established in 2006 to create better outcomes for New York City's adult education system. Prior to this role, Mr. Tassi served as the Health Policy Advisor to the Deputy Mayor for Policy. He initiated New York City's health literacy initiative, which has grown to include dozens of adult education programs and health care providers. Mr. Tassi began his career in public service in the Washington, D.C., office of Senator Edward M. Kennedy.

Fatima Ashraf is the Health Literacy Coordinator in the New York City Mayor's Office of Adult Education, where she directs the Health Literacy Fellowship and the New York City Health Literacy Campaign. Previously, Ms. Ashraf worked for the New York City Department of Health and Mental Hygiene as a social epidemiologist. She began her career in public health at the Michigan Department of Health as an outreach worker to minority communities.❖

For More Information

For more information about the New York City Health Literacy Fellowship, please visit www.nyc.gov/healthliteracy. A 25-minute video provides a more in-depth picture of the fellowship and of health literacy issues. It is available on the Web site and also on DVD free of charge by e-mailing the New York City Mayor's Office of Adult Education at adulteducation@cityhall.nyc.gov.❖

WORLD EDUCATION

The Influence of Low Health Literacy

by Lilian H. Hill

The link between poor health outcomes and low health literacy has been well established (Andrus & Roth, 2002; Baker et al., 1996; Berkman et al., 2004; Schillinger et al., 2003; Youmans & Schillinger, 2003). Health literacy is commonly defined as the ability to read, understand, and act on health care information, or more formally as "the ability to obtain, process, and understand health information and services to make appropriate health decisions" (Healthy People, 2010; Ratzan & Parker, 2000). It entails the ability to perform basic reading and numeric tasks in the health care context including comprehending prescription labels, appointment slips, insurance forms, and other health-related information distributed to patients (Andrus & Roth, 2002; Schillinger et al., 2003). Zarcadoolas, Pleasant, and Greer (2005) propose an expanded model of health literacy in which the concept refers to a "wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life" (p. 196). Recent conversations about defining health literacy are making reference to health communications as a shared responsibility between patients and health providers.

Regardless of the definition chosen, health literacy is a type of functional literacy with a focus on what people can do with their skills, for example, seek information, establish relationships with healthcare providers, or act on information to improve health. Prior knowledge of health information is helpful and can include health-related vocabulary and conceptual knowledge regarding health and how the body functions. Both of these tend to correlate with basic literacy skills, however, people who function well in familiar contexts may struggle in the healthcare setting because of unfamiliar vocabulary and concepts.

People with low health literacy have difficulty with written and oral communications that can limit their comprehension and retention of health information provided to them. Low health literacy can impair communication about risks and benefits of treatment options (Davis et al., 2002), which is critical in the management of chronic diseases because "patients must cope with complex treatment regimens, manage visits to multiple clinicians, monitor themselves for changes in health status, and initiate positive health behaviors" (Schillinger et al., 2003, p. 84). People with low health literacy have more difficulty naming their medications and may hold health beliefs that interfere with adherence, meaning a patient's ability to follow healthcare provider's instructions.

Lacking the ability to decipher medical terms and educational material hinders individuals and their family members understanding of information needed to manage illness and negotiate the healthcare system, thereby engendering non-adherence to prescribed treatment regimens and preventive care. In fact, low health literacy is an independent predictor of medication nonadherence (DiMateo, 2004) and poor health (Mayeaux et al., 1996).

> *"The link between poor health outcomes and low health literacy has been well established."*

The aim is not to have people simply be able to read patient education materials, but to prevent the consequences that can ensue when patients are unable to decipher medical information (Ad Hoc Committee on Health Literacy, 1999). For example, a patient having trouble reading and comprehending medical documents and prescriptions may fail to follow directions or misinterpret them, causing potential disease complications. This engenders more hospitalizations and use of health care systems, which increases human costs for patients as well as economic costs to society (Gazmararian et al., 2003).

This special issue of *Focus on Basics* addresses health literacy in the context of different ways that health and literacy professionals are partnering to address health literacy problems. When medical workers and adult educators partner to integrate health topics into literacy programs, adult learners can gain health knowledge and greater confidence to navigate complex healthcare systems. Healthcare providers turn to adult educators to learn how to develop greater sensitivity to the needs of low literate populations. "Adult educators can help health practitioners understand the underlying assumptions prevalent in public health and in healthcare, the nature of the demands made on adults, and the need for a better match between these demands and adults' skills" (Rudd, 2007, p. 35). By the same token, literacy educators may feel they lack sufficient medical knowledge and confidence to provide effective instruction. Greenberg (2001) recommends that literacy instructors begin with students' prior knowledge of health topics, discover what adult learners want to learn, provide students with choices especially regarding sensitive health topics, and partner with healthcare providers. While health providers and adult educators may benefit from working together, the ultimate beneficiaries are the adult learners they partner to serve.

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Literacy Students as Health Advisors

When an adult basic education program and a health alliance partner to train students to be community health advisors, everyone wins

by Barbara Garner

From the perspective of the Cambridge Community Learning Center (CLC), its partnership with the Cambridge Health Alliance offers adult basic education (ABE) and English for speakers of other languages (ESOL) students a chance to contribute to their community as they use their English skills. For Cambridge Health Alliance (CHA), a regional healthcare system that serves more than 70,000 patients a year, the partnership offers access to potential volunteer health advisors from the very communities the CHA is trying to serve.

This particular partnership began when the Massachusetts Department of Education (MA DOE) included funds for collaborations between literacy and health providers in a request for proposals it issued in 2005. CLC teachers had been talking about the need to integrate health information into their classrooms but up until then, their efforts were hit or miss; they wanted to apply for the funds. The CLC had previously partnered with the Cambridge Public Health Department's Agenda for Children initiative to train CLC students to talk with others in their communities about the value of talking to children at a certain age. Happy with that partnership, and with the model of using students as leaders in their communities, Carole Sousa, coordinator of CLC student leadership initiatives, approached the CHA about creating a model around health.

Pre-Existing Model

The Cambridge Health Alliance already had a model: the CHA Volunteer Health Advisory (VHA) program was established in 2001 as a multicultural, multilingual health education and outreach initiative designed to improve community health status. CHA trains volunteers to conduct health promotion activities where they live, work, and worship. "The woman who originally started the CHA program," explains Sousa, "was Maude Guerrier, a Haitian woman who had been a student here [at the CLC]. She really knew how to set up a program for community members. Of all the collaborations we've done, theirs is the only one for which I have not had to rewrite materials into easier English." The CHA prides itself on its ability to work with people with a wide range of literacy and English language skills; with a public health mission, they explain, they need to know who the people in the communities are and match services to them. All their materials and signage are in four languages.

With a winning proposal, the CHA and CLC health partnership was born. Although they were building upon CHA's pre-existing model, some modifications had to be made to fit the specific needs of this partnership, but they turned out to be minor. The CLC students recruited into the program were trained at the CLC, rather than in training rooms at the CHA. The length of the training was shortened and the content truncated, but only a bit. The student participants, who became official CHA volunteer health advisors, sign two contracts rather than one. In addition to the usual one with the CHA explaining that they will participate in at least a minimum number of community health events, they also

Cambridge Health Alliance's Swayne Blackmon trains volunteer health advisors on the importance of primary care.

sign a contract with the CLC outlining the responsibility they have to give presentations to their fellow students.

> *"The Learning Center's role in this partnership is to recruit the students and arrange times during which they, having been trained as volunteer health advisors, can make presentations to their fellow CLC students."*

Learning Center's Role

The Learning Center's role in this partnership is to recruit the students and arrange times during which they, having been trained as volunteer health advisors, can make presentations to their fellow CLC students. The Massachusetts Department of Education funding pays for part of Sousa's salary and covers stipends for the students when they attend the CHA training. Sousa recruits in September, visiting ABE and higher level ESOL classrooms to explain student leadership opportunities to the students. Anyone can sign up to be a health advisor. Those who are parents have two additional choices: they can encourage others to talk and read to their young children, or they can teach others to navigate the school system more successfully. She explains all three programs and the level of commitment they require and has students complete their applications while she is still in the classroom. "We have such an incredible turnout," she explains. Their funding for the health advisor program can support 12 advisors, but 16 took the training. "I told them we couldn't pay them the full stipend, but people say 'don't worry about it, we want to do it.' I expect people to drop out in great numbers when I tell them they can't get paid but they don't." CLC students are interested in these opportunities for a number of reasons, Sousa reports. Those who were health professionals in their home countries have an interest in the area or may want to go into a health career here and see it as a good opportunity. Others want to give back to the school and see it as a way to do so or are generally active in their communities. "If someone says to me," she explains, "that they want to be a Health Advisor because, 'I want to make some money,' or '...because I need a job,' I tend to screen them out, because their expectation of the program is different than the goals of the program. The goals of the program are to serve the community through preventative health education, not to find jobs for folks."

Soon after her recruiting efforts, Sousa sends letters to the students selected as participants, inviting them to the first training, which does not start until January. This gives the students who work plenty of time to arrange to get time off if they are employed. The trainings are held on Saturday mornings in the Community Learning Center; in 2008 they ran for 17½ hours over five weeks.

Newly-minted volunteer health advisors Marie Osiris, Miriete Wass, Claudia Tamsky, Marie Maud Jean-Pierre, Maria D. Mendonca, Zahara Mohammed, Wesnel Rene, Jacqueline Morales, Semirete Esheta, Rabeya Akthur, XiaoRong Zhong, and Amy McClintock crowd the hallway at the Community Learning Center to display their certificates.

Health Alliance's Role

The CHA's role in the partnership is twofold: it teaches the student volunteers the health knowledge and presentation skills they need to carry out their responsibilities as volunteer health advisors; it also alerts the new volunteers to community health activities in which they can take part. They conduct the training in English, pre- and post-testing participant's health knowledge. The last day of the training focuses on how to be a good presenter and includes time to practice. The trainers are medical residents in a special CHA program that connects them to the community, CHA-affiliated doctors and health educators, and CHA staff. CHA prepares the doctors and residents by providing a curriculum and explaining who the population is and what their literacy levels and English skills are. Upon completing the training, CHA presents the newly-minted volunteer health advisors with a binder of materials, a certificate, and a badge.

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To fulfill their commitment to the CHA, the volunteer health advisors are required to attend 20 hours of additional training given by CHA and participate in a number of community health events. The CHA calls, e-mails, and sends mailings to the volunteers to alert them to the trainings and volunteer activities; they ask the volunteers to submit monthly reports on their activities. One health advisor from the CLC/CHA partnership, a nurse in her native country, set up a health presentation in her own church rather than wait for an opportunity to serve. Others have volunteered at "Hoops N Health", a basketball tournament for men living in Cambridge at which volunteers perform glucose, cholesterol, blood pressure, height, and weight screenings, as well as providing health education information on tobacco cessation, nutrition, and physical activity.

> *"The CHA's role in the partnership is twofold: it teaches the student volunteers the health knowledge and presentation skills they need to carry out their responsibilities as volunteer health advisors; it also alerts the new volunteers to community health activities in which they can take part."*

Supporting the Students

To help the CLC community health advisors fulfill their commitment to CLC, Sousa arranges for the advisors, working in teams, to do their presentations at the CLC in their first languages to students from the two highest levels of ESOL. These students have achieved some level of fluency in speaking, reading, and writing English, and have sufficient English language skills to negotiate systems like shopping, using the services of a bank, filling out job applications, participating in their children's education, and joining a class to study for the tests of General Educational Development (GED). Classes divide up by language group; if someone's home language is not represented they go to a presentation given in English; ABE students attend the English-language presentations. In 2008, presentations were made in Korean, Creole, Spanish, Portuguese, and Mandarin. In earlier years Bengali and Amharic were included.

At the end of their presentations, the volunteer health advisors ask participants to complete assessment forms that gather information on how well they did as presenters. The presenters fill out self assessments and classroom teachers give Sousa feedback. Sousa also visits the presentations, making sure all is going well. If someone has problems or is or unprepared, she works with them.

"The biggest thing we've found with ESOL students," Sousa explains, is saying 'I don't know'. It's fine [to say 'I don't know'] in this country but not so fine in other cultures. We do a lot to get them ready to say that. I did have to step in one time when a student health advisor was making up information [rather than admitting he did not know the answer to a question]."

During or after relevant presentations on blood pressure, blood sugar, and cholesterol, the Cambridge Health Alliances does screenings at the CLC of the same. If they find, for example, someone with high blood pressure they do not let them leave, instead, they call in a nurse and then do follow up. This year the CHA brought a health insurance access person to talk to students about Massachusetts' new health insurance laws, which require everyone above a certain income level to have health insurance.

Impact

Besides the obvious positive impact the presentations and related screenings and referral services have on those who attend the presentations, the students who become health advisors report that their English and self confidence improve greatly. Teachers report not only seeing students who would not speak in class now standing to make oral presentations, but also the positive impact on students receiving health advisor presentations. ESOL teacher Erin Reardon explains, "I think students feel positive about learning from student leaders. My students felt good about being able to recognize vocabulary and major ideas that were presented in the workshop."

Health advisor Yong Min Chao, a Korean known as Irene, explains that she learned a lot about the health topics, improved her English, and grew confident around her English-speaking doctor. Now that she's pregnant, she pointed out, this is especially important. Antonnia Nascimento, also a volunteer health advisor, is studying for her GED and hopes to become a medical interpreter. She speaks Cape Verdean, Spanish, and Portuguese along with English. She recommends to fellow CLC students that they become health advisors too. "There are a lot of people who have never heard about heart disease and high blood pressure," she explains. "We work with partners, another classmate. You learn a lot." She is looking forward to being trained by

the CHA in how to screen for glucose levels and check blood pressure.

From the CHA's perspective, the student volunteers are like any volunteers: some are active, others aren't. "There's one difference between the CLC group and others, though," Anu Rao, Volunteer Health Advisor program coordinator explains. "The CLC community is more diverse. That has allowed us to incorporate greater diversity into the health advisory group and learn more about newer immigrant communities. They have also helped support some other outreach." The CHA's work with other literacy programs involves providing health education to students, rather than training the students to be health advisors themselves. "With the CLC," Rao explains, "every person increases the capacity of the community. He or she is talking to friends and family, helping others to connect to other resources. For a lot of these communities, these informal networks are important." Having this partnership in place is also less resource intensive for the CHA because they don't have to establish a new relationship or recruit the students.

Challenges

No partnership is without challenges, but good communications and being clear about expectations helps this one go smoothly. After students become volunteer health advisors, keeping them engaged and active as CHA advisors is a challenge in every group, explains Rao. After the first year of the partnership the CHA realized that the CLC students were identifying only with their role as presenters to fellow students within the Learning Center, so they made adjustments. "Now we send Carole [Sousa] information about continuing education and Carole shares it, encouraging the students to participate." They also emphasize from the beginning the two-pronged commitment the students are making.

For the CLC, finding funding to support all the students who want to participate is one challenge, explains Sousa. While the CHA is funded to do this work, the state funds do not cover all of the CLC's costs related to the program. The CLC and CHA are looking for other funding to supplement the state funds.

And although CLC teachers suggested that their school participate in this project, recognizing that health is a topic of interest and importance to their students, giving up precious class time is always hard. Sousa works with the teachers to find ways to weave the concept of student leadership and the role of volunteer health advisor into lessons. She has two binders of lesson plans and curriculum for teachers as well as an orientation packet on how to prepare their classes for these activities.

Conclusion

This health and literacy partnership grew out of a pre-existing relationship and enabled both partners to meet organizational needs. The Cambridge Health Alliance gets a stream of motivated community health advisors who give them access to communities they otherwise would have struggled to reach. The CLC provides its students with leadership experiences in which they use and strengthen their English and literacy skills as they give back to the community, gain valuable health knowledge and confidence, and learn how to navigate the local health care system. Even those students who are not active participants learn health information from trusted peers. The challenges seem small in comparison to the results.

About the Author

Barbara Garner is the editor of *Focus on Basics*.❖

WORLD EDUCATION

Take Charge of Your Health:

A Collaborative Health Literacy Intervention Linking Adult Education and Maternal-Infant Health Care

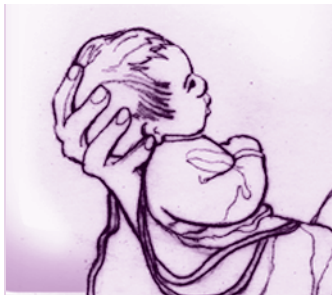
by Ian M. Bennett, Pamela Pinder, Regina Szesniak, & Jennifer F. Culhane

Parents from low income populations are likely to have limited literacy that interferes with pediatric care (Davis et al., 1994; Sanders et al., 2007). The health literacy challenges faced by mothers are complex, involving both the mother and infant through prenatal, pediatric, and women's health care. Despite a documented need, very few programs target obstacles faced specifically by mothers with low literacy (one notable exception is the Baby Basics program, www.whattoexpect.org). An approach to overcoming obstacles to care that makes use of the principles of adult learning would identify the women's educational interests that relate to these health services and build skills that would endure and be transferable to a range of settings (Knowles, 1970). While learner-derived priorities may not fully overlap with the priorities of medical providers, they have the advantage of inherently garnering commitment from the mother. By focusing on the development of literacy and problem solving skills through specific obstacles to care it is also likely that these skills can be applied to new obstacles that may arise.

These concepts underlie "Take Charge of Your Health" (TCYH), a collaboration between adult educators and medical and public health providers developed over the past several years. Work first focused on conceptualizing how to make this collaboration function and then became a process of developing and refining a feasible model with pregnant or parenting mothers with limited literacy skills. In this article we describe this process and share a number of lessons that adult educators and health providers may want to consider as increasing numbers of us examine ways to work together to augment the services that we each provide to the vulnerable populations of adults with low literacy.

Developing TCYH

The development of the TCYH intervention began in 2003 and continues today. Dr. Ian Bennett, a new faculty member at the University of Pennsylvania School of Medicine (Penn) and a physician-researcher (and co-author of this article) had been an adult literacy tutor and had grown up with parents deeply involved with adult literacy and education. As a family physician who delivers babies and then takes care of both the mothers and children he saw firsthand the added difficulties that low literacy creates for young families and wanted to explore the potential benefits of connections between adult education and maternal-child health services. Dr. Bennett contacted the Center for Literacy (CFL), a community-based organization that provides adult basic education (ABE) services in the Philadelphia region. The CFL saw in the collaboration a chance to enhance the education services provided to their learners and to document empirically what they had experienced: the positive role adult basic education could play in increasing ABE students' access to health care.



At the initial meetings, which included faculty from Penn and administrators, supervisors, and adult educators from CFL, a target group was identified – pregnant and parenting women with low literacy – based on the particular health care demands they face and the overlapping interest and experience of the health researchers and educators. Over the next year, the adult educators and Penn faculty wrote a health literacy curriculum that uses materials that have as their content how to navigate the health care system. The goal was for the participants to increase their literacy skills as they increased their knowledge of the health care system. To increase the likelihood that the program would be valued by the target group, the curriculum writers consulted with a community advisory board comprised of mothers of preschool age children participating in Philadelphia Even Start programs run by the CFL (Tao et al., 1998). The board suggested the name "Take Charge of Your Health" for the program. As described by the CFL manual for students and tutors, the goal was "putting adult learners in control of their own learning" (Pomerance, 2007).

This team of health researchers and adult educators then carried out a two-month pilot program in mid-2003 with nine learners, recruiting them from a mandated full-day welfare-to-work literacy program run by CFL to participate in a twice-weekly class of two hours per meeting. Lunch was included for the participants as an enticement and the class was held in the same building as their welfare-to-work program, an office building in downtown Philadelphia. The nine learners tested at below basic literacy levels, or ≤ 6th grade on the Test of Adult Basic Education (TABE). The learners included seven African Americans, one Latina, and one White, all from the inner city. The TCYH course was facilitated by an ABE teacher and a fourth-year medical student.

Measures of success for this pilot project included interest among learners with low literacy, participation, self reported value of the classes (in discussions and in very brief anonymous surveys), reports that the participants felt more comfortable using the health care system for their children, and reports that participants used the skills they developed in the class in their daily lives. By all of these measures the pilot was a success with high participation (the class was limited to nine), moderate continuation (more than half of the students were at each of the classes), and very positive reviews of the benefits of the classes.

Preterm Prevention Project

Based on the success of this pilot program and the growing strength of the collaboration, we felt ready to implement the model as a full intervention. In July, 2005, TCYH was included as one of seven interventions for women with preterm birth who participated in the Philadelphia Collaborative Preterm Prevention Project (PPP) directed by Dr. Jennifer Culhane at Drexel University School of Medicine and funded by a grant from the Pennsylvania State Department of Health. This randomized clinical study was designed to address multiple risk factors of preterm birth among 1,400 women who had early preterm births in a Philadelphia hospital between 2004 and 2008. Focusing on the period in between the end of one pregnancy and the start of another, the study examines whether addressing multiple risk factors simultaneously results in lower rates of repeat preterm birth, measured by comparing the rates of preterm birth between the treatment and comparison groups over the 24 months that women are in the study. TCYH was included because of evidence that low literacy creates stresses such as shame and psychological distress (depression symptomatology) among adults including pregnant and parenting women (Bennett et al., 2007; Poresky & Daniels, 2001; Baker et al., 1996). Different types of stresses, including psychological distress, have been found to increase the risk of preterm birth possibly through a link to the inflammatory state of the human body (Wadhwa et al., 2001a; Wadhwa et al., 2001b).

The TCYH Intervention

The challenges of utilizing the health care system are multiplied if the mother has a preterm infant. Premature birth accounts for the majority of pediatric disabilities and results in a wide range of health problems for the child (Barros & Velez, 2006). The mothers of preterm infants are often burdened with the additional care needs of these infants but are also more likely to come from disadvantaged communities and so must also struggle with the challenges of poverty and lower quality care services.

The predominant model of ABE instruction by professional adult educators at CFL and throughout the United States is classroom based. Given that, and supported by our successful pilot study, we initiated a classroom-based TCYH program for women as one of the PPP interventions. Instruction was provided by full-time professional ABE instructors from CFL in conjunction with physician faculty from Penn.

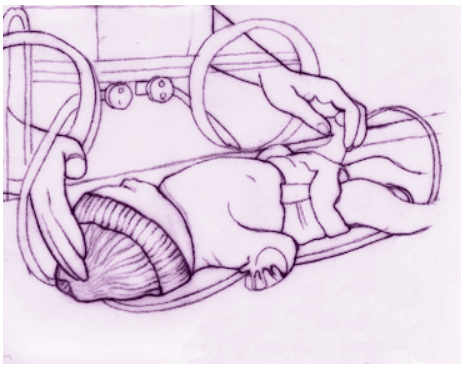
Choosing an appropriate literacy assessment was an issue. The Test for Adult Basic Education, or TABE, is commonly used in adult basic education and CFL staff are skilled in administering it. Time, however, was a factor. The full TABE assessment takes

45 minutes to complete, a length of time which was prohibitive in this medical research setting. The TABE-Locator takes approximately 15 minutes and we feel it to be superior to the extremely brief literacy screening instruments (2-7 minutes) commonly used in health settings. The Rapid Estimate of Adult Literacy in Medicine (REALM) can identify a similar range of low literacy while the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA) only identifies adults with very low literacy levels (low ceiling). Also, both instruments have been validated as literacy measures only against a very limited range of general literacy instruments. So we used the TABE-Locator, setting at or below the 9th grade equivalent as the eligibility point for TCYH.

Of the 500 women enrolled in PPP, those who were assessed at below 9th grade equivalent in literacy via the TABE-Locator were invited to TCYH class sessions six months after the birth of their infants. This six month delay was deliberate: we hoped that allowing the immediate crisis of preterm birth to settle before addressing educational needs would improve participation. Classes two hours in length were scheduled twice weekly at midday and included catered meals. These classes were held in a classroom at the medical site (first in a hospital then in a free-standing clinic) where the women were coming for other PPP study activities. We used the learner-centered contextual health literacy model tested in our pilot study. We made great efforts to recruit women to participate in this class. More than 60 percent of those eligible registered for the program, however, only four of the more than 75-eligible women in the first year ever attended any of the sessions. Only two of the four persisted in the program and completed the targeted 20 hours of instruction. While the few who did participate reported great satisfaction with the class, the majority who had signed up and yet never attended appeared to be voting with their feet.

> *"...low literacy creates stresses such as shame and psychological distress (depression symptomatology) among adults including pregnant and parenting women."*

To provide experience for the instructor running the health literacy classes we invited a traditional adult basic education (ABE) class of eight students to come to the TCYH sessions for a four-month period. Once again we found that the students in the adult literacy program were enthusiastic participants and rated their experience very highly. We were initially puzzled by the great difference between learners from literacy programs and the women with equivalent literacy skills who were part of the PPP but were not participating in the class. It appeared that the adult basic education model of class-based instruction was not appropriate for the women in the PPP. Two important differences existed between these two groups: 1) the competing demands of women with infants (preterm or not), and 2) the frame of mind regarding the perceived priority of education among women who were not seeking educational programs. While the participants from the ABE class had children, none were younger than one year old and none had significant health problems. These ABE class women had also self-identified a need for adult education services and registered for classes themselves rather than being identified and invited to a class. This self-selection is likely to represent a range of personal factors that could be summed up as "readiness" for an educational program at least like the one we had developed.



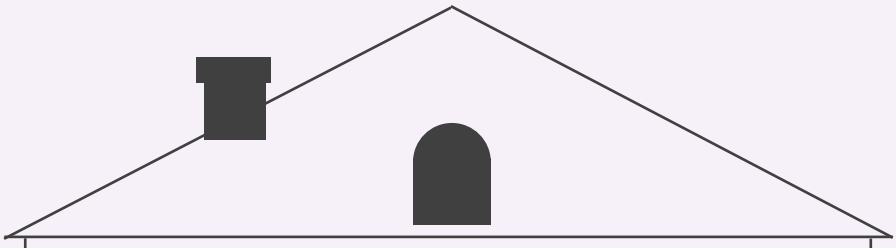
A New Model: Home Visits

After reviewing possible alternative models for this intervention, we chose to modify the program and make use of a home visiting design commonly used in nursing and parenting education programs for low income mothers with young children (Olds et al., 2000; Olds, 1992; Olds, 2002). The home visiting program was redesigned as a longitudinal one-on-one experience similar in some ways to the individual tutoring model also used in some adult literacy programs (Buswell, 2005). We limited the goals of the intervention to improving health navigation skills in women, dropping the formal literacy improvement outcomes that had been initially incorporated into the design of the study. This decision was based on two main factors: 1) less formal literacy instruction would be carried out in this design, and 2) the literacy assessments

used to measure improvements in literacy were proving to be too onerous for the participants.

The revised program was dubbed TCYH-GOAL (GOAL) to reflect the learner-generated-goal-oriented design of the program. The GOAL curriculum was comprised of four types of home visits: 1) assessment/planning, 2) preparation, 3) action, and 4) follow up. Together these visits comprise a single cycle of activities focused on a particular goal. We invited eligible patients to participate; they were considered to have completed the program after four cycles based on the estimate that each cycle would involve approximately five hours of instructional activity for a total of twenty hours of time spent in the full intervention. Because of the higher intensity of work involved with an individualized program, we changed the eligibility criteria to a narrower group of women, those who scored ≤ 6th grade equivalent on the TABE-Locator. This is equivalent to the "below basic" level used in the 2003 National Assessment of Adult Literacy (NAAL) (White & Dillow, 2005) and has been associated with poor health measures when assessed by literacy assessments including those designed for the health setting such as the REALM and the S-TOFHLA (Davis et al., 1993; Bennett et al., 1998; Davis et al., 1996). Particularly relevant to TCYH, this level of literacy (both in English and Spanish) in mothers of young children has also been shown to be related to less use of pediatric care and emotional distress in mothers (Bennett et al., 2006; Sanders et al., 2007; Bennett et al., 2007).

In addition to providing services to English speakers the PPP included a proportion of primary Spanish speakers with limited English proficiency (LEP). We carried out an LEP-GOAL program over the course of nine months with an adult educator fluent in Spanish and English. Although this group contained only six learners, we were



Take Charge of Your Health-GOAL

The newest Take Charge of Your Health model consists of a series of home visits. The first is an assessment/planning session during which the facilitator uses a brainstorming exercise to review the most pressing issues in the participant's life. For example, Shirley, a 42-year old mother of four, worried about the cost of formula, the dislike she felt for her pediatrician, and concern about her pre-term baby's health. Each learner and instructor prioritized the list and selected a tentative list of potential goal topics. The most common topics generally fell into three categories: 1) medical care, usually for a child or the mother, 2) family management and economics such as utilities, food costs, housing, and employment, and 3) education: completing high school, GED, and other adult education programs. When the list included health topics the instructor suggested these as a goal but did not force them into the final list. Each learner and instructor pair agreed upon one to three topics for the initial cycle and together they assessed what it would take for the learner to attain the goal. For Shirley, setting up Women, Infant, and Children (WIC) services was a possible solution for the cost of formula. Each instructor and participant jointly developed a plan, noting intermediate goals and creating a timeline. In the preparation visits the instructor facilitated a process that enabled the participant to gain the skills needed for the action visits to follow. Such skills included preparing documents, reviewing reference materials, preparing lists of questions, developing interpersonal communication skills through role playing scenarios, and making needed appointments. After preparation was completed, the learner carried out an action visit, generally to a health facility or related site such as a health benefits office, in which the goal was accomplished (or attempted). The instructor accompanied the learner when possible, particularly in the early cycles or with more complex goals, in order to provide role modeling, facilitation, and an objective view of the process involved with carrying out the action. Finally the instructor and learner met in a follow up visit to review the topic and activities that were carried out and reflect on what went well and what did not. When appropriate, additional role playing was carried out to solidify specific skills and lessons.

While the instructor tried to maintain focus on the chosen topic, goals were modified based on the unfolding experience of the learner or as priorities and challenges shifted. When Shirley's husband objected to home visits, for example, the instructor limited them and substituted biweekly phone calls. Sometimes the learner and instructor scaled back goals if it became clear that the initial goal was not attainable in a single cycle. Sometimes family crises demanded immediate attention. The instructor worked to incorporate these acute needs into goals whenever possible to maximize the value placed on these learning activities by the participants.❖

interested in exploring the needs of non-English speakers. Women were invited to participate in this program based on low English literacy, but the participants had varying literacy in Spanish.

The Experience with TCYH-GOAL

In contrast to the classroom-based program, GOAL has high rates of participation and persistence. Of the 297 women who have completed the TABE-Locator assessment, 23 percent were eligible for the intervention and of those 68 percent were willing to participate in the program (40 English speakers and six with limited English proficiency). Of those who agreed to participate, 29 (63 percent) completed the intervention. Feedback from participants was highly complimentary to the instructors and the PPP more generally. Graduates of the program commonly re-contacted the instructors with requests for further work which was provided until the participants completed the overall PPP study (two years after birth).

> *"...it is critical to be humble in the development of programs to work with this vulnerable population."*

Although the instructors were highly experienced in working with low-income inner-city adults in classroom settings, this model afforded them a surprising amount of insight into the challenges faced by these young parents in their everyday lives. These challenges include the management of households, transportation, and navigation of health concerns for the whole family. The instructors reported new-found appreciation and understanding for the difficulties that learners face to participate in educational programs and to utilize health care services. The educators also reported high levels of personal reward from working with these learners in this setting.

The range of topics covered by the TCYH interventions was diverse and is instructive. The medical care topics primarily focused on utilizing care from primary care and specialty providers for both the mother and her children. Family management and economics included medical insurance issues, employment (including workforce development), housing, and child services. Education was primarily focused on completion of secondary education (for teens) and initiating adult education programs for women in their twenties or older. Some women joined formal ABE programs to complete the tests of General Educational Development (GED) and alternative adult diplomas. All four participants with low English proficiency joined classes of English for speakers of other languages for the first time. These examples illustrate the success of the program in addressing outcomes of interest to both the health and education components of the TCYH collaboration. From the health providers' vantage point the program was successful in helping the women enrolled overcome obstacles to health care services including those related to scheduling, patient-physician communication, and the use of reference materials for pediatric care. These participants were able to identify specific goals, develop a plan to achieve them, and then carry out the plan. The outcomes of these activities included moving to new pediatric offices (after dissatisfaction with a provider), changing insurance plans, feeling more confident in getting the medical

information needed to care for a child, organizing the health records of an infant with special needs, avoiding an unnecessary emergency room visit through effective communication with a primary care office, and many other concrete health care needs. These health navigation achievements represent important outcomes for a health literacy intervention. From the educators point of view this program resulted in tangible linkages to formal educational programs in both secondary and adult education settings. While scaled back from the goal of increasing measurable literacy skills, this may be an effective means of linking women to formal secondary education and ABE programs who would not otherwise make it to these services.

Challenges

While the TCYH-GOAL intervention provided a set of clear successes and rewards for the efforts of the teachers and staff involved it also involved some significant challenges. First, although the program made great strides in engaging this vulnerable population in an educational program through moving to an individualized home visiting model, this design is labor intensive. Unlike the classroom model where a group of women could be taught at once with minimal travel requirements for the educator, GOAL required a great deal of scheduling and travel time to complete the intervention goals. This requires a great investment in time for any progress with individual learners and in turn requires financial support which will need to be justified

by benefits to the women and their children through careful assessment. While we feel that this program has educational and health benefits it remains to be seen if it is affordable.

A number of challenges associated with working in the community with low income women living in impoverished neighborhoods should be mentioned. The difficulty that many women faced maintaining stable housing and telephone service (cell phone or land line) made staying in touch with learners throughout the program a challenge. Also, while no acts of crime were committed against any of the instructors during the intervention, the instructors noted personal discomfort with the frequency by which violent crimes occurred in the neighborhoods where the TCYH learners lived. Tragically, one of the learners was actually killed during the course of this study, a victim of violent crime.

Future Directions

Based on the lessons that we have learned thus far, we are moving to quantitatively assess the TCYH and TCYH-GOAL interventions with a non-intervention comparison group. Specific domains of interest include the utilization of appropriate pediatric and women's health care services, self-efficacy to communicate with physicians, and satisfaction with primary care physicians. In addition we plan to explore more fully the potential for adding intermittent group classes to the individual programs to help participants build a sense of solidarity and community in educational efforts. While group classes did not work alone and with women with whom we did not have an ongoing relationship, it is possible that learners who have been involved with the individual program will be more likely to come to group sessions as part of the services delivered. Future areas for exploration include potentially linking an intervention like TCYH-GOAL to national preschool education programs such as Head Start, Early Head Start, and Even Start. It is our hope that other health providers and adult educators will gain some insight from our experience as they develop their own collaborative health and literacy programs to serve this highly vulnerable population.

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We learned several important lessons that we feel have implications for any programs in which adult educators and health practitioners work collaboratively. First, it is possible to develop programs in which outcomes of interest to educators and health providers, while not identical, are addressed and measurable. These collaborations can take advantage of the strengths adult basic educators have in working with adults with low literacy to build health navigation skills while providing adult basic educators with access to a population that is not engaged in adult education programs.

Second, women in the maternal-infant care setting (and probably health care settings in general) are not the same as women who choose to seek out adult education services (i.e. those with whom adult basic educators usually work). The consequence is that traditional classroom models of adult education are not necessarily going to be successful in attracting a significant proportion of the women who would benefit from these programs. We found that an individualized home visiting approach overcame many obstacles to the use of these services. We also found evidence that this type of approach may act as a bridge to more traditional adult basic education programs. Some of the challenges of this approach include the amount of resources needed to deliver these services. This is a model that is commonly used for nursing and social work services for young mothers however, suggesting that the economics of such an approach may be favorable if improvements in care utilization (amount and efficiency) result from the intervention. Linking women with low literacy who would not otherwise access adult basic education to formal literacy services would likewise be valuable to adult educators.

Adult educators working in this model need to be comfortable outside of the walls of a traditional classroom. Finally, we have learned that it is critical to be humble in the development of programs to work with this vulnerable population. If our goal is really to increase services to women with low literacy then we need to listen to what they tell us, with both their words and actions, and create programs that fit into their lives rather than forcing women with many other competing priorities to change their lives to access our programs.❖

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Partners in Training:

A Cross-disciplinary Approach to Preparing Adult Literacy Practitioners and Health Professionals

by Maricel Santos & Lynette Landry

"A maturing partnership" was how public health expert Rima Rudd described the relationship between adult educators and health professionals who collaborate to improve health outreach and services to adults with low literacy skills or limited English proficiency, in the 2002 issue of Focus on Basics. *Here at San Francisco State University (SFSU), we are working to strengthen our graduate students' abilities to contribute to collaborations between the health and literacy fields and ultimately to improve services in the health and adult education worlds. In this article, we focus on the scope and impact of a new course, Seminar in Immigrant Literacies, which aims to cultivate partnership skills in frontline professionals who work with immigrant communities (e.g., teachers, health care providers, counselors). What knowledge, attitudes, and skills do we—whether we work in literacy or health care—need to be effective partners? Organizing this seminar has moved us closer to being able to articulate answers to this broad question.*

The course is offered through the university's graduate degree program in Teaching English to Speakers of Other Languages (TESOL). Maricel Santos is currently responsible for teaching the course, although colleagues from applied linguistics, health education, library sciences, and nursing have helped shape the content. Lynette Landry has been instrumental in recruiting students from the School of Nursing (SON) to participate. During the summer of 2007, a pilot group of nine graduate students from the TESOL and SON programs enrolled; in summer 2008, the enrollment more than doubled, with 22 students from TESOL and SON, as well as current adult educators and health professionals working in the San Francisco Bay Area.

To frame our discussion, we begin by sharing the perspectives of two graduate students who participated in the course's 2007 pilot. A graduate student in nursing wrote: "One of the ideas raised by the course was the idea of literacy, especially health literacy, as a political force [and] right.... From a nursing perspective, while I think the health literacy that allows individuals to take care of their bodies on a day to day basis is vital, I also think that the aspects of literacy that empower individuals and communities to create desired changes in existing health care access is critical."

"One thing is for sure," wrote a graduate student in TESOL, "I will never look at literacy through the same lens. The ripple effect of this course will have long lasting effects on my [teaching] career because we worked together on real projects, which were focused on problem solving and finding applications in different communities."

These perspectives reflect some of our course goals (see the box on page 22), which address three major themes regarding effective partnership:

knowledge of literacy; attitudes about immigrant communities; and skills for tapping into and representing immigrant experiences, managing communication, and building strong relationships. Together, these themes can be viewed as an evolving framework for our thinking about what we'd like all professionals who work with immigrant communities to have. Over time we expect to strengthen the links between "partnership" concepts with specific training activities (e.g., carrying out a service-learning project). Ultimately we want to offer training opportunities that help our students make sense of what partnerships can and should be in their work contexts.

About the Course

The course begins by having students examine the shaping role of language, literacies, and culture in contexts that immigrant families have to navigate: schools, health care settings, the workplace, and the community. We compare traditional definitions of literacy as reading and writing skills with broader views on literacy as social action and situated practice; we also explore ways that school-based literacies often overshadow everyday literacies. We discuss qualitative studies that reveal the struggles and sources of resilience of immigrant adults as they learn to

navigate new literacies. We turn this reflection and knowledge about literacies into practical ideas and focus on developing collaborative solutions that address real-life concerns affecting Bay Area immigrant communities, such as access to health care and health information. The students work in teams to design a community-based project that addresses the needs of a specific immigrant or refugee community. For example, one TESOL and SON student pair designed a service-learning model that would increase the intercultural competence of nurses and ESOL teachers to improve preventive health care to immigrant women. As part of the students' practical training, the course also includes hands-on workshops on participatory and action research methods, use of online information resources such as MedlinePlus (www.medlineplus.gov) and PubMed (www.ncbi.nlm.nih.gov/sites/entrez), and grant proposal writing. See box on page 24 for selected course readings.

Why Teach This Course?

The need for sustainable health literacy partnerships to address immigrant health care concerns is critical, given the growing body of evidence linking limited literacy or English proficiency to poor health status, inadequate quality of care, higher rates of chronic disease and mortality, and excess health care costs (Schillinger, 2004; Sudore et al., 2006). The U.S. Department of Health and Human Services (2000) emphasizes that "community partnerships... can be among the most effective tools for improving health in communities." These partnerships, which bring together institutional partners such as health departments or university academics with community partners such as local adult education programs, help to ensure that adult learners who are directly affected by health problems play a part in the creation of solutions (Rudd, 2002; Singleton, 2002; Tassi, 2007; Johnston et al., 2006).

Despite recognition of the need for partnerships, little is being done to address how to partner in the training of adult ESOL teachers or nurses. Literacy and health professionals need a common vocabulary for talking about the needs of immigrant and refugee communities. This course gives the students an opportunity to share what they know about fundamental concepts, such as literacy, comprehension, and preventive health (cf. Zarcadoolas et al., 2006). The class discussions compel the students to examine from multiple perspectives the teaching interactions between ESOL teachers and learners and between nurses and patients.

An increasing number of San Francisco State University's TESOL and SON graduate students, alumni included, want to improve their skills to prepare to work in community-based settings. For example, many TESOL students express interest in learning how to contextualize instruction to address learners' real-life needs in multiple domains, such as work or

Knowledge, Attitudes, and Skills

These are the knowledge, attitudes, and skills needed to work in successful partnerships that form the basis for the learning goals for *Seminar in Immigrant Literacies*.

Knowledge:

- To demonstrate knowledge of multiple perspectives on literacy, including literacy as skill, literacy as practice, and literacy as social action
- To demonstrate knowledge of the multiple contexts for literacy development, including school, home, work, community, and health care

Attitudes:

- To reflect on our own cultural backgrounds and beliefs about language, literacy, and immigrant communities, and the ways these views influence our community interactions and perspectives
- To value the complex ways that social and cultural forces influence how 'language and literacy problems' are defined and addressed
- To demonstrate commitment to the creation of language and literacy environments and positive experiences that help immigrant adults and their families see themselves as capable, competent, engaged participants of society

Skills:

- To acquire tools for inquiry (e.g., ethnographic methods, curriculum design) for exploring language, literacies, and the immigrant experience
- To acquire tools (e.g., Web-based search engines) for promoting meaningful access within immigrant communities to information and services
- To begin developing the communication and organizational skills to build sustainable community partnerships

health care. Responding to this need seems critical to improving the health and well-being of this vulnerable group. Many of the nursing school graduate students, particularly those focusing on community and public health nursing, are interested in learning strategies that can help them to work more effectively with diverse populations. Traditionally, nursing educators do emphasize that educational materials must be geared to low literacy populations, but our regular programs provide little on what that means and how to best work with low literacy populations (Owens & Walden, 2007). The collaboration with the TESOL program allows nursing students the opportunity to gain a theoretical understanding of the issues at hand, such as the difference between educational level and literacy, or that literacy involves more than just reading ability. The importance of integrating this knowledge into nursing education is highlighted in this comment, made by a nursing student enrolled in the course in 2007: "the course laid a theoretical framework for considering the many factors influencing the concept of health literacy. Since so much of community health (or acute care) nursing involves educating individuals and communities, the course's content on the varying definitions, approaches, and consequences of literacy gave me a broader context from which to consider the educational needs of my patients. If nothing else, the course reminded me that the basic assumptions that health educators have about literacy, learning, and education may need to be reworked to be more inclusive to non-traditional ideas."

The collaborative course addresses several concerns that have been identified by nurse educators as essential to assuring that the nurses have the skills necessary to effectively work with low literacy populations, such as communicating with patients – both orally and in writing – who have limited literacy skills, and identifying community resources such as adult literacy programs that work with low literacy individuals (Owens & Walden, 2007). In addition, advocacy in the nursing curriculum can assume many different guises including advocating for patient's rights in an acute care setting by assuring that the best quality of care is being provided to advocating for improving the health status of vulnerable populations by becoming involved in the political process. This collaborative course allows nursing students to gain a much deeper understanding of the importance of advocacy to nursing practice as exemplified by the following comment, made by a nursing graduate student: "As a nurse, I strongly feel that access to health care is a fundamental human right. This access includes being able to negotiate the complicated bureaucracies in order to apply for, obtain, and successfully use available health care to its maximum potential. It also includes being empowered to raise a voice to demand the access that is missing to so many."

> *"Literacy and health professionals need a common vocabulary for talking about the needs of immigrant and refugee communities."*

Challenges

We have experienced some challenges over the course of developing and implementing the course. On the nursing side, the prescriptive nature of the nursing curricula because of the requirements of both regulatory and certifying agencies makes it hard for students to fit the class in. For students in both programs, the enthusiasm for the course sometimes competes with their desire to graduate and either enter the workforce or resume full time employment as soon as possible. Faculty are working to address these issues since this collaboration is viewed as integral to assuring that we are providing our students with the theoretical foundation and practical skills needed to work with immigrant communities who possess a range of literacies in English and other languages.

Rewards

One of the greatest inspirations comes from seeing the graduate students look for new ways to teach others about their own disciplines, and learn more themselves in the process. One TESOL student wrote that "[the course] blew my mind and fundamentally altered they way I understand and conceptualize literacy, schooling, and education."

Another commented, "I came away...with a more nuanced and contextualized understanding of the concept of literacy. I now have a broader perspective on and appreciation of how issues of literacy are interwoven with other societal issues such as health, community development, and aging." The students begin to understand how other disciplines think about 'literacy problems' and to question their own assumptions. For example, in a recent class discussion, the students examined how public discourse around literacy in health and adult education typically favors a 'skills view' of literacy. In reaction, SON students asked a powerful question: in what ways does the idea of 'literacy as skill' *not* help us understand what a patient needs to know to effectively navigate the health care system? TESOL students also

posed a critical question: what are effective models for teaching literacy that go beyond reading and writing as workforce skills, and which learners benefit most from each model? While these questions do not have simple answers, it is significant that the SON and TESOL students are confronting popular assumptions about literacy and exploring multiple ways of defining literacy. This kind of inquiry lays the foundation for focused discussions about "not just whether their practices work, but for whom, in what ways, and why" (Johnson, 2006, p. 249).

These cross-disciplinary discussions are rehearsals for conversations that the students will have with future colleagues within and outside their fields of work. As we gain more experience teaching the course, we will look for additional ways to help the students learn about literacy, culture, and health through one another's professional lenses. At the same time, we do not expect TESOL educators to be health experts, nor do we expect nurses to become experts on language and literacy issues. However, as illustrated in the previous paragraph, we do expect our students to ask thoughtful questions about health and literacy and look for answers by reaching out to other disciplines. We recognize that it is often difficult for community practitioners to figure out how to access health information, decide which information is relevant to the communities they work with, and how to respond to the information they do find (see Gaventa, 1993). Our hope is that in training our students to use these information resources, they will in turn be able to train others in the community to do the same.

Looking Forward

This seminar is part of a larger initiative at SFSU to launch a graduate certificate program, under the direction of the newly established Center for Immigrant and Refugee Community Literacy Education (CIRCLE) (circle.sfsu.edu). This certificate will enable students to carry out the community-based project they develop in the Seminar in Immigrant Literacies over a year-long period and thereby gain prolonged direct experience with community partnerships.

The planning discussions between TESOL and health (including nursing and health education) has helped to launch the certificate efforts, and we hope the partnership lays the foundation on which other cross-disciplinary collaborations can be built such as TESOL and business to address immigrant workplace issues. Future directions for collaborative work include identifying community

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partners, such as healthcare institutions, that may be willing to organize health literacy classes for adult learners on their campuses. For example, health literacy could be the focus of vocational ESOL classes for hospital workers, or classes could take the form of one-day orientations designed for adult learners, such as the ones modeled by the the Mid-Manhattan Adult Learning Center in collaboration with Harlem Hospital and featured in Andersen and Rudd's 2006 *Focus on Basics* article "Navigating Healthcare". Another approach is to establish a literacy resource center within a hospital, such as the one run by VISION LITERACY at Santa Clara Valley Medical Center (www.visionliteracy.org/health.html). Recently, one of Maricel's TESOL graduate students was asked to create an ESL class at a community health clinic in San Francisco's Mission District so that patients could have a place to study English before and after appointments. Our hope is that SFSU students who participate in the certificate program will contribute to the development of similar initiatives, enabling them to develop an understanding of the strategies that can be used to reduce health disparities within the adult learner population.

The program described here focuses on the need to educate current health care and education students, but we realize that many working professionals have similar training needs. The seminar and eventually the certificate program are open to working professionals; however we meet many professionals who would like to participate but do not have the time or resources to do so. On a hopeful note, this year we are able to award scholarships to two adult ESOL teachers (alumna of SFSU's MA TESOL program) which will cover their seminar fees. As we look to the future, we will be actively strategizing about how to address the learning needs of care providers and educators in the workplace.

To truly have an impact on health literacy and thereby reduce health disparities in high-risk populations, educators and health professionals must have a requisite skill set. This includes the ability to work collaboratively to identify interventions specific to the needs of diverse populations. Our collaborative efforts are a first step in that direction.

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A Collection of Health Literacy Curricula

For more health literacy curricula designed to train adult educators and health care providers, visit this site: www.advancinghealthliteracy.com/curricula.html

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Partnerships in North Carolina, Wisconsin, and New York

by Julie McKinney

The connection between literacy and health is increasingly acknowledged. Researchers are finding more and more evidence that literacy challenges result in poor health outcomes and that better literacy skills are associated with better health. Health care providers are finding that improved communication practices can improve their patients' health. To capitalize on this connection, professionals in both the literacy and health communities are finding creative ways to bring the two fields together to improve not just individual's literacy skills but also to improve health care access, communication, and ultimately health outcomes for the 90 million adults who have literacy challenges as well as for those who do not. These creative partnerships have become more common and more varied in approach. They have evolved to a point where both the health and literacy fields, along with other partners, are nurturing and reaping the benefits, creating a mutually beneficial situation for the literacy field, health agencies, and community members.

In this article I describe three fairly recently established partnerships, examining how they came about, what they do, the challenges they face, and the rewards they offer. They represent only a few of the types of partnerships currently in practice around the country, others are featured in other articles in this issue. By no means an exhaustive list, these partnerships were chosen as models from which we can draw lessons, ideas, and inspiration for future health literacy partnerships.

What is Health Literacy?

Today health literacy, while perhaps not a household term, is well known to many literacy practitioners, health practitioners, and public health advocates. The definition, like the types of partnerships, has been evolving. A common definition of health literacy is one that was used in the Institute of Medicine's 2000 report, *Health Literacy: A Prescription to End Confusion*: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." This report seemed to serve as a wake-up call to the health community by relating the data from the National Adult Literacy Survey to their work. By publicizing the fact that 90 million Americans had marginal literacy skills, the report promoted a new awareness of health literacy issues to the health field, and is often cited as a rationale for proposed health literacy initiatives.

Some, like health literacy advocates Pleasant, Zarcadoolas, and Greer, (2006), believe in a broader definition of health literacy: "The wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, reduce inequities in health and increase quality of life."

Yet another definition, a revision of the Institute of Medicine's seminal definition, was suggested by Smith (2008) in an electronic discussion list on health and literacy. This version shifts some responsibility onto the health organizations and their ability to communicate information and seems to be embodied by the newer partnership profiled in this article. His definition reads: "The degree to which individuals, organizations, and systems have the capacity to obtain, process, understand and communicate basic health information and services needed to make appropriate health decisions."

A Bit of History

Much of my understanding of the trends in practice and thinking about health literacy comes from facilitating the collegial discussion of ideas, practices, and resources that takes place on the National Institute for Literacy's Health Literacy Discussion List (nifl.gov/mailman/listinfo/Healthliteracy/). This is an online forum where professionals from around the country e-mail about issues related to health literacy. The list members include adult literacy practitioners, health care providers and educators, public health professionals, librarians and people from many other disciplines. I put out a call on this list for city- or state-wide partnerships to feature here.

Many early health literacy activities were not partnerships as much as localized projects focusing on improving the literacy skills of adult students while introducing them to some basic health content. The main goal was to improve health by improving basic skills and the ability to understand health information.

Literacy providers sometimes enlisted local health providers to advise on integrating health information into the literacy curriculum and to act as guest speakers in the classrooms.

Then health educators began to realize that many of the printed materials they created were written at too high a reading level for many of their patients. Developers of health information materials learned how to write in plain language, and use clearer formatting and more pictures. Some of these material developers partnered with adult literacy programs to enlist adult literacy students to test and pilot these materials. I see this practice as the beginning of valuing the expertise of adult literacy students. The projects I describe here reveal how this practice is evolving. The expertise of the adult literacy community — learners and practitioners — is being recognized as having great value to the health community; at the same time, the knowledge of the health community is being recognized as key to those in adult literacy interested in health and literacy. This mutual recognition strengthens the partnerships that are created between the two fields.

North Carolina

In 2006, the North Carolina Division of Public Health asked the state Institute of Medicine to a state-level health literacy task force. The goal was to inform policy change to improve health literacy in North Carolina. The task force invited participation from 49 health care policy, medical education, and clinical groups as well as literacy providers such as state and local community college systems and literacy councils and prominent state leaders and representatives from foundations.

The task force met seven times over the course of nine months and featured speakers from the fields of adult education, pharmacy, medical care, and public health. Each spoke about the effect of health literacy issues on their field. The task force also conducted a needs assessment. One result was recommendations to the state legislature, described in a report in the peer-reviewed *North Carolina Medical Journal*, in an issue on patient-provider communication (www.ncmedicaljournal.com/sep-oct-07/holmes.pdf).

> *"An individual with a foot in both the health and literacy worlds can be a very effective champion in a partnership."*

Challenges faced by the task force included the commonly-cited issues of getting busy people to come to regular meetings, and getting people from different fields to see the value of the work. But the task force found that these issues were manageable, and in fact members of the task force quickly seemed to see the worth of the interdisciplinary approach.

The North Carolina task force reveals the significance of inter-sector communication in a number of ways. The task force did build better relations between members of the health and literacy fields, including a better understanding of how each field can benefit from the expertise of the other. According to one task force member with experience in adult literacy and health, the medical professionals in particular were surprised to learn how much the adult educators could do for them in terms of guidance in how to reach their patients and making recommendations for clear language. The process of using adult literacy students, with teachers' support, in piloting health educational materials was built into the recommendations of the task force, as was the allocation of funding for this process.

Via policy recommendations, the task force highlighted to legislators and the broader medical community in the state the important role of adult literacy students as a pool of people from a much sought-after target audience of underserved health consumers. Furthermore, the task force publicly recognized the role literacy teachers can play effective liaisons between the health field and this target audience.

While the impact of the recommendations to the legislature still remains to be seen, the task force has seen participant agencies put the issue of health literacy into the public arena, while at the same time reinforcing relationships with funders and researchers. These relationships may lead to future projects. One goal is to bring some of the health partners, including researchers, to the next annual state adult basic education conference in order to discuss health literacy.

Wisconsin

Wisconsin's collaboration began with an individual who noticed a problem, researched it informally, and decided the first step would be to bring together professionals from a variety of disciplines and explore their mutual health literacy challenges and ideas for addressing them.

In 2003, Dr. Paul Smith was in a unique position from which to initiate such a gathering. As a family physician, he was faced with the challenges of health literacy in his practice, and threw himself into the task of finding a way to address them. He was also the director of a medical research network, the Wisconsin Research and Education Network, and in this capacity was charged with creating and promoting research. He did a Web search and connected with Wisconsin Literacy, a coalition of adult, family, and workplace literacy providers. He joined their board of directors and worked

with them in planning an initial Health Literacy Summit in 2004. They brought together 120 professionals from literacy and health agencies from around the state to explore ways that they could collaborate in trying to deliver more effective health care to lower literate patients throughout the state.

Dr. Smith continued to work with Wisconsin Literacy and got funding from the American Academy of Family Physicians to do a series of focus groups with English for speakers of other languages (ESOL) and adult basic education (ABE) students to learn about their experiences and challenges with the American health system. This allowed Dr. Smith, a physician and researcher, to be involved on a personal level with adult learners and really understand their needs and points of view. His role as facilitator of these focus groups allowed him a level of interaction that is not possible in clinical encounters because of time constraints and other factors related to patient-provider interaction.

The focus group project also allowed Dr. Smith to learn from literacy teachers about their methods of reaching adult learners. This was a new aspect of the literacy-health partnership, which had mostly been centered around the concept of health professionals "helping" literacy teachers to teach health information. Here was an example of literacy learners "helping" the medical and research community to understand their needs, and literacy teachers helping the health community to learn effective methods of instruction.

In 2007, this partnership planned a second summit to report the results of these focus group studies and find new ways to continue health literacy work in the state. The medical community came out in droves to support the effort. "There are more partners out there who are interested in collaborating with literacy programs than you can even imagine or find the time to cultivate," says Michele Erikson of Wisconsin Literacy.

It seems that everyone they approached was interested in participating, and they had representation and financial support from the Mayo health system, Wisconsin Hospital Association, the National Institute for Literacy, Metastar Health, Proliteracy, the Wisconsin Newspaper Association, and private health care providers. With so many interested partners, they had a great opportunity to build further collaborations, and they made good use of it.

The summit included breakout sessions during which participants from the four regions in Wisconsin met to plan how to engage in projects in their regions based on the partnerships formed at the summit. The fundraising for the summit had been so successful that there was seed money for the continued work. Committees were formed and went on to plan projects that included awareness raising activities, surveys to further assess needs, and projects to train health care providers and literacy students in using the AskMe3 program, which is designed to encourage patients to ask questions at their medical appointments (see www.askme3.org).

At the summit, Dr. Susan Levy presented her research that demonstrated that using health literacy curricula not only improves students' health knowledge, but also enhances the acquisition of literacy skills (see page 33 for more on this research). This research was showcased to encourage partnerships that support adult literacy. The positive research findings addressed adult literacy practitioners' concerns that time spent on health topics might slow their student's development of literacy competencies. Health community participants realized that the collaborating with literacy providers can help to improve literacy skills in their state, which may in turn result in better health outcomes.

The partners in this collaboration all agree that it took a lot of work. With very little initially in the budget, they spent countless hours on the phone and in meetings. Much of it was accomplished "by force of will," according to Erikson. However, that force was pretty strong, and they found that people were more willing than they expected to be involved. At one point, there was so much excitement and momentum that Erikson found herself needing to be careful not to neglect other aspects of the literacy program.

Despite the challenges, the state has a lot to show for these efforts. The four regions of Wisconsin now each have their own working task force, each of which is working within their local area to raise awareness of health literacy issues, develop programs to address the issues, and raise funds to support these programs.

New York

New York's literacy and health partnership began in an unusual way, in the mayor's office. Anthony Tassi, who was at the time the deputy mayor's health policy advisor, realized that a large number of the city's uninsured residents were sitting in adult literacy classes. So in 2002 he approached the Literacy Assistance Center (LAC), an organization dedicated to supporting adult literacy services in New York City. Of the 60 literacy programs funded by the New York State Department of Education, those in New York City serve two-thirds of the state's adult literacy students. Mr. Tassi's original plan was to get the LAC's help in creating a Health Literacy Resource Center, which could help connect adult literacy students with health services. However, a more ambitious health literacy project emerged from the partnership.

The LAC at the time was looking for a new model of professional development for literacy educators, and had also been exploring a new model of addressing health literacy based on teaching communication and access skills rather than health content. As they were exploring the goal of connecting students with health services, they discovered the new *Health*

Literacy Study Circles from the National Center for the Study of Adult Learning and Literacy (NCSALL, see www.ncsall.net/index.php?id=25) and decided to pilot them instead of creating the health literacy resource center. The study circle approach involves training literacy teachers to include health in their curricula by partnering with local health agencies. The four pilot programs involved did so, but deepened the partnerships beyond the usual roles of guest speakers, advisors, and providing a target population. For example, the Mid-Manhattan Literacy Center met with the heads of each department at Harlem Hospital to get an overview for the students of what the departments do. The students were taken on tours of the hospital and ultimately gave feedback to hospital administration on how to improve the signage to make it more accessible for patients with lower literacy skills. Students pointed out that many medical departments were named after a person, and the person's name was prominent on the sign rather than what that department did.

This partnership between the Mid-Manhattan Literacy Center and Harlem Hospital, which grew out of the partnership between the NYC mayor's office and LAC, enhanced the role of literacy students in informing health center policy. Now they were valued as "wayfinding" advisors in addition to pilot testers of written educational materials. It also brought another important realization to the medical community. By including adult literacy programs and learners not only in their outreach efforts, but also in their policy decision-making, the hospital improved their image in the community.

What emerged from the original partnership was a more ambitious project than the health literacy resource center, which was its original goal. The LAC Health Literacy Initiative has become a leader in partnering between health and literacy organizations, and has even developed a guide called: *Healthy Relationships: A Guide to Forming Partnerships between Health Care Providers and Adult Education Programs* (www.lacnyc.org/resources/healthlit/Health.pdf). This guide is only a part of a training program that the LAC offers to health professionals, in which they use the expertise of adult educators to train health care providers in effective communication with lower literate patients and the development of appropriate educational materials. They also continue to provide professional development to literacy teachers to address health literacy with a skills-based approach, helping students acquire the tools to access health care, communicate with providers and advocate for their health needs.

A spin-off of the partnership between the LAC and the deputy mayor's health policy office is another example of the health field's acceptance of adult literacy programs as vehicles for their own education. Anthony Tassi was sufficiently convinced of the literacy field's contribution to health literacy that he went on to create Health Literacy Fellowships for medical students. (See the cover article for more on the fellowships.)

Lessons

Bringing together professionals from both the health and the literacy fields and charging them with a mutual set of tasks is an effective first step in creating opportunities for further partnerships. Mixing the health and literacy fields creates a mutual familiarity and respect for each other's expertise that does not occur without some sort of catalyst. Once the partners have this familiarity and respect, they have greater willingness and ability to find concrete ways to help each other.

An individual with a foot in both the health and literacy worlds can be a very effective champion in a partnership. This can be someone who has experience in both fields, connections with professionals or policy-makers from both fields, or simply a passionate belief in what these two fields can offer each other. A champion is often the driving force behind a project, attracting other advocates who help ensure that the partnership accomplishes its tasks.

> *"One project often leads to spin-off projects, deeper relationships, and more sources of support for health literacy efforts,..."*

One project often leads to spin-off projects, deeper relationships, and more sources of support for health literacy efforts, including financial support and community buy-in. The result is mutually beneficial for all.

By partnering with adult literacy programs, health agencies not only find an eager pool of underserved health consumers but also receive guidance in communicating with them more effectively. They gain a venue in which they can easily pilot-test materials and programs with their local target population.

By partnering with health agencies, adult literacy practitioners are better able to serve their students by giving them meaningful life skills, and by connecting them with real health resources in their community. As a further boost to students' confidence and self-advocacy skills, some partnerships also allow them to inform the delivery process of the health services they are learning to access. *continued on page 30*

The students, of course, benefit in many ways. They are more motivated and engaged in learning literacy and English skills, allowing them to participate more fully in a variety of life-improvement goals. They are called upon as health consumers to advise efforts at communication and service delivery. And ultimately, they can improve their overall health by having the skills, confidence, and connection to their community services to use these services to help them stay healthy. Not just adult literacy or English language students, but everyone trying to take care of their health in this complicated world can benefit from these partnerships.

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About the Author

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Collaborating for the Health of San Diego County

by Kelli Sandman-Hurley & Chris McFadden

Whether they know it or not, the health of San Diego County, California, residents is a concern to Community Health Improvement Partners (CHIP), a 12-year-old coalition of San Diego health care systems, hospitals, community clinics, insurers, physicians, universities, community organizations, and the County of San Diego that has evolved into a formal organization. A needs assessment CHIP conducted in 2007 indicated that health literacy was a concern, particularly as it related to the health of individuals served by San Diego's healthcare safety net, a patchwork of systems that provides health care to low income, un- and under-insured, and other vulnerable populations. So CHIP approached the San Diego Council on Literacy (SDCOL) to discuss a partnership to address health literacy needs in San Diego County.

The San Diego Council on Literacy provides leadership and support to a network of more than 20 literacy programs that serves about 70,000 adult learners annually. SDCOL convened an initial meeting of 12 literacy programs and learned that health was a concern for literacy learners and health literacy was a concern for San Diego literacy programs. With the assurance that literacy providers were invested in the issue, CHIP and SDCOL began to explore approaches to improving health literacy in the county.

A first stop was the Health Literacy and Patient Safety Conference held in Chicago. Representatives from CHIP and SDCOL, funded by a San Diego health care organization, attended and were struck by both the amount of information available and the lack of participation of literacy professionals. It was as though the healthcare field was trying to solve the health literacy problem without input from the literacy field. CHIP and SDCOL staff agreed that their efforts to create a health literacy plan for San Diego Country would involve equal input from both fields.

Shortly after the conference and with renewed commitment to the newly formed partnership, SDCOL and CHIP approached Kaiser Permanente for funds and received from them a planning grant that allowed them to hire two consultants: Michel Moder with expertise in health care and market research and Kelli Sandman-Hurley with experience in literacy. It was their job to conduct a literature review, examine best practices in health literacy, define the target population, and recommend an implementation plan. It was an ambitious agenda for the five-month time frame they were given.

Defining Health Literacy

From the beginning, Moder and Sandman-Hurley knew they had to educate each other about their respective fields. Their first task was to determine what definition of health

literacy to adopt. They started with the U.S. Department of Health and Human Services' 2000 definition:

"Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."

They added to it writing, listening, speaking, arithmetic, and conceptual knowledge in addition to reading skills and the idea that health literacy is the responsibility of both the individual and healthcare systems.

Developing a Common Language

At the start, the consultants met a few times simply to figure out if they could agree not only on the vocabulary they were going to use, but also on the target population and the way they would go about gathering our information. After much discussion, they slowly began to comprehend each other's perspectives. Throughout the process, their work was informed by an advisory committee comprised of healthcare and literacy professionals. The advisory committee had to go through a process similar to that which the consultants experienced: getting to know each other, understanding health literacy issues from both perspectives, and developing a common language and mutually acceptable set of objectives.

The Local Situation

Sandman-Hurley and Moder surveyed San Diego adult literacy practitioners and learned about what literacy programs were doing in regards to health literacy and what they would like to do in the future. The consultants conducted two focus groups of adult learners for a total of 22 learners who read at or below the third grade level. The focus groups were held in English. What was most striking was not what learners said during the focus groups but how they said it, the consultants reported. The learners seemed very angry. They told stories of loved ones who had life threatening emergencies and were not given needed information because they could not read the forms. They reported signing consent forms they could not read. They reported checking off "no" to almost all questions on forms. They reported that they felt that medical office and emergency room front desk staff did not have the sensitivity or training needed to help them. They explained that they bring along friends and family to help them understand physician's instructions. They described their encounters with the medical world as embarrassing.

The learners gave the consultants some ideas for solutions. They asked for advocates to be in the waiting rooms to help them with forms and questions. They asked for help with medication instructions. Many asked for more classroom instruction to prepare them for visits to the doctor.

The consultants held three separate focus groups of healthcare providers, one for physicians, one for promotoras (community health workers), and one for front office staff. The seven physicians who participated were already involved in health literacy at some level. They warned against creating another "initiative" and were wary of duplicating existing health literacy efforts implemented in other programs or cities. They suggested disseminating information about health literacy via continuing medical education.

During the promotoras focus group, which was conducted in English, three themes emerged. The first was that for the Latino/ Spanish speaking population the physician plays a critical role in health-related decisions. The second theme was community members' connection to physicians in Tijuana. Due to San Diego's proximity to Tijuana, promotoras explained, it is common for some Latinos to visit physicians there. They went on to report that they feel this migration is often a result of American physicians tendency not to sit down with their patients to discuss their health issues. Last, promotoras reported receiving little or no formal training on how to handle health literacy issues among the population that they serve.

In the focus group held with front office staff from three community health centers, participants reported that medical language and terminology used by physicians and staff is too complex for patients to understand. They also reported that they felt that they have received little training on how to help patients with low literacy and low health literacy, and that consent forms are complex and require a high level of literacy to understand.

The Report

The outcome of all this activity was a report, *When Words Get in the Way: A Collaborative Plan to Address Health Literacy in San Diego*

County. The report includes a literature review, information about health and literacy resources in San Diego County, focus group results, and an implementation plan which SDCOL and CHIP will work together to implement. The underlying theme in all the recommendations is cross-training. The plan recommends that literacy professionals train healthcare professionals to identify and help low literate patients, and that healthcare professionals train literacy professionals about what is required of patients in health care settings.

The implementation plan includes the following specific recommendations, designed to build upon each other:

- Establish, through the leadership of CHIP and SDCOL, a joint taskforce of literacy and healthcare professionals to champion the awareness of health literacy in the San Diego community. This taskforce will ensure that the remaining recommendations are completed and/or funded.
- Identify and/or create health literacy curricula that will focus on health related vocabulary and paperwork for inclusion in adult literacy courses and healthcare settings. This curricula will be adapted for use in short workshops for patients in the healthcare setting, such as a community clinic.
- Create a SDCOL and CHIP sponsored Web site that would include resources and referrals for adult literacy and healthcare professionals as well as increase awareness.
- Develop appropriate methods, tools, and policies to help medical organizations train their front and back office staff to better understand and interact more effectively with low literacy and low health literacy adults.
- Increase awareness of low literacy and low health literacy issues within the healthcare community.
- Develop and implement a pilot program utilizing trained volunteers on-site in the healthcare setting to work as advocates for low literate patients.
- Create a marketing campaign whose target audience and content will be identified after the previous steps are completed and reveal where the need for marketing needs to be focused.
- Implement health literacy sharing forums among healthcare professionals, adult learners and adult literacy professionals.
- Investigate the inclusion of multimedia formats to improve the health literacy of San Diego County adults.

The report has been well received by San Diego literacy and healthcare professionals and has prompted many to ask how they can become involved.

Implementation Begins

The health literacy project in San Diego County is moving forward. The boards of both CHIP and SDCOL have endorsed the committee's efforts and are committed to helping. The original team has made numerous presentations to policy makers and stakeholders such as the Literacy Network, the Council of Community Clinics, the San Diego Diabetes Coalition, and South Bay elected officials.

A health literacy taskforce has been constituted with representatives from literacy, universities, hospitals, CHIP, SDCOL, public relations firms, elected officials, community clinics, health care plans, the county health department, pharmacies, and physicians. Its role is to advise, prioritize, and help CHIP and SDCOL roll out the health literacy report recommendations, identify funding sources and opportunities, review and adapt curriculum to meet the needs of learners, coordinate activities, and participate in working groups. The taskforce members will create small groups based on the interests of members. The groups will be in the areas of (1) development and implementation of a health literacy curriculum, (2) design and implementation of the pilot program at a community clinic, (3) frontline medical staff training, (4) communications including Web site development, and (5) resource development. Non-taskforce participants will be invited to participate in the working groups.

"...staff agreed that their efforts to create a health literacy plan for San Diego County would involve equal input form both fields."

In April, the taskforce hosted a preview of the health literacy curriculum developed for a five year research study and now being published by the National Institute for Literacy (see page 33). Literacy and health care professionals attended.

Lessons Learned

In any project such as this, many lessons are learned. The time it took to complete the project was underestimated. The project was originally planned to start in February 2007 and end in June 2007 but the final report was actually published in January 2008. It took more time than anticipated to come to a consensus on whom the implementation plan should target and what should be recommended. For example, the discussion on whether or not to include senior citizens as a targeted group spanned three meetings.

Creating a health literacy partnership between literacy and the healthcare field has been a complex and complicated endeavor. Participants had to learn each other's vocabulary, priorities, and challenges. The time it took to accomplish what was only a first step was more than anticipated but the opportunity to make a difference and improve the health of all in San Diego County was worth the effort.

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WORLD EDUCATION

Health Literacy Curriculum Works for Adult Basic Education Students

Research Findings

by Susan R. Levy, Sue Pinzur Rasher, Sarah Deardorff Carter, Lesley Maradik Harris, Michael L. Berbaum, Janice B. Mandernach, Laura Segal Bercovitz, & Laura Martin

The inability of patients to understand and act on health-related material has negative consequences. Patients with low literacy are more likely than their literate counterparts to report poor health status, have difficulty understanding prescription directions, suffer adverse health outcomes, and receive incorrect diagnoses due to communications problems with health care providers (Ad Hoc Committee on Health Literacy, 1999; Baker et al., 1998; Weiss et al., 1992). Adults with low health literacy experience four times the annual health care costs of those with high health literacy and cost the health care system in excess of $73 billion per year (American Medical Association Foundation, 2007; National Academy on an Aging Society/Center for Health Care Strategies, 1998). Participants in adult basic education (ABE) and classes of English for speakers of other languages (ESOL) are at greater risk than the general U.S. population for potential health problems.

A partnership of adult literacy educators, curriculum planners, and university researchers came together in 2002 to design a research project that would test whether the health knowledge and health care access skills of adults with limited literacy would improve while they were also developing their literacy skills if both sets of skills — literacy and health — were addressed simultaneously via one curriculum. During the study, more than 50 ABE sites across Illinois were randomly assigned to experimental or control conditions, teachers at each site received training, and teachers tested the newly-created health literacy curriculum for effectiveness. Eventually, 42 of the more than 50 sites across the state were used in the study. More than 2,000 adults from ABE (equivalent to grade levels 0 - 8.9), adult secondary education (equivalent to grade levels 9 - 12), and English for speakers of other languages (beginning, middle, and high levels) classes participated.

Curriculum and Implementation

Our research team of experienced adult literacy educators and curriculum planners knew that ABE teachers often include some sort of health information as a topic in their classes. However, few implement health topics in consistent ways across sites and at different levels of student literacy ability. To conduct a research study

using multiple sites, we needed to develop a curriculum that integrated health information and skills with the activities needed to increase literacy suitable for the full range of adult student skill levels.

The health field offers almost limitless topics to study, but class time is limited. To ensure that the health information and skills included in the curriculum were of high priority to both the learners and to health providers, the curriculum team convened a panel of national health experts to discuss what health providers see as needs in working with low literate populations. The expert panel brought together six adult education and ESOL teachers, representatives from the Illinois Department of Human Services, the American Medical Association, pharmacy, dentistry, hospitals, and socials work, as well as the curriculum planners and the researchers. Input from students was incorporated after a pilot phase. The topics which were prioritized are shown in Table 1. Examples of the literacy skills embedded in the curriculum and emphasized in different literacy skill levels through health related activities are in Table 2 (see page 35).

Table 1: ***Health Literacy Curricula Objectives***

No.	Objective
1.	Describe what different health professionals do.
2.	Identify where to get health care.
3.	Describe the differences among preventive, self-, non-emgency, and emergency care.
4.	Describe activities in practicing the continuum of health care from preventive to emergency care.
5.	Describe how to talk to health professionals about health needs for self and family.
6.	Create a family history including self-history, medication record, and immunization record.
7.	Identify patient responsibilities regarding payment for health services.
8.	Identify the types and duration of moderate physical activties that one needs to do to help one's body stay healthy.
9.	Create a plan to maintain or increase one's level of physical activity to meet the recommendations for moderate physical activity.
10.	Describe which foods to eat to stay healthy.
11.	Describe how to plan and prepare healthy meals.
12.	Identify safe and dangerous practices with drugs.
13.	Describe changes people can make to become healthier.

This experimental health literacy curriculum was used for 42 classroom hours. The control sites used their own literacy activities and curricula as their standard practice. To eliminate teacher training as a variable, all teachers — control and intervention — received teacher training including an overview of the project and an overview of teaching methodologies and best practices. In addition, teachers from control sites received training in methodology in a non-health-related content area, and the teachers teaching the health curriculum received an orientation to the curriculum. The total training time was five hours for the control sites and seven for the experimental sites. All sites received compensation to offset increased paperwork.

The final challenge was to evaluate whether the curriculum enabled the teachers to teach the health information in a way that effectively increased the learners' priority health knowledge and abilities to navigate through the health care system. This was done in two steps. The first ensured curriculum fidelity across the multiple levels of literacy in which the curriculum was to be used and

Defining Literacy

While investigating the two different "worlds" of adult literacy education and health literacy, we noted different interpretations of the idea of literacy or what it means to be literate. Both worlds may think they are communicating well with each other, but in reality they may be hearing different messages. Health care professionals and providers generally take a narrower view of the relationship of health literacy to overall literacy. They are interested in "ability to read, understand, and act on health care information" (American Medical Association [AMA], 2002). Adult education professionals define literacy more broadly as "an individual's ability to read, write, and speak, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals and develop one's knowledge and potential" (National Literacy Act, 1991). A third world also became clear to us when we were more active in the field and met many populations of adult education students. We found in our work that adult education students often regard "literacy" as being able to "pass the GED". All these views were important to us, as we felt strongly that our research must first and foremost fit the needs of classroom participants. Then hopefully each view might enhance study outcomes, including literacy and health, in the everyday lives of people as well as leading to satisfying, successful research for us.❖

Table 2: ***Examples of the Literacy Instruction Taught in the Seven Instructional Levels of ABE, ASE and ESOL***

HEALTH INSTRUCTIONAL COMPONENTS	LITERACY OR ENGLISH LANGUAGE SKILLS	ADULT LITERACY INSTRUCTION ABE B = Literacy/Beginning Level I = Intermediate Level A = Advance Level and ASE	ESOL B = Literacy/Beginning Level I = Intermediate Level A = Advance Level
Pictures	Oral Language	B, I, A	B, I, A
	Vocabulary Development	B, I, A	B, I, A
	Writing	B, I, A	B, I, A
Picture Sequence for Story Development/ Group Story	Oral Language	B, I	I
	Phonemic Awareness	B, I	I
	Phonics/Word Analysis	B, I	I
	Sight Word Recognition	B, I	I
	Fluency	B, I	I
	Sequencing/Organizational	B, I	I
Picture Sequence for Story Development/Individual	Sight Word Recognition	A, ASE	A
	Fluency	A, ASE	A
	Sequencing/Organizational	A, ASE	A
Context-Based Text (Curriculum Reading Passage, Health-Based Articles)	Word Analysis	B, I, A, ASE	I, A
	Fluency	B, I, A, ASE	I, A
	Reading Comprehension	B, I, A, ASE	I, A
Vocabulary Exercises	Lexicon Development	B, I, A, ASE	B, I, A
	Word Analysis	B, I, A, ASE	B, I, A
	Semantic	B, I, A, ASE	B, I, A
Comprehension Check	Constructing Meaning From Text	B, I, A, ASE	B, I, A
	Critical Thinking	B, I, A, ASE	B, I, A
Dialogue	Oral Language/Grammar		B, I
	Socio-lingual		B, I
Role Play	Oral Language/Grammar	B, I, A, ASE	I, A
	Social Interactions	B, I, A, ASE	I, A
	Critical Thinking	B, I, A, ASE	I, A
Cultural Histories	Oral Language	B, I, A, ASE	B, I, A
	Writing	B, I, A, ASE	I, A
	Critical Thinking	B, I, A, ASE	I, A
	Diversity Awareness	B, I, A, ASE	I, A
Authentic Writing (Simplified Realia)	Reading	B, I	B, I
	Writing (e.g. letters, forms)	B, I	B, I
Authentic Writing	Reading	A, ASE	A
	Writing (e. g., forms)	A, ASE	A

established the number of times a skill or literacy topic was addressed and practiced. This involved developing a matrix of curriculum activities by lesson in each of the levels of curriculum and confirming that topics were covered adequately in each curriculum level. This comprehensive content analysis also served as the basis for the second step. We needed an evaluation instrument which could measure knowledge acquisition as a result of our intervention as well as measure some of the skills and health behavioral intentions we were trying to teach within the health topic areas of the curriculum. We created, piloted, and validated a health literacy instrument which directly related to our curriculum and its content. Established literacy standardized measures required by the state of Illinois, the Test of Adult Basic Education (TABE-R) for native speakers, BEST Literacy and Combined English Language Skills Assessment (CELSA) for English language learners, were used to measure literacy gains.

Sample at Pre-test by Health Knowledge and Literacy Level

The pre-intervention literacy scores and literacy levels of participants were gathered by researchers at the 42 sites. Literacy scores were the scores generated by the standardized tests administered by the sites in order to meet Illinois testing requirements. These scores were also used to investigate whether a participant's literacy level had a relationship to health knowledge, skills, or intentions before the intervention as measured by our health literacy instrument. The literacy scores and the health knowledge scores were measured again at the end of the 42-hour intervention to assess if, and how much, change in knowledge and behavior could be attributed to the intervention. The original participant literacy levels and health knowledge scores were used to generate the information in Table 3, which displays the breakdown of the health knowledge portion of the Health Literacy Assessment instrument by literacy level for the adult basic and secondary education students and English language level for the ESOL students. The health literacy tests were read to students at all levels to insure that the assessments were testing health knowledge rather than reading levels. Mean scores on the health literacy knowledge portion of the assessment were relatively low at pre-test for all literacy levels. Table 3 shows the direct relationship between literacy level and health literacy in fundamental survival-type health knowledge as measured by major constructs in our health literacy assessment instrument. It is directly indicative of the health vulnerability of anyone, ABE or ESOL, who is low literate. As the literacy level rose, so did the overall health knowledge scores. The highest health knowledge score possible was 24. In data not shown here, males (specifically the lowest literacy level ESOL Hispanic males, who heard the test once in English and once in Spanish) were the adults at greatest risk both in literacy level and health literacy knowledge at pre-test. These men scored a total mean of 9.1 items correct, making them the lowest scoring group within all literacy levels, whether native or foreign born. Their scores were lower than all females at any other literacy level as well. They were by far the highest risk group in knowledge of the health care system and its utilization.

More information regarding the adults in the study is displayed in Table 4, Demographics by Literacy Group and Primary Home Language. A major

Table 3:
Waves 1-5: Mean Pre-Test Health Knowledge Scores

Pre-test Literacy Level	N	Mean	SD
ABE			
Literacy/Beginning	63	10.82	3.60
Intermediate	284	14.04	3.54
Advanced	75	16.76	3.49
ASE	80	18.56	2.78
ESOL			
Literacy/Beginning	494	9.42	3.37
Intermediate	431	11.17	3.67
Advanced	141	13.60	3.73
TOTAL	613	11.94	3.73

Table 4:
Waves 1-5: Demographics by Literacy Group

Primary Home Language	ABE/ASE		ESOL	
	N	%	N	%
English	552	94.4	13	1.0
Spanish	26	4.4	1069	80.9
Other	7	1.2	240	18.2

trend became apparent. The growing number of adults participating in our classes who were not born in the United States and who live in homes where languages other than English are also spoken are the largest (and growing throughout the study) part of the study population. In data not shown, approximately 75 percent of all the adults who participated in the study are female. The 240 students in the ESOL "other" category represent several Asian and European immigrant groups.

Another important observation relating to the characteristics of the participants in this study was the difference in numbers of students represented in each literacy level (beginning, intermediate, and advanced) for adult basic education/adult secondary education (ABE/ASE) classes versus ESOL classes. The ABE/ASE group had more adults in the intermediate levels moving towards ASE (and the GED), while ESOL had more adults within the basic and intermediate range with very few in the advanced range (data not shown). This fact became essential when we began to interpret the outcome data and explore trends: which participants completed the curriculum and study, who dropped out, and who were the most successful in achieving greater health literacy and general literacy after the 42 hours of classroom instruction.

Major Results

The key overall result in terms of literacy is that participants in classes that used the curriculum developed for this study (experimental group) increased their literacy scores at least as much and usually more than those participants in "common practice" classrooms (control group). In no group (ABE/ASE or ESOL) or literacy level was the experimental classes' students' improvement less than those of the control students. This is heartening because as we mentioned, we provided training to all the teachers to try to ensure that the teachers' skill levels were as much the same as possible. We were testing the efficacy of the curriculum rather than the talent and skills of the teachers.

None of the students in either the experimental or the control group were able to advance through an entire literacy level (as tested by the required standardized tests) within the 42 classroom hours. Six years ago when we began our study, Illinois tested adults with the standardized tests of literacy after a minimum of 35 classroom hours, thus dictating the approximate hours we felt our curriculum could contain and still reasonably test success in a realistic situation.

The health literacy impact of the study was more dramatic in its success. The adults significantly improved their health knowledge and skills in every literacy level in ABE and ESOL through the experimental curriculum. The participants in the control sites had no change in the health knowledge/skills acquisition after 42 classroom hours of regular "as offered" classes. This was somewhat surprising as we knew many of the adult control site classes also taught health information in their programs. We also knew that health literacy information has always been an important topic in ABE and ESOL, and that adult students in the higher literacy levels had probably covered some of the major issues in previous classes.

Discussion

We believe that this scientifically-based literacy research study adds evidence of the success and value of a curriculum based on specific objectives, laid out with prescribed, timed activities and content including teacher training in the field of adult education. While comprehensive data analysis investigating our research hypothesis is still underway, we will discuss some important process and initial findings here. This study demonstrates that the needs and usage of important health information and life skills, such as navigating the health care system in the United States, differ

by major literacy group (ABE/ASE versus ESOL). All levels of the ABE/ASE group self-reported greater competency and greater confidence in using health care at pre-test than the ESOL group. This may be because these students had more hands-on life experience with the U.S. health care system. Even with this greater pre-test difference, students in the experimental group were able to make gains in knowledge, efficacy, and intention changes by the post-test, narrowing the gap between them and the ABE/ASE students and still scoring significantly better than the control group. Although the most vulnerable intervention group, Hispanic males, remained lower at post-test than the other intervention groups, they did advance and attained scores significantly higher than the control group at the same literacy level. At post-test there was again a direct and progressive association between literacy level and health knowledge, intentions, and self-efficacy. As the level of literacy increased (i.e., beginning to intermediate, intermediate to advanced), so did student scores in both literacy and health, showing success of the intervention. The intervention moved the progressive association in a positive higher direction at all levels. The health-related scores showed a greater increase than the literacy scores in the same time period, indicating that the literacy deficits probably need more instructional time to move levels. The positive news is that adults with low literacy levels can master the health content and health competence at a greater speed than general literacy skills when the skills and information are presented in a well-planned literacy program. We observe from our research that the lower levels of literacy need more than 42 hours of classroom literacy instruction to be expected to progress to the next literacy level.

State and national policy regarding adult literacy education should reflect that the curricula and content focus for lower literate adults in ABE and ESOL programs differ because of the needs and emphasis the individuals bring to the classroom. Students in ABE/ASE higher level groups focused solely on passing the GED. If students viewed anything as not contributing to doing well on the test, they saw it as irrelevant to their needs. We found, however, no comparison with the ESOL group, and in fact, attendance was better in almost all literacy levels for ESOL. The higher-level beginner and all intermediate levels had the most stability out of all the programs. As discussed previously, males (especially ESOL Hispanic males) scored lower than females across all levels. As a result, adult literacy education policy should also focus on ways to both recruit and retain males, especially Hispanic lower literate males, into adult literacy programs. This would eventually provide large potential gains to all program outcomes.

The needs of the research design required that we offer our curriculum in a format which kept the health units in a continuous 42-hour course, replacing the literacy portion of whatever the current adult education content would have been in all the experimental sites. After observing the curriculum in the field and with continuous and outcome feedback from the adult education teachers, we would now recommend that the 42 hours be integrated and interspersed with other topics and not as concentrated as it was for the research study. This strategy might keep adults more interested in the content, even those who may have had some health material previously. In any case, it is likely that extra time and topics would benefit literacy scores on the standardized tests and perhaps cause scores to progress up a level.

"We believe that this scientifically-based literacy research study adds evidence of the success and value of a curriculum based on specific objectives, laid out with prescribed, timed activities and content including teacher training in the field of adult education."

While this study was a practical pursuit to fill a need in the world of literacy for adult education, as well as a serious intellectual pursuit answering research questions, the outcomes point loudly to the situation that low literate adults will continue to be a population at great risk for poor health outcomes unless there is strong and continued intervention. Our program was able to generate positive results in a relatively short period, however, there is far greater room for continuous and necessary positive improvement in all health and literacy outcomes. Since health and literacy outcomes are so entwined, both must be addressed to cause change in the future vulnerability of these adults and their families. We need to learn to bridge the divide between the understanding of health literacy in the health care community and the adult education community to begin to change the overall health of our adult population. Low literate

adults, whether in ABE/ASE or ESOL programs, have been shown to be able to master content in realistic health content and realistic health vocabulary. Therefore, policies supporting sustained, planned, and practical health and literacy curricula in adult education programs have the potential to benefit all.

Finally, it is with great pleasure and anticipation that we are able to announce that the National Institute for Literacy (NIFL) has supported the development of an online version of our curriculum for beginning ABE with an original teacher training manual to accompany the curriculum. These materials, which have themselves been piloted in Georgia, should be available in Fall 2008 through the NIFL Web site at www.nifl.gov.

> *"The positive news is that adults with low literacy levels can master the health content and health competence at a greater speed than general literacy skills when the skills and information are presented in a well-planned literacy program."*

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WORLD EDUCATION

The Role of Visuals in Communicating Health Information to Low Literate Adults

by Lilian H. Hill

Many materials intended to communicate with patients are written well above the average reading ability of American adults (Baker et al., 1996; Estey et al., 1994; Kutner et al., 2006), and may be more meaningful when they are written at or below the fifth grade reading level (Mansoor & Dowse, 2003). Some research indicates that even this may be too difficult for up to one-fourth of the U.S. population. Andrus & Roth (2002) state that many "patients, regardless of literary level, prefer simple, easy-to-read materials" (p. 294). Mayeaux and colleagues (1996) describe a test performed to see which of two patient education brochures patients preferred: one written at sixth grade level or one at 10th grade level. Even highly educated patients chose the sixth grade version. With difficult reading materials, the captions of diagrams may be all that low literate patients will attempt to read. Low literate patients may take information out of context, skip over words, and become easily tired and frustrated.

Many sources and studies have promoted the idea of making literature user-friendly. Trying to simplify materials intended to communicate with patients about health issues without compromising meaning can be challenging. Initially the focus was on patients' reading ability and consequently the reading level was lowered. Youmans and Schillinger (2003) argue that "information sheets written at grade 5 level may be readable by more patients, but may not improve a patient's comprehension of the written words or alter behavior" (p. 1727). Little documentation is available to indicate that simplified versions have been useful, particularly to those with the lowest health literacy.

Enhancing Written Materials

Given the serious consequences of low health literacy, better methods of communication must be found. One possible way to enhance written patient education materials is to include pictorial images, or visuals, to support the communication of health information. Researchers worldwide have explored the use of visuals to communicate health information to low literate patients (see Houts et al., 2006, for a comprehensive review of the research on how pictures affect patients' comprehension, recall, and adherence).

Patients prefer attractive simple materials and "most people, even those who read well, rely on visuals to reinforce learning" (Facts about Health Literacy). Visual aids can include cartoons, illustrations, pictograms, posters, photographs, or even photonovels where text and cartoons are combined, much like a comic book. Visuals provide interest and meaning to the written word and can aid comprehension, recall, and even adherence. People with low health literacy develop sophisticated coping strategies. They pay more attention to visual cues and verbal messages to compensate for their lack of reading skills (Baker et al., 1996). Mansoor and Dowse (2003) suggest that, "if well designed, pictograms have the advantage of being understood faster [and] remembered longer" (p. 1004). Some evidence indicates that people more easily retain pictorial information than written information.

Recommendations for Using Visuals

Recommendations found in the literature indicate that simple, realistic pictures with limited content and familiar objects and symbols communicate well (Figure 1). Illustrating body parts in context is also helpful. For example, an illustration of a complete face is less confusing than an isolated facial feature (Figures 2 and 3). A good practice is to use graphic elements such as color, bullets, highlighting, bolding, text size, arrows, and/or white space to lead the reader's eye to the most important points. Visuals used should reinforce the message conveyed by the text and closely accompany relevant text. One study found that when only some instructions are accompanied by pictures, patients only attended to the illustrated instructions and skipped over others (Sojourner & Wogalter, 1998).

Figure 1: Illustration of women walking for exercise

Figure 2: USP Pictograms for "Place drops in ear"

Figure 3: USP Pictogram for "Place drops in nose"

Pictures should be concrete and portray realistic scenarios. For example, photographs or illustrations of real people (Figures 4 and 5) may be preferred to abstract symbols (Figure 6). Caution should be used when employing abstract symbols, especially symbols depicting motion, time, and causality.

Figure 4: Woman eating healthy meal (photograph)

Figure 5: Woman eating healthy meal (illustration)

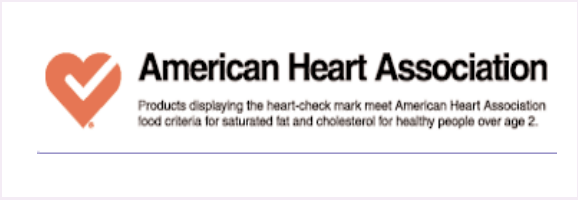

Figure 6: American Health Association Heart-Check Symbol

Mathematical symbols and graphics containing numbers may be misunderstood (Weiner et al., 2004). Multi-stage pictures suggesting a sequence of activities also require careful thought (Figure 7). Pictures included for decorative purposes and unnecessary details not directly related to the intended message should be omitted.

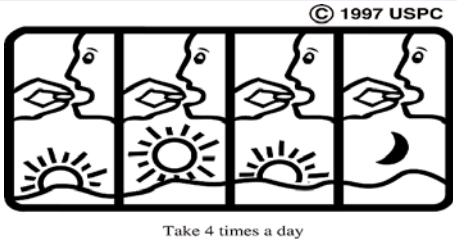

Figure 7: USP Pictogram for "Take 4 times a day"

See Figure 8 for a patient education brochure blank template with an extraneous image that adds no meaning and may be visually distracting. Simple language should be used to accompany visual images. More than 85 percent of people should be able to interpret a visual correctly for it to be considered effective (American National Standards Institute, 1991). For best recall, multiple sensory experiences should be employed to encode memory with vision, hearing, and relationships (Hill, 2001). For example, patient education materials could include visuals and be accompanied with verbal patient counseling within an ongoing patient/health provider relationship. In some cases, patient education is incorporated in videos as well. Virtually every researcher in this arena recommends that visuals should not be used as a stand-alone communication tool, but should always be accompanied by verbal patient counseling.

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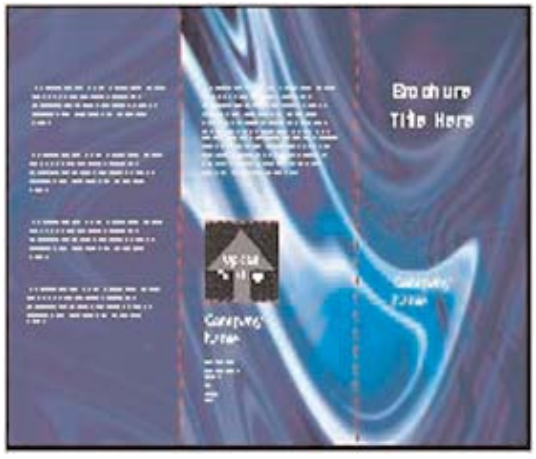

Figure 8: Patient education brochure blank template.

To ensure that health information portrayed is accurate, health professionals and adult educators can work together in the creation of visuals, rather than either group working alone. "Adult educators can help health practitioners understand the underlying assumptions prevalent in public health and in healthcare, the nature of the [literacy] demands made on adults, and the need for a better match between these demands and adults' skills" (Rudd, 2007, p. 35). Healthcare providers provide expertise about health conditions and the experience of having worked to communicate health information to patients.

The representation of racial/ethnic groups in drawings or photographs incorporated in patient education materials appears to have a positive influence on retention and use of health information by members of those groups (Figures 9 and 10) (Baty et al., 2003; Guidry & Walker, 1999; Weintraub et al., 2004).

Figure 9:
Patient and physician interaction

Figure 10:
Patient and physician interaction

For example, culturally and linguistically appropriate interventions were found to enhance the rate of cervical screenings in Chinese women residing in North America (Taylor et al., 2002). Culturally relevant patient education materials developed with a focus group technique that engaged patients as part of the cancer pain care team appeared to lessen patients' pain (Lasch et al., 2000). However, people may bring their stereotypes to their perceptions of the meaning of visuals; for example, they may perceive all female healthcare providers as nurses unless special care is taken to identify female physicians (Weiner et al., 2004).

While visuals do appear to improve comprehension and recall of medical information, and may potentially influence health behaviors, time must be invested to develop visuals that communicate with the intended population. It is best to develop visuals in collaboration with members of the intended audience, for example, through the use of focus groups or by working with medical staff regularly involved in patient education with the relevant population group. Houts and colleagues (2006) point out that explaining visuals and pre-testing is especially important for populations who are unfamiliar with western medicine. Before implementing the use of a visual tool, numerous researchers have stressed the importance of pre-testing visuals to determine if they can be easily understood and correctly interpreted, and whether they are culturally appropriate. Communicating about sensitive issues such as contraceptives or HIV/AIDS needs to be approached with special care. No pictures or symbols are recognized universally, and visuals may be culturally inappropriate or misunderstood, potentially leading to adverse events.

Creative Examples

A successful visual is the Wong-Baker FACES Pain Rating Scale (Figure 11) (Hockenberry et al., p. 1259), which was originally designed for children over age three as a substitute for the numerical scale (Figure 12) which is often expressed verbally: "On a scale of 1 to 10, how severe is your pain?" The Wong-Baker FACES Pain Rating Scale is used with the explanation, "Point to each face using the words to describe the pain intensity. Ask the child to choose face that best describes own pain and record the appropriate number." It is now often found in many physicians' offices, for use with patients of all ages.

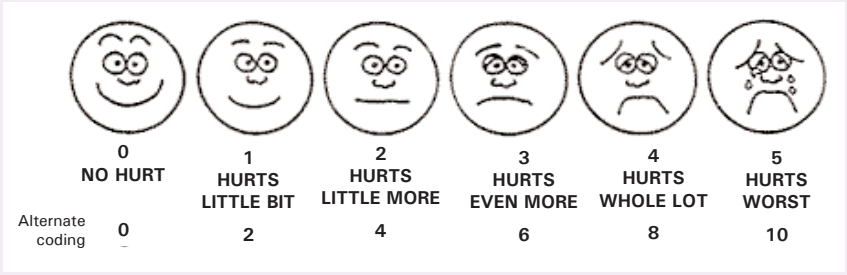

Figure 11: Wong-Baker FACES Pain Rating Scale
[Used with permission]

Figure 12: Numerical Pain Scale

Dr. Oralia Bazaldua (A Picture of Health) led a team of medical residents to develop pictograms on stickers that can be applied to the labels of prescription medications to help patients identify and differentiate their medications from one another (Figure 13).

Figure 13: Stickers to help patients identify their medications

This is critical because many patients have more than one health condition and may become confused about which medication is which, especially if the patient is relying solely on letter recognition. The illustrations were designed to improve long-term disease outcomes in patients with diabetes, high blood pressure, or high cholesterol by improving patients' medication adherence.

As the only Spanish speaking bilingual member of a medical missionary team, Nancy Faux describes the creation of a tool she designed to help physicians communicate medication information to patients in Bolivia who were Spanish speaking (2004). Faux could not be available for every consultation so she designed a multilingual, pictorial tool on a single sheet of paper that contained several pictograms and other pictorial icons for how much medication was to be taken, whether it should be taken with or without meals, when to take the medication, for how long, and what the medication was intended to treat (Figure 14). Physicians selected the relevant visuals for a particular patient who could then take the paper home as a way to remember how to take the medication. Despite some skepticism at the outset based on the tool's informality, the physicians quickly came to appreciate its potential for increasing patients' understanding and thereby improving patients' adherence to their medication regimens. Although this tool was designed to be used by health providers to help cross a language barrier it could be easily adapted to communicate with low health literate patients.

Concept maps can incorporate meaningful pictograms to diagram a flow or hierarchy of ideas. As a graphic knowledge representation tool, a concept map diagrams key ideas in a topic area and demonstrates the relationships among them. They provide written, visual, and spatial information and this combination is more likely to be retrievable from memory than written information alone (Robinson et al., 1999).

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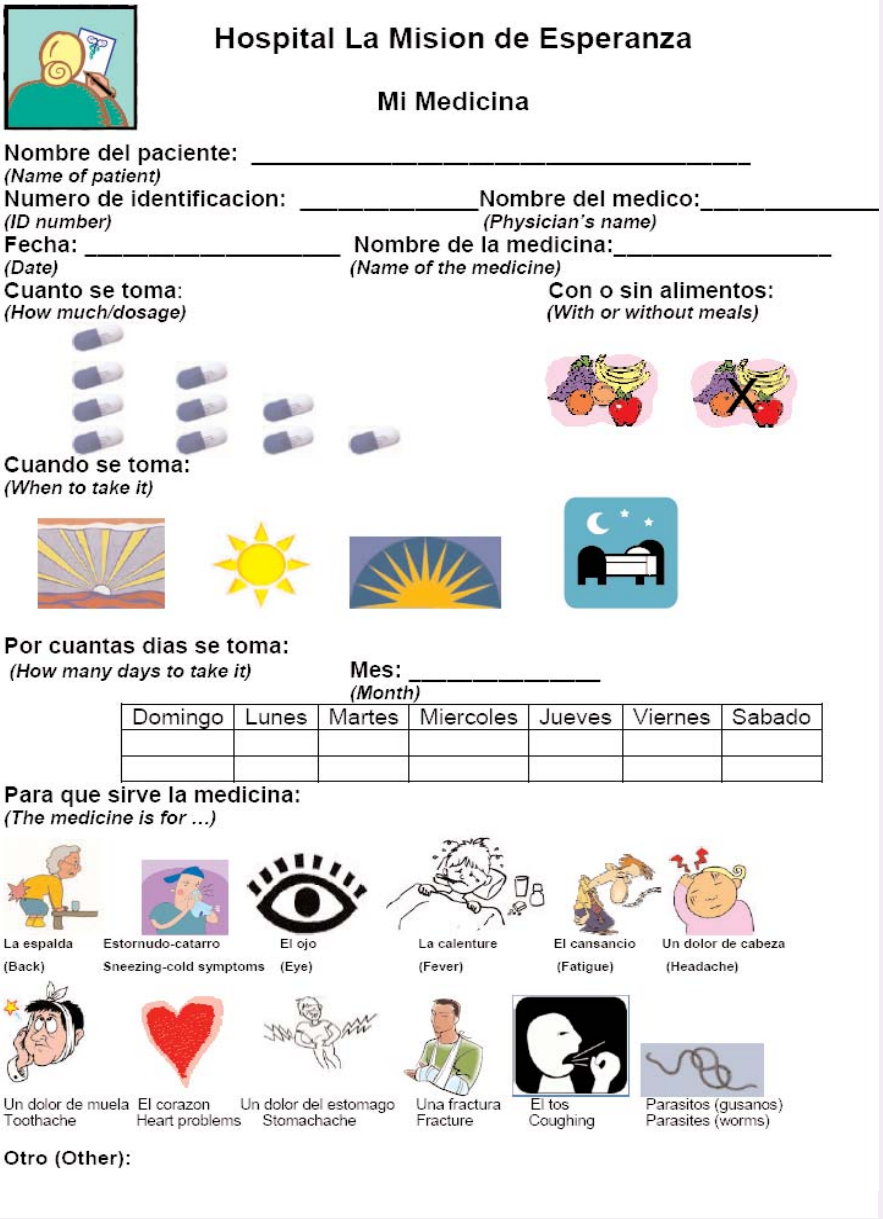

Figure 14:
Communicating Medication Information across the Language/Literacy Divide. [Used with permission]

One experiment conducted by Hill (2006) used a visual concept map to demonstrate the daily pattern of medication use, Glucophage™ twice a day with meals and Ditropan™, once daily at bedtime (Figure 15). One potential advantage of a printed visual medication concept map is that it is a portable tool that a patient can carry with them as a reminder of when to take his/her medications. A visual concept map could be easily updated as a physician makes changes to a patient's medication regimen.

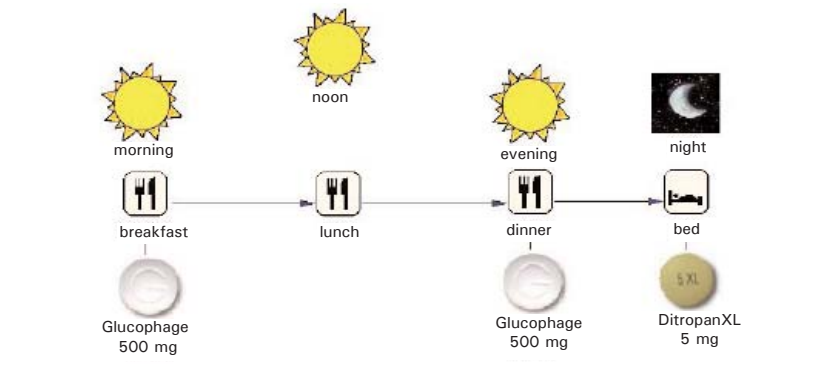

Figure 15: Concept Map Illustrating the Use of Glucophage™ and Ditropan™

A literacy educator teaching a class in English for speakers of other languages (ESOL) worked with women in the class and a health educator to create participatory photonovels that incorporated culturally representative photographs and comprehensible text to communicate nutrition information (Nimmon, 2007). Photonovels are something like comic books in that they incorporate simple text with either cartoons or photographs. Creating a participatory photonovel can be an empowering, educational process that helps to improve literacy skills, and at the same time, the photonovel can be used to communicate to future classes with similar language skills. A photonovel placed on the Internet can also include audio with the pages timed to coordinate. Only a few pages of one example have been reproduced here (Figure 16). The complete photonovel may be viewed at this Web site: www.photonovel.ca/about.htm.

Figure 16: Excerpts from a photonovel by Laura Nimmon and her students. [Used with permission]

Cautions

What communicates a message to one group may be understood differently by another. For example, the United States Pharmacopeia pictogram intended to indicate "Take until gone" (Figure 17) can be misunderstood as "Take one half, then the other." Images that represent isolated or internal body parts can be a source of confusion (Figures 18 and 19), as can images that represent abstract concepts such as time or a sequence of events (Figure 7).

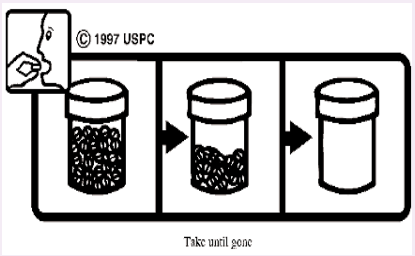

Figure 17: USP pictogram for "Take until gone"

Figure 18: USP pictogram for "Place drops in lower eyelid"

Figure 19: USP pictogram for "For lung/respiratory problems"

Images that use a plate with knife and fork to represent food assume that everyone sits down to formal meals when many North Americans eat more casually or with different utensils such as chopsticks (Figure 20). The diagonal cross within a circle intended in North America to convey '*do not*' does not communicate that meaning in all cultures (Figure 21). This is not intended to criticize the United States Pharmacopeia (USP), which performs valuable work in standard setting for medications, supplements, and other healthcare products and also makes available a selection of pictograms for download. However, it illustrates what the USP indicates in their licensing agreement that "It is possible that an individual reacting to the Pictograms will have a different interpretation than what is intended. Because of this potential for misinterpretation, the Pictograms should not be used as the sole means of transferring information to the patient" (USP, 2008).

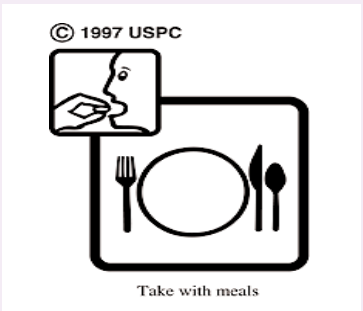

Figure 20: USP pictogram for "Take with meals"

Figure 21: USP pictogram for "Do not smoke"

Conclusion

Visuals have value, and our society may see the incorporation of more visual images in patient education materials in future. Most researchers recommend that visuals should not be the sole means of communication with patients and emphasize that verbal patient counseling remains essential (Dowse & Ehlers, 2001). Patients need to be educated about the intended meanings for the visuals, and all healthcare professionals should make it a point to verify that their patients have a clear understanding of instructions and visuals in patient education materials given them.

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A Second Look at the Health Literacy of American Adults and the National Assessment of Adult Literacy

by Andrew Pleasant

In the United States, the field of health literacy has been steadily emerging since the early 1990s from two original streams of research and practice. On the one hand, health care professionals began investigating literacy effects on health and the provision of health care. On the other hand, adult basic education and literacy professionals began incorporating health into curricula and community empowerment efforts. A third approach has more recently emerged that incorporates a public health approach as a means to bridge the gap and create new opportunities to advance health literacy. However, many in those two original streams remain somewhat isolated from each other. The field of health literacy has come a long way in a short time, but advances are still needed to reach a complete understanding and use of health literacy. For instance, the field needs to advance from treating health literacy as an individual issue of fundamentals, at times referred to as basic literacy, which consists of reading, writing, speaking, and numeracy skills in a health context and move toward treating health literacy as an important, yet complex, social determinant of health.

That move will necessitate fully acknowledging that health literacy is not simply an individual characteristic or something some people are lacking. Health literacy is a product of individuals and the social, cultural, political, educational, and organizational contexts they live within. Further, health literacy is a means to increase individual and community empowerment.

This article analyzes the health literacy component of the 2003 National Assessment of Adult Literacy (NAAL) as an illustrative example of how a primary focus on health literacy as a 'problem' for individuals can gain from an expanded analysis based on a broader conceptual approach.

The National Center for Educational Statistics (NCES) conducted the NAAL, which measured English literacy and health literacy of American adults over 16 years old. The NAAL assessed three types of fundamental literacy – prose, document, and quantitative (Kutner et al., 2005). Embedded within the NAAL are 28 questions (12 prose, 12 document, and four quantitative) that make up the NAAL health literacy scale (Kutner et al., 2006). These questions address three health content areas: clinical (three questions), prevention (14 questions), and navigation (11 questions).

The attention given to the NAAL has certainly helped fuel the continuing surge of interest in health literacy research, practice, and policy. Since NCES began publishing NAAL results in 2005, health literacy presentations across the country have directly relied on the graphs and the analysis presented in NCES' reports.

The goals of this article are to highlight opportunities to present the NAAL data in understandable and more effective ways, to urge future efforts at measurement to more accurately reflect the reality of health literacy in people's lives, and to help advance health literacy research, practice, and advocacy. This effort begins in the next section with a discussion of how the NAAL results have been analyzed and visually presented.

Presenting NAAL Performance Levels

The percent of American adults at each performance level is generally the first and most frequently presented finding from the NAAL assessment of literacy and health literacy. This data is consistently grouped into four performance levels descriptively labeled as "Below Basic", "Basic", "Intermediate", and "Proficient." In explicit and implicit ways, the presentations emphasize the "Below Basic" and "Basic" levels as proof that the NAAL reveals a serious 'deficit' of health literacy and literacy among certain individuals (Figures 1 and 2).

The labels also inherently prompt questions about which level is sufficient, but the question is not directly answered in NCES reports. "Below Basic" sends a strong signal that this performance level is not good enough. In their graphic representations, NCES also isolates "Below Basic" to the left of a zero point on the X-axis (bottom of the graph). This sends a message that the 'problem' lies among the 12 to 22 percent of U.S. adults at the "Below Basic" level in the types of fundamental literacy assessed and the 14 percent at the "Below Basic" level of health literacy. In purely statistical terms, the zero point is not meant to indicate a judgment. But the negative implications are unavoidable. The area to the left of zero on a graph is negative, implying less than and deficient. To the right of zero is positive, implying more than and sufficient. Even if unintended, the implied meaning is clear. People at the "Below Basic" level are presented as a loss — a drag on a literate society — while people at the "Basic", "Intermediate", and "Proficient" levels are presented as at or above a norm.

Alternative Presentations of NAAL Health Literacy Data

A too common outcome of applying the principles of health literacy is a 'simplify' approach. This generally means removing any complexity in content or language, increasing font size and white space, and adding simple illustrations. The goal is to fill a presumed deficit of information in people with 'low health literacy'. Unfortunately, that process can dumb down information

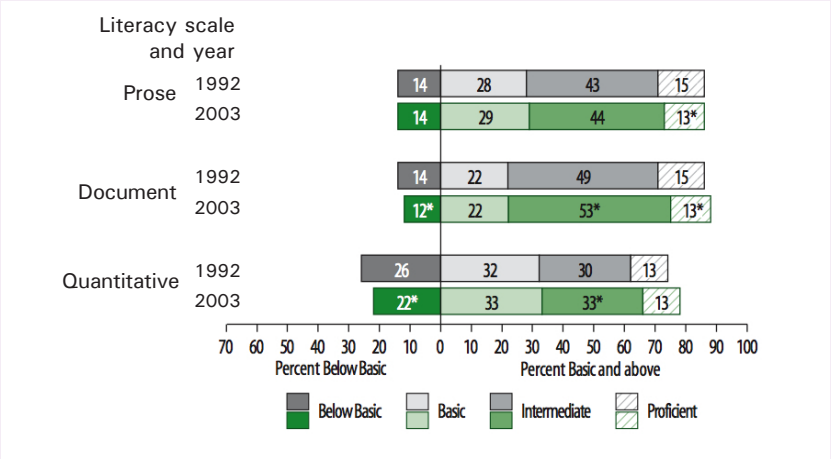

Figure 1. NCES' Presentation of Fundamental Literacy Performance Levels (Kutner, Greenberg & Baer, 2005)

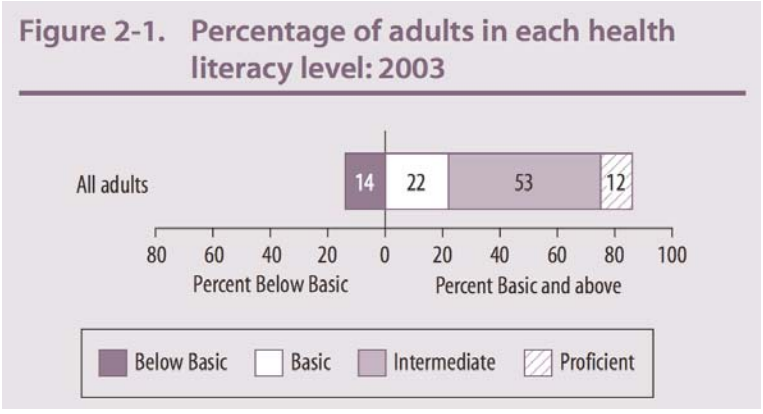

Figure 2. NCES' Presentation of Health Literacy Performance Levels (Kutner, Greenberg, Jin, Paulsen & White, 2006)

and devalue the skills and abilities people do have. A sole focus on delivering simplistic explanations through the use of plain language can limit the effectiveness of health promotion and educational materials as research indicates that understanding information may be requisite but is certainly not always sufficient to create behavior change.

An alternative approach attempts to reduce barriers to finding, understanding, evaluating, and using information by explaining complex issues in understandable ways. This is not the same as removing complexity. One way to accomplish that is to follow what I call the "Golden rules" of health literacy to (1) know your audience and (2) involve them early and often.

The following examples demonstrate how a health literacy analysis can help inform alternate presentations of the NAAL data to improve effectiveness and reduce the possibility for misunderstandings while maintaining or even adding complex information.

The NAAL data presented in Figure 2 can be accurately presented in an easier to access and much less judgmental manner, as demonstrated in Figure 3. There are four large differences between this alternative and how NCES presents the same data. The suggested alternative uses a different type of chart and removes the zero point, switches the emphasis from those at the lowest levels to where most Americans are at, adds context, and highlights additional information.

First, the suggested alternative uses a pie chart versus a bar chart with a zero line. While accurately reporting the NAAL data, the pie chart minimizes any implication that society is divided between those who have more health literacy skills and those who have less. Everyone is part of the same pie. The pie chart also removes any implied judgment of individuals with fewer skills as being deficient. Thus, health literacy is more appropriately presented as an issue everyone faces, not a social burden caused by a minority. Presenting the NAAL health literacy data in this way also minimizes any potential for inadvertent shaming of individuals by health literacy researchers or health professionals who use NCES reports in their work.

Second, the emphasis is dramatically shifted away from the 14 percent of American adults at the "Below Basic" level and placed on the important finding that nearly nine out of 10 American adults (88 percent) are below the "Proficient" level. That message is delivered in multiple fashions to accommodate individual skills and preferences for understanding statistical data.

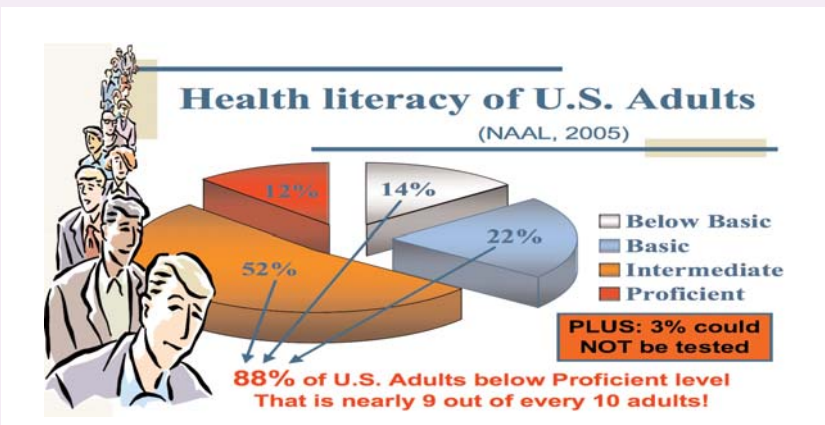

Figure 3. Alternative Presentation of NAAL Health Literacy Performance Level Results

A third difference in the alternative presentation of the NAAL data is simple, but worth noting. The context provided by the image of a long line of figures forwarded by a white male reminds the audience this is about people, not just numbers. A well-chosen image can counter racial or ethnic prejudices that population estimates of low literacy and health literacy unfortunately often encounter. While this image may not be the best for all audiences, as a few more women would be a welcome addition, context matters and it is simply naive to ignore the stereotypes of people with low literacy in the United States.

While NAAL performance levels are presented in racial and ethnic categories in NCES reports, the NAAL does not provide evidence about why different people performed differently. That should prompt a cautionary approach to presenting or interpreting this data. For example, using the NAAL findings to justify focusing interventions on a Hispanic or Black population without full consideration of the many possible and deeply rooted structural, cultural, methodological, or historic causes may lead to interventions that produce no results or, worse yet, reinforce a counter-productive stereotype.

Fourth, and finally, the alternative presentation adds information by including the fact that 3 percent of American adults could not be assessed by the NAAL. This occurred for a variety of reasons (including cognitive deficiencies as well as not speaking English or Spanish well enough to complete the initial screening). This fact is in NCES reports. But those simply and most commonly using only a few of NCES' graphics may lose this important point.

Overall, more information and more complexity are presented in the alternative while reducing possibilities for misunderstanding the most important message. At the same time, shifting health literacy to an issue facing almost everyone certainly increases the value of the data for advocacy and intervention efforts.

Presenting Association with Self-assessed Health Status

Of the many NAAL findings worthy of a second look, an important example is the association of health literacy levels with self-assessed health status. This should be an area of great interest as self-assessed health status is generally a strong predictor of actual health (McGee et al., 1999; Shi et al., 2002).

NCES presents the relationship between health literacy and self-assessed health in much the same fashion as the health literacy and literacy performance levels (Figure 4). So, the earlier analysis of that presentation style remains relevant. The previous examples presented only performance levels, but in this example the relationship between performance levels and self-assessed health must be depicted. That prevents the use of a simple pie chart as a solution.

A simple reorganization of the bar chart makes it easier to 'read' and begins to allow for a deeper understanding of this important relationship while reducing the possibility for misinterpretations (Figure 5). Removing the zero point that divides the data into 'have' and 'have-less' categories makes the presentation less judgmental, as noted. Combining that change with reversing the order of self-assessed health levels (putting "Excellent" first) further highlights another important finding. As health literacy improves so does self-assessed health status.

However, in differing degrees both NCES and the suggested alternative assume that readers can or will perform a more complete analysis to understand the complex relationship between health literacy and self-assessed health status. Gigerenzer and Edwards (2003) accurately described this problem when they wrote, "Statistical innumeracy is often attributed to problems inside our minds. We disagree: the problem is

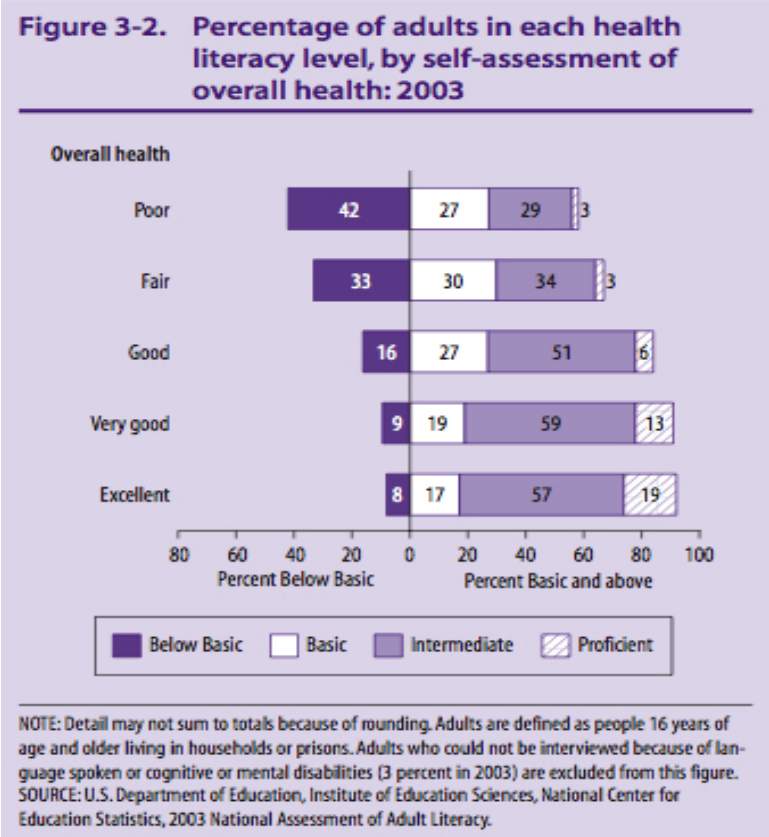

Figure 4. NCES Presentation of Relationship between Self-assessed Health Status and Health Literacy Level (Kutner, Greenberg, Jin, Paulsen & White, 2006)

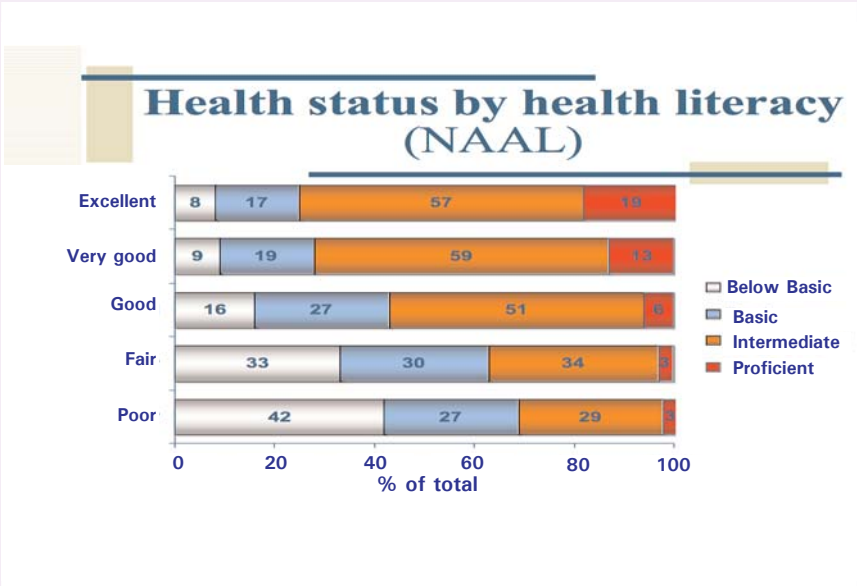

Figure 5. An Alternative Presentation of the Relationship between Self-assessed Health Status and Health Literacy

not simply internal but lies in the external representation of information, and hence a solution exists. Every piece of statistical information needs a representation — that is, a form. Some forms tend to cloud minds, while others foster insight. We know of no medical institution that teaches the power of statistical representations; even worse, writers of information brochures for the public seem to prefer confusing representations" (p.741).

Two important yet complex aspects of the data are 'clouded' by the presentations. First, at the lowest two levels of health literacy, a higher percentage reported "Poor" health versus "Excellent" health. That relationship reverses at the highest two levels of health literacy. There a higher percentage of people reported "Excellent" rather than "Poor" health. The reversal could be taken as evidence that the "Intermediate" level is the baseline for what is 'sufficient'. A more subtle interpretation is that health literacy just begins to have a positive effect for more people at the "Intermediate" level. Both interpretations argue against a primary or sole focus on the "Below Basic" and "Basic" levels. That counters what is implied by the original NCES presentation of this finding from the NAAL.

Second, there may be a small but perhaps important change in the strength of the relationship at different health literacy levels. At the "Proficient" level, the percent reporting "Excellent" health is 6.3 times greater than the percent reporting "Poor" health. At the "Below Basic" level, the percent of people reporting "Poor" health is only 5.3 times greater than the percent reporting "Excellent" health. Thus, hidden in these graphs is a hint that the positive relationship between better self-assessed health and higher health literacy may be stronger than the negative relationship between lower health literacy and poorer self-assessed health. Improved self-assessed health is certainly the more desirable effect.

> *"Even if unintended, the implied meaning is clear. People at the "Below Basic" level are presented as a loss — a drag on a literate society — while people at the "Basic", "Intermediate", and "Proficient" levels are presented as at or above a norm."*

The implication for the research agenda is that a productive place to gather evidence about how health literacy works is among people with higher levels of health literacy. However, much if not most research focuses on finding negative effects associated with lower health literacy. That deficit model focuses on what people can't do versus what they can. To map out a causal relationship between health literacy and better health, research must also look where effective levels of health literacy exist.

Also unmentioned in the NAAL reports or the field at large is an important point that the levels of self-assessed health at the "Below Basic" level may simply reflect a baseline that has more to do with the health care system in the U.S. rather than any relationship with health literacy. Gains in self-assessed health above the lower levels may indicate an effect of the health literacy skills measured, assuming all other factors remain equal.

The preoccupation on the "Below Basic" and "Basic" health literacy levels means people are focused on where health literacy isn't, versus where it is. This again argues for shifting emphasis away from the lowest levels of individual skills and looking at a broader picture of health literacy.

The most direct and understandable way to present this finding from the NAAL — without using a chart or graph — is something like this: As health literacy improves, people said they are increasingly healthier. We still need to better understand why that happens.

The next section is a discussion of how the conceptual approach underpinning the NAAL methodology limits our ability to reach that and other more complex understandings about health literacy with the NAAL data.

Definitions Do Count: What is Health Literacy?

While the exact methodology of the NAAL is hidden from public view as the result of a deliberate policy decision by NCES, the conceptual approach is fairly well documented. The NAAL defined literacy as "using print and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential" (Kutner et al., 2006, p. 2). In nearly an exact parallel, the NAAL defined health literacy as "the ability to use printed and written information associated with a broad range of health-related tasks to accomplish one's goals at home, in the workplace, and in the community (including health care settings)" (NCES, n.d., para. 1).

The parallels in those two definitions predetermined important

outcomes. The approach allowed NCES to include performance on the health literacy questions as a part of the literacy scores. That guaranteed a correlation between the health literacy and the literacy data. Also, it limited the nature of possible questions because health literacy questions had to fit within the conceptual approach to literacy. By definition, the NAAL limits health literacy to only being a subset of literacy. Thus, the only aspect of health literacy the NAAL was designed to measure is an individual's fundamental literacy in a health context.

Reflecting that limitation, the NAAL health literacy component seems to only assess the ability to find information in text and sometimes employ that information in a numeracy skill. As far as can be ascertained from what has been published, there is no assessment of the skills to critically evaluate information about health or to put information to use.

A further and important limit is that what may have predominantly been a practical choice to limit assessment to individual skills prevented the NAAL from assessing the context in which health literacy skills are used in actual practice. In that sense, the NAAL measures only half the issue. This is not limited to the NAAL as it is true for all existing measures of health literacy. These limitations reflect methodological, epistemological, and political challenges inherent to assessing health literacy as the attempt involves bridging diverse disciplinary perspectives such as public health, clinical medicine, education, linguistics, and communication (Pleasant & Kuruvilla, 2008).

Despite the clear challenges, the match or mismatch between an individual's health literacy skills and the context in which those skills are used is critically important to assess (Rudd et al., 1999). Through the early part of this decade a wave of articles reported "over 300 published articles document that most health materials are beyond the comprehension skills of most Americans" (Paasche-Orlow et al., 2005, p. 175). The NAAL data clearly indicates that the only place "most Americans" are at is below the "Proficient" level in health literacy. Therefore, the "most health materials" deemed too difficult for most Americans must require a "Proficient" level of health literacy. While this may seem extreme, the only other possible explanations are that the 300 studies are incorrect, the NAAL is incorrect, or the limited approaches to health literacy do not capture the broad range of skills and abilities that people actually use.

The final explanation seems the most productive, that the NAAL methodology only addresses a part of the skills that people actually use to make decisions about their own, their family's, and their community's health. A number of broader approaches to health literacy do exist in the peer-reviewed literature. While wording varies, those variations always seem to fit within a definition of health literacy as "the wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life" (Zarcadoolas et al., 2005; 2006).

At its core, the argument for such a broader approach is simple. If people can't access information, they can't understand it. If they can't understand it in a fundamental sense, they are not able to evaluate its utility in the context of their lives. If they can't make that critically important evaluation there is little to no chance that they will put the information to use in making informed decisions about their own, their family's, and their community's health and well-being.

> *"To map out a causal relationship between health literacy and better health, research must also look where effective levels of health literacy exist."*

Wrapping Up: A Second Look

An illustrative example of just how powerful and rich health literacy can be recently occurred not in a research project or promotional video but in a book club in a homeless shelter.

Nine men sat in a circle and discussed the book *Finding Fish*, later made into the feature film Antwone Fisher. In less than one hour the group demonstrated a comprehensive range of health literacy skills. They helped each other understand difficult vocabulary and story structure. They addressed the mechanism and effects of addiction as well as cultural barriers to disclosing mental health issues or being sexually abused. In short, the discussion worked to empower them to find and use health services and better understand their own health.

In that simple situation, these men put complex health literacy skills to action by reading the words in a book and then, in the spirit of the Brazilian education practitioner and researcher Paulo Freire, transferring that to reading the conditions of their own health and the world they inhabit (Freire, 1980). While some of these men might (and some might not) score low on the NAAL health literacy scale, they also demonstrated skills not

captured by the NAAL. For example, they went beyond finding and understanding information about health. They began to evaluate that information in the context of their own lives and discussed how they could use that information to improve their own health.

To conclude, a primary focus on measuring health literacy as simply an individual's fundamental literacy in a health context seems to inevitably lead to a focus on individuals at the lowest level of health literacy. This article has demonstrated that is the case for the conceptual approach underpinning the NAAL's methodology and for how the findings are commonly analyzed and presented. Focusing only on the lowest levels of health literacy misses much of the reality of health literacy in people's lives, limits the abilities to understand and measure the strength of health literacy, and limits the ability to identify the complex causal mechanisms that connect health literacy with personal empowerment, better health, and reduced inequities in health.

The NAAL produced many important findings and positive effects. This second look simply suggests more is possible. For instance, it is worth repeating the important NAAL finding that 88 percent, or nearly nine out of 10 U.S. adults, are below the proficient level in health literacy. Health literacy is an issue everyone faces, but the field has a long way to go to fully advance health literacy research, practice, and policy.

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WORLD EDUCATION

Health Literacy Electronic Discussion List

The Health Literacy list provides an on-going professional development forum where literacy practitioners, healthcare providers, health educators, researchers, policy makers, and others can discuss literacy issues in health education programs and in health care settings; health education efforts being undertaken within literacy programs; literacy screening measures being piloted in health care settings and the readability of health materials

To participate in the Health Literacy discussion list (it's free!) go to http://www.nifl.gov/lincs/discussions/discussions.html. Scroll down to and click on Health Literacy. Follow the directions to subscribe. You will be sent an e-mail requesting confirmation of your subscription.

The manager of this list is Julie McKinney. She can be reached at jmckinney@worlded.org.
Please DO NOT send subscription requests to this address.❖

BLACKBOARD

Resources

Online Discussion List

NIFL Health Literacy Discussion List. This list provides a continuous professional development forum where literacy practitioners, healthcare providers, health educators, researchers, policy makers, and others can discuss literacy issues in health education programs and in health care settings; health education efforts being undertaken within literacy programs; literacy screening measures being piloted in health care settings; and the readability of health materials. To subscribe, follow instructions at www.nifl.gov/lincs/discussions/subscribe_all.html

Web Sites

General Resources

- **ALE Wiki.** The Adult Literacy Education Wiki has a health page which has a good listing of resources (research, books, Web sites), promising practices, and discussions from the Health Literacy Discussion List that is sponsored by the National Institute for Literacy. It is a good starting point for getting acquainted with the information available on health literacy.
- **Health & Literacy Curriculum.** This site allows users to directly download or link to online health literacy curricula. Materials have not been screened. www.advancinghealthliteracy.com/curricula.html
- **Health & Literacy Special Collection.** From 2001-2006 the National Institute for Literacy provided support for this special collection of materials on health and literacy suitable for literacy learners, teachers, and health educators. www.healthliteracy.worlded.org/index.htm
- **Sites for English Language Learners.** A teacher of English for speakers of other languages put together this list of his 10 favorite health and literacy sites appropriate for English language learners. www.larryferlazzo.edublogs.org/2008/01/03/the-best-health-sites-for-english-language-learners
- **Literacy and Health Resources on the Web.** This Web site is run by Literacy Partners of Manitoba and includes links to health sites, literacy sites, full-text documents, and other Web resources. www.health.mb.literacy.ca/health/health2.htm
- **National Assessment of Adult Literacy** *Assessing the Nation's Health Literacy: Key Concepts and Findings of the National Assessment of Adult Literacy (NAAL)* describes health literacy results from the 2003 NAAL. Published by the American Medical Association (AMA) Foundation and written by Sheida White, PhD, NAAL Project Officer, this 100-page report will be of interest to clinicians, researchers, educators, insurers, and policy makers in both the health and education fields. *Assessing the Nation's Health Literacy* can be downloaded as a PDF at no charge by visiting www.ama foundation.org/go/healthliteracy
- **MEDLINE/PubMed Search and Health Literacy Information Resources** This site, from the National Library of Medicine, provides a detailed MEDLINE search strategy for Health Literacy articles. This allows users to perform a professional literature search with the click of a button and retrieve a comprehensive set of English language citations. It also includes a short list of other Health Literacy Information Resources. www.nlm.nih.gov/ services/health_literacy.html

Web-Based Courses

- Health Literacy: New Field, New Opportunities www.healthliteracy.worlded.org/docs/tutorial/SWF/flashcheck/main.htm
- Unified Health Communication 101: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency www.hrsa.gov/healthliteracy/training.htm

Materials

- **National Center for the Study of Adult Learning and Literacy.** NCSALL published an earlier issue of *Focus on Basics* as well as research and professional development materials on health and literacy. All items are indexed on www.ncsall.net/index.php?id=60
- **Ask Me 3.** Getting patients to ask their doctors three simple questions is the goal of this Web site. It includes materials (useful for literacy programs) that introduce the questions, as well as information for health providers on health literacy and communications. A succinct set of resources are included. www.npsf.org/askme3/PCHC/what_is_ask.php
- **Staying Healthy, An English Learner's Guide to Health Care and Healthy Living.** The Florida Literacy Coalition published a resource book on health for students with an accompanying teachers guide. The student book is written at the fourth to fifth grade reading level and includes photographs and illustrations that help English learners grasp concepts and vocabulary. Both student and teacher books can be downloaded from the Web site. www.floridaliteracy.org (click on Staying Healthy)❖

Focus on Basics

New From World Education

World Education Publications & Resources

New England Literacy Resource Center

The Change Agent is published twice a year in March and September. The new issue, #27, September 2008, is on "Making Sense of Climate Change". Learn about greenhouse gases, energy-saving tricks that also save money, green jobs, justice-based solutions to climate change, and how adult learners are teaching their kids about conservation, saying no to junk mail, and lobbying their mayors to do more for the environment. For more information visit www.nelrc.org/changeagent

National College Transition Network

National Conference on Effective Transitions in Adult Education, November 17-18, 2008, at the Crowne Plaza Hotel in Providence, RI. Hosted by the National College Transition Network at World Education in partnership with the Nellie Mae Education Foundation, the two-day conference will focus on strategies and promising practices that help adult learners succeed in postsecondary education and training. To register, go to: www.collegetransition.org/conference08/registration.html

College for Adults is a website that helps adults who are attending college for the first time plan for college. The site helps learners walk through the application process and find money to pay for college classes, and provides resources to help them prepare for college-level work. College for Adults is partially funded by the Verizon Foundation. www.collegeforadults.org

The College Transition Toolkit is a comprehensive guide to program planning and implementation that draws on the expertise of practitioners from The New England ABE-to-College Transition Project and around the country. It contains detailed information to help adult educators and administrators plan for the needs of students interested in pursuing postsecondary education and training. Chapter titles include: Program Models; Partnerships and Collaborations; Recruitment; Assessment; Counseling; Curriculum and Instruction; Planning; and Using Data for Program Development. The toolkit also provides templates that you can download and adapt for use in developing your college transition program, links to a variety of online resources, and supplementary printable resources. For more information visit www.college transition.org/toolkit.html

Integrating Career Awareness into the ABE and ESOL Classroom curriculum guide provides guidance to adult educators on how better to equip students with career awareness and planning skills through lessons and activities correlated to the SCANS competencies. The curriculum is available in CD form, with handouts and worksheets that can be downloaded and modified. A new addition is available, published by NCTN in collaboration with the Massachusetts System for Adult Basic Education Support (SABES).

Contact Leah Peterson at literacy@worlded.org or 617-385-3740 to order a copy of the *College Transition Toolkit* ($75.00 plus $5.00 for shipping/handling) or the *Integrating Career Awareness Curriculum Guide* (the CD is free, but costs $5.00 to ship).

System for Adult Basic Education

Field Notes is a quarterly, theme-based publication in which Massachusetts adult basic education practitioners share innovative and reliable practices, resources, and information. Published by the System for Adult Basic Education Support (SABES) and funded by the Massachusetts Department of Secondary and Elementary Education, Field Notes is also of interest to readers outside the state. Past themes have included numeracy, social justice, assessment, technology, student leadership, workforce education, and learning disabilities. Find back issues at www.sabes.org/resources/publications/fieldnotes/index.htm

The SABES Math Bulletin. This bulletin is a vehicle for sharing math/numeracy research and professional literature in an accessible, abbreviated platform. It is published electronically quarterly. Funded by a Massachusetts DESE grant, available at www.sabes.org/resources/publications/mathbulletin/math-bulletin-apr2008.pdf

The Problem Solver. This serves adult basic education (ABE) practitioners by offering math activity outlines, math problems, Web links, and stories about ABE math-related events in Massachusetts and around the United States. Past issues are available at: www.sabes.org/resources/publications/problemsolver/index.htm

Online Professional Development

ProfessionalStudiesAE.org is a portal for online professional development in adult education and literacy. Users can explore evidence-based practices suitable for work with adult learners. Topics available:

- Adult Multiple Intelligences
- College Transitions
- Engaging Students in Learning
- ESL Instruction
- Numeracy
- Reading
- Serving Young Adults
- Student Assessment
- Student Persistence

To register, go to: www.ProfessionalStudiesAE.org

For back issues of *Focus on Basics*, go to NCSALL's Web site at www.ncsall.net and click on "Publications" and select *Focus on Basics*.

Focus on Basics
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