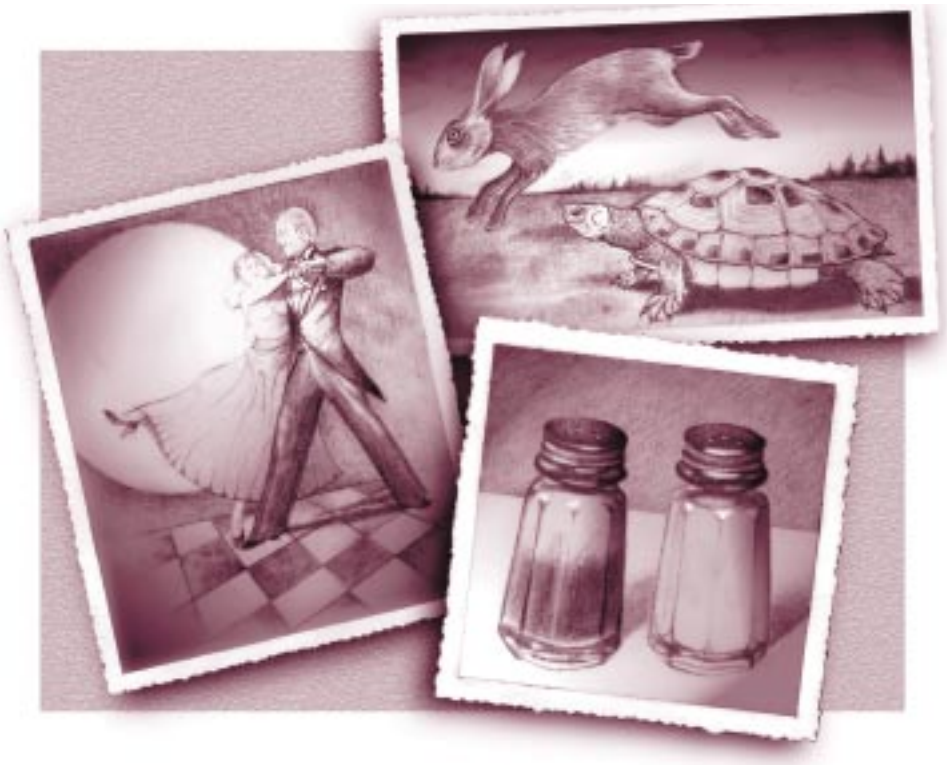
Focus on Basics
CONNECTING RESEARCH & PRACTICE

IN THIS ISSUE:

Literacy and Health



A Maturing Partnership

by Rima E. Rudd

How did the literacy and health fields come to work together? Now that this partnership, tentative as it is, has begun, what direction should it take? As a public health researcher, I have worked to bring these two worlds together, believing passionately that the relationship will be beneficial for both fields, and, most importantly, for the clients of the health and literacy systems. In this article I will trace early innovations in this movement, through some current activities, and provide some suggestions for next steps.

Demographic information such as measures of age, race, income, and education are traditionally collected in all health surveys so that researchers can examine differences among various population groups. Two of these items, income and education, are considered measures of socioeconomic status. We have strong evidence that socioeconomic status and health are linked. Of course, adult educators who work with low-income learners will not be surprised to learn that those who are poor or have lower educational achievement *continued on page 3*

Focus on Basics is the quarterly publication of the National Center for the Study of Adult Learning and Literacy. 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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NCSALL
National Center for the Study of Adult Learning and Literacy

WORLD EDUCATION

Welcome!

Peanut butter and jelly, Mom and apple pie, literacy and health...they're pairs that fit together naturally. In this issue of *Focus on Basics*, we explore some of the many ways in which literacy and health partnerships are enacted. They tend to fall into two categories: approaches that seek to empower students to navigate more easily the often overwhelming US healthcare system, and approaches that seek to educate literacy students about and alleviate health problems.

NCSALL researcher Rima Rudd sketches out the history of the growing interaction between the two fields. In addition, Rudd describes the diffusion of innovation theory, which helps to explain how and why this interaction came about. This theory also sheds light on why students are so effective in catalyzing their peers to act on health-related issues.

Students acting together in activities related to health are described by Beth Russett, on page 30, in an account of her year as a nurse practitioner providing health education in a Laubach program in Maine. Also concerned about students' health needs, ESOL teacher Kate Singleton turned familiar issues into evocative classroom materials. As students built their conversation skills, they learned how to access resources available in Virginia, such as low-cost health care and translation services within the health care system. Her story starts on page 26.

Violence is not always recognized as a health issue, but teachers across the country are increasingly recognizing its role in impeding learning. The Women, Violence, and Adult Education project described in the article by Elizabeth Morrish, page 15, enabled participating programs to explore ways to address this educational barrier, not necessarily by dealing with it directly but by focusing on wellness itself. On page 11, Leslie Ridgeway and Dale Griffith provide an inside view of how this worked at their program in the York Correctional Institute in Connecticut.

A successful marriage between literacy and health — and all the related benefits that result — cannot come about solely through the acts of individuals and programs. State-level policy must play a role as well. Marcia Hohn interviewed five state policy-makers to learn how they are supporting efforts to bring health and literacy together in their respective states. She shares six strategies in the article that starts on page 20.

To share your experiences with integrating literacy and health, or to ask questions of this edition's authors, join the *Focus on Basics* electronic discussion list. See page 14 for information on how to subscribe. We look forward to expanding and enriching this conversation with your participation.

Sincerely,

Barbara Garner

Barbara Garner
Editor

A Maturing Partnership

continued from page 1

have more health problems than do those with higher income or higher educational achievement.

The Secretary of Health and Human Services prepares an annual report to the President and Congress on national trends in health statistics, highlighting a different area each year. The 1998 report focused specifically on socioeconomic status and health (Pamuk et al., 1998). This report offered evidence from accumulated studies that health, morbidity — the rate of incidence of a disease — and mortality are related to socioeconomic factors. For example, life expectancy is related to family income. So, too, are death rates from cancer and heart disease, incidences of diabetes and hypertension, and use of health services. Furthermore, death rates for chronic disease, communicable diseases, and injuries are inversely related to education: those with lower education achievement are more likely to die of a chronic disease than are those with higher education achievement. In addition, those with less than a high school education have higher rates of suicide, homicide, cigarette smoking, and heavy alcohol use than do those with higher education. The lower your income or educational achievement, the poorer your health.

Thus, links between critical health outcomes and income/education are well established. However, until recently, health researchers had not examined any particular components of education such as literacy skills. This is because education itself was not the major consideration; education was only considered a marker of social status. Another barrier to examining any specific role that education might play was that specific skills such as literacy were not consistently defined or measured. A number of events have led some researchers to explore the possibility that limited literacy skills might influence a person's health behaviors and health outcomes.

Key Events

Dozens of articles in the 1980s and scores of articles in the early 1990s offered evidence that written documents in the health field were very demanding and were often assessed at reading levels beyond high school (Rudd et al., 1999a). While this comes as no surprise to anyone who tries to read the inserts in over-the-counter medicines, what is common knowledge had never been systematically documented.

> *"...links between critical health outcomes and income/education are well established."*

In addition, a number of health analysts writing in the 1980s had noted connections between illiteracy and health (for example, Grueninger, 1986; Kappel, 1988). A literature review published in the *Annual Review of Public Health* highlighted growing evidence in international studies that a mother's literacy was linked to her child's health (Grosse & Auffrey, 1989). In 1991, the US Department of Health and Human Services published *Literacy and Health in the United States* (Aspen Systems Corp., 1991), which highlighted the importance of paying attention to literacy issues. It offered an annotated bibliography of journal articles and books that assessed health materials as well as studies that showed a relationship between literacy skills and health-related knowledge and behaviors. For example, some differences between people with high educational achievement and those who reported that they could not read were noted (Perrin, 1989; Weiss et al., 1991). A number of studies conducted in Ontario, Canada, drew attention as well (Breen, 1993).

The main focus of most of the literacy and health inquiries, however, were studies of the reading level of written health education materials. Among those researching this subject was Terry Davis, a medical school faculty member and researcher (Davis et al., 1990). Davis and colleagues wanted an easy-to-use tool to assess and document the reading level of patients so that they could study some health-related differences between people with limited and with strong literacy skills. They developed and tested a health-related literacy assessment tool called the Rapid Estimate of Adult Literacy in Medicine, or REALM (Davis et al., 1991). This tool enabled them to examine differences between people with high and low scores for literacy and health behavior differences, such as engaging in screening tests for early disease detection. Later, for example, Davis and colleagues found that women with limited literacy skills did not understand the purpose of a mammogram and did not access screening (Davis et al., 1996). The REALM tests a person's ability to read through a list of medical words, moving from short and easy words to difficult and multisyllabic words. It correlates well with reading tests and offers a good marker of literacy level. This tool helped a small group of researchers around the country to make health-related comparisons between those with and without strong literacy skills.

Further interest in this type of research was fueled by the first national assessment of functional literacy skills. The 1993 publication of the first wave of analysis of the National Adult Literacy Survey and the findings that half of the US adult

population had limited literacy skills provided critical information (Kirsch et al., 1993). The National Adult Literacy Survey (NALS) focused on functional literacy, defined in the National Literacy Act of 1991 as "an individual's ability to read, write and speak in English, 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."

The NALS measured people's ability to use the written word for everyday tasks. Thus, people's functional literacy skills were examined in terms of their ability to find and apply information from commonly available materials such as newspapers (prose), forms (documents), and common math processes such as computation for addition or percentages (numeracy). The NALS established a uniform measure of functional literacy and offered a portrait of literacy among adults in the United States. Fully 47 to 51 percent of adults scored in the lower range: unable to use the written word to accomplish many everyday tasks such as finding a fact or two in a newspaper article, finding information on a Social Security form, or calculating the tip on a bill.

This information was a wake-up call to some researchers in the health field. We must remember that it takes a while for information to spread and, especially, to cross over disciplinary lines. Of course, the 1993 NALS findings are still 'news' to many people in health and even in education (see the side bar on page 8 for a discussion of the diffusion process). But, as a result of these published findings, some health researchers began to think about people's ability to function in health care settings and carry through with tasks many doctors and nurses take for granted: the ability to read announcements and learn about screening, to read directions on medicine labels, to follow recommended action for self care.

Among those at the forefront were Ruth Parker and Mark Williams, medical doctors practicing in a public hospital in Atlanta. They were interested in measuring and documenting people's functional literacy skills related to medical tasks. In 1995, Parker and Williams worked with colleagues in education and measured people's ability to read appointment slips, medicine labels, and informed consent documents. They then used these tasks to develop a functional test of health literacy for adults in both English and Spanish (TOFHLA) modeled on the NALS. Studies undertaken by a team of researchers working with patients in a public hospital indicated that 41 percent of patients did not understand basic instructions, 26 percent did not understand appointment slips, and 60 percent did not understand informed consent forms (Parker et al., 1995; Williams et al., 1995). Findings from these studies are being used to convince doctors that literacy is something to which attention should be paid.

With the development of the REALM (1991) and the TOFHLA (1995), people assessing the readability of written health materials could now more precisely examine the match between the materials and the reading ability of members of the intended audience. Furthermore, researchers now had tools for a quick assessment of literacy skills so that they could include measures of literacy in health studies. As a result, we've learned that people with low literacy skills come into care with more advanced stages of prostate cancer (Bennett et al., 1998); that they have less knowledge of disease, medication, and protocols for asthma, hypertension, and diabetes (Williams et al., 1996, 1998); and that they are more likely to be hospitalized than are patients with adequate literacy (Baker et al., 1998). These studies set the foundation for rigorous research into ways that limited literacy skills may affect health.

"... teachers and directors were cautious about the appropriateness of asking adult education teachers to teach health content. This is not, after all, their area of expertise."

On the Literacy Side

Health topics have long been included in curricula for students in adult basic education (ABE) classes and in English for speakers of other languages (ESOL) courses. Making appointments and identifying body parts in English were seen as necessary survival skills, particularly, for example, in refugee resettlement classes in the 1980s. Topics such as nutrition and hygiene were popular with many teachers, who reported that health issues interested their students and could be used as the subject of reading materials for developing reading and writing skills (Rudd et al., 1999a).

In the early 1990s, links were being forged between health educators and adult educators. For several years, the National Cancer Institute supported regular working group meetings of health and education researchers. Local initiatives such as those developed by Sue Stableford at a medical school in Maine, Kathy Coyne at a cancer center in Colorado, and Lauren McGrail at a nonprofit organization in Massachusetts worked across disciplinary lines and linked health researchers and practitioners with adult educators. They could now work together on developing appropriate health materials and on bringing

health curricula to adult education programs. Over time, some model program funds from the National Institutes of Health, the Centers for Disease Control and Health Promotion, and, in some cases, state Departments of Public Health, supported the development of adult education curricula in specific topic areas such as breast and cervical cancer or smoking prevention. The idea of integrating health topics into adult learning centers was based on the assumption that health curricula would enhance the goals of the health field while also supporting the goals of adult education. Health practitioners working with the adult education systems gained access to and communicated with adults who are not reached through the more traditional health outreach efforts and communication channels. Thus, adult education learning centers provided the health field with an ideal site for reaching poor, minority, and medically underserved populations.

Bringing health topics to adult education programs was similarly viewed as beneficial to the adult education system. Teachers focused on health-related lessons would be building skills for full participation in society. In fact, NCSALL studies indicated that state directors and teachers considered that a health-related content would likely engage adult students and thereby increase learner interest, motivation, and persistence (Rudd et al., 1999a, b). Several curricula, such as the *Health Promotion for Adult Literacy Students* (1997), *Rosalie's Neighborhood, What the HEALTH?*, and *HEAL: Breast and Cervical Cancer* offered substantive full curricula for teachers who wished to offer in-depth health lessons incorporating basic skill development.

However, the NCSALL survey revealed that teachers' and directors' were cautious about the appropriateness of asking adult education teachers to teach health content. This is not, after all, their area of expertise.

Literacy for Health Action

Teachers' and directors' discomfort with responsibility for certain health information led a number of us working in this area to move away from a focus on health content towards a closer examination of literacy skills needed for health-related action. After all, adult educators have the expertise to help learners build basic skills related to reading, writing, vocabulary, verbal presentation, oral comprehension, as well as math. These skills are critical for adults who need to fill out insurance and medical forms, describe or monitor symptoms, manage a chronic disease, listen to recommendations, and make health-related purchases and decisions. Furthermore, many of us were interested in expanding our work beyond the medical care setting and a focus on disease to a more public health focus with attention to maintaining health at home and in the community.

> *"Professionals in public health and health care do not have the skills or mechanisms to improve the literacy skills of their community population or of their patients. They can, however, work to improve their own communication skills ..."*

New opportunities for productive partnerships may come about because of a growing emphasis on health literacy. The term has been defined in several ways. The US Department of Health and Human (HHS) Services' publication *Healthy People 2010* defined health literacy in terms of functional literacy related to health tasks: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (US DHHS, 2001). This definition, although focused on health care, is general enough to include health-related activities outside of medical care settings such as maintaining our well being, caring for ourselves and others, and protecting our health at home, in the community, and on the job. Tasks can include reading a patient education brochure, deciding whether to buy a brand of food based on nutritional labeling, figuring out how to use a particular product, or choosing a health insurance plan.

A partnership between the US Department of Health and Human Services and the developers for the National Assessment of Adult Literacy (NAALS) planned for 2002 led to the inclusion of health-related tasks in this second wave of adult literacy assessment. Therefore, the 2002 NAALS will include three different clusters of key types of health and health care information and services that the general population is likely to face, identified as clinical, prevention, and navigation. The clinical area will include activities such as filling out patient information forms or determining how to take a medicine. The prevention area will include tasks such as identifying needed changes in eating or exercise habits. Finally, the

navigation area will include tasks related to understanding rights in health care or finding information in health insurance plans.

In addition, health literacy is included in the goals and objectives for the health of the nation. *Healthy People 2010* is the planning document that sets health objectives for the nation and is used in national and state plans and to shape requests for proposals for federal funds. It offers 467 objectives in 28 focus areas, making this decade's report, according to the Surgeon General's report, an encyclopedic compilation of health improvement opportunities (US DHHS, 2001). This document now includes literacy-related objectives for the first time. Objective 11.2 is *to improve the health literacy of persons with inadequate or marginal literacy skills*. The listing of a specific literacy-related objective is listed under health communication and is also referenced under oral health. This attention is viewed as a milestone.

Professionals in public health and health care do not have the skills or mechanisms to improve the literacy skills of their community population or of their patients. They can, however, work to improve their own communication skills, the procedures followed for communicating with and interacting with people, and the forms and materials they write. Health workers at all levels would benefit from interactions with adult educators who could help them better understand the communication needs and learning styles of people with limited literacy skills. In addition, those in the health field are increasingly aware that a population with good literacy skills may make better use of health information and health services than those with limited skills. The potential benefits from partnerships between those in the health fields and those in adult education are becoming clearer.

New Collaborations

The health literacy objective in *HP 2010* may offer new and different opportunities for collaboration between practitioners in health and in education. Many of the early partnerships, as noted above, were focused on bringing health-related topics and curricula to basic education or language programs. The emphasis was on bringing new information to adult learners. Because the health literacy objective in *HP 2010* focuses on skills, new partnerships may more easily emphasize health-related tasks and related literacy skills rather than specific health topic areas such as cancer or diabetes.

> *"Health workers at all levels would benefit from interactions with adult educators who could help them better understand the communication needs and learning styles of people with limited literacy skills."*

Adults take health-related action in multiple settings; they determine priorities and consult and solve problems with family, friends, neighbors, and fellow workers about health-related issues and actions. In today's society, adults may need to find information on the Internet, differentiate fact from myth, or establish the source of information. Thus, skill-building opportunities related to forms, directions, and information packets are important but do not suffice.

For example, adults who have accessed care and successfully developed the needed skills to follow the complicated regimen to manage asthma may still face difficulties with asthma triggers beyond their control. Living in a multifamily dwelling with exposure to cigarette smoke, dust, mold, mildew or roaches; living in a neighborhood with heavy traffic or idling buses; and working with a variety of chemicals all have asthma-related consequences. Becoming aware of new findings, gathering information, participating in tenants' associations, and involvement in community or labor action groups require skills related to research, discussion, analysis, decision making, and action. Thus, as we explore this area and define needed skills, we must be sure to move beyond the realm of medical care and include action taken at home, at work, in the community, and in the policy arena.

Many of these broader communication skills are already being taught in adult education programs. Adult educators focus on language and vocabulary acquisition, reading, writing, numeracy, oral comprehension, dialogue, and discussion. Their expertise can support and enhance health literacy goals. Health-related curricula incorporating attention to these skills can enrich adult learners' experiences and will support health literacy goals. With a focus on health literacy skills, the *HP 2010* objectives will encourage health practitioners to work with adult educators on the delineation of needed skills to support health literacy rather than on a transfer of health information.

Another task is at hand as well. Many of the health-related literacy tasks under discussion involve the use of existing medical documents such as appointment slips, consent forms, and prescriptions. An underlying assumption is that the materials and directions are clear and appropriately written. Yet, we know from the results of more than 200 studies that the reading level of most health materials is well beyond the reading ability of the average reader and that the format or presentation of information is similarly inappropriate (Rudd, 1999a).

The links between literacy skills and oral comprehension have not been explored in health studies and the vocabulary of medicine and health may well provide barriers in spoken exchange.

Twofold Strategies

As a consequence of these findings, strategies must be twofold: increase adults' health-related literacy skills and increase health professionals' communication skills. Adult educators can contribute to these efforts. Their skills and experience can help health professionals to understand better the factors that contribute to reading and oral comprehension. Educators can also help health professionals to improve written materials and, perhaps, verbal presentation of information as well. The Canadian Public Health Association, for example, has mandated that all materials geared for the general public use so-called plain language and avoid the jargon, scientific vocabulary, and complex sentences that make materials difficult to read. Accreditation committees are increasingly encouraging hospitals and health centers to examine and redesign their documents and procedures for informed consent. Expert advice from adult education professionals will clearly be needed and welcomed.

A new partnership between health and adult education researchers and practitioners can also contribute to improved teaching and learning in both fields. Studies of participatory programs, participatory pedagogy, and efficacy-building in classrooms, community programs, and doctors' offices indicate that learning is enhanced and change is supported through experiential learning opportunities. Roter and colleagues (2001), for example, provide evidence for the value of adopting lessons from participatory pedagogy in doctor/patient encounters. Minkler (1989) and Green and Kreuter (1999) have long supported such approaches for health promotion on the group and community levels. However, participatory programs and experiential learning are still not the norm in either heath or adult education settings. Perhaps partnerships among practitioners in both fields will lead to rich explorations of approaches that support adult learning.

Health literacy is a new concept that is getting a good deal of attention. We can support healthful action by considering the skills needed for active engagement and by envisioning the adult, healthy or ill, as an active partner and decision maker. Educators, researchers, and practitioners can work together to explore strategies for improving communication, increasing needed skills, and fostering efficacy.

"A new partnership between health and adult education researchers and practitioners can also contribute to improved teaching and learning in both fields."

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Diffusion of Innovation

Health teams are often put together by literacy programs that run literacy and health projects; for a report on one such team, see the article on page 30. These teams of self-selected participants explore health issues and then teach their friends and neighbors what they have learned. The underlying literacy assumption in this model is that using literacy skills for purposes outside the classroom enhances motivation and learning. The underlying theoretical assumption is that change is promoted through ideas or information introduced by people with whom you can identify. This assumption is supported by a model called *diffusion of innovation*. This model is very useful in helping us answer two critical questions: How do ideas spread among a group of people over time? How can we speed up this process?

> *"How do ideas spread among a group of people over time?"*

The diffusion of innovation model offers a lens through which we can better understand the growing interest in literacy within the health field. It might also help us shape a strategy to speed up the diffusion process: to build further interest as well as to design health literacy programs. This model is well over a hundred years old and comes out of agricultural extension, anthropology, and sociology. It has been most recently defined by Everett Rogers (1995), a communications expert and academic, who began his studies with an examination of how new agricultural techniques spread in a farming community.

The diffusion of innovation model describes the way an idea or product enters a social system and is "adopted' by groups of people within that system. For example, findings from the National Adult Literacy Survey (NALS) were published in 1993 and disseminated within the education field and among policy-makers focused on education. These findings began to spread slowly into other fields. A small but growing group of health researchers and practitioners recognized the importance of these finding and began to conduct research studies linking health to literacy skills. Others among them created educational presentations and training programs for their colleagues. Health literacy is now included in the goals and objectives for the nation in *Healthy People 2010*. In addition, functional literacy tasks related to health will be included in the National Assessment of Adult Literacy Survey (NAALS) scheduled for 2002. At the same time, however, the findings from 1993 and the work that followed are still news to many researchers, practitioners, and policy-makers in medicine and public health. The dissemination efforts must continue.

How would we describe this diffusion process thus far? What helped it along? The diffusion of innovation model reminds us that the diffusion and change process is often gradual and depends on a number of key factors: the characteristics of the innovation itself, the social system within which the

innovation is introduced, the available channels of communication, and the change agents who help spread the idea.

The Innovation

An innovation is defined as something new to the people to whom it is being introduced. In our discussion, the innovation is the awareness of possible links between literacy and health. This innovation is complex because it requires knowledge about the NALS survey and NALS findings as well as the implications for health action. Because the NALS findings were perceived as an education issue, the characteristics of this innovation hindered rather than helped its diffusion among people in the health fields.

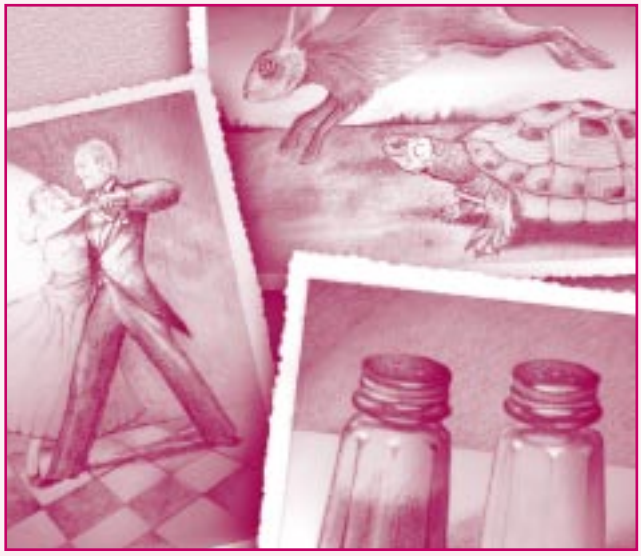
The Social System

The diffusion model informs us that the spread of information or ideas is influenced by the social system. The health field is a complex system comprised of many different professional groups. Each group identifies with its own discipline: public health, medicine, nursing, and so on. And, of course, there are subspecialties within each group.

In addition, the social systems in health and medicine are hierarchical. For example, medicine tends to have more political clout than does public health. The letters following a researcher's name have layers of subtle influence. And, finally, more attention is drawn to research findings in medicine than in other health fields such as nursing, considered a lower-status field.

Channels of Communication

New information related to health is diffused through professional peer-reviewed journals and face-to-face at meetings. However, each discipline has its own journals. Nutritionists, epidemiologists, health educators, medical doctors, hospital administrators, and public health program specialists may all read different journals. Contemporary professionals struggle to keep up with publications in their own field, let alone any others. As a result, professionals do not necessarily read research published in other fields. In addition, public health epidemiologists, for example, tend not to go to the same professional conferences as public health educators or public health nurses. Generally, doctors and nurses do not attend the same meetings and do not take part in the same professional education courses. On the surface, the limited channels of communications — journals, professional meetings — makes it appear that the communication process could be easy, but the multiple layers of professional groups within the health field slow down the diffusion process.



Change Agents and Channels of Communication

The diffusion model informs us that information and ideas are best transferred by people like those to whom the new ideas are being introduced. Health educators and nurses, perhaps because they were most closely linked to the education field and are often responsible for patient education, became aware of the NALS early. Many of the first studies related to literacy and health were published in nursing and health education journals and were often focused on examinations of the many pamphlets, informational booklets, and directions used with patients. Most of the studies published in the 1980s and throughout the 1990s were concerned with assessments of materials. More than 200 studies found these materials to be inappropriately written, often at reading grade levels above high school. Professionals from other health fields did not necessarily know about this body of evidence.

In the early to mid-1990s, a few researchers at medical centers and schools began think about patients' ability to comprehend medical instructions. Study findings, written or coauthored by medical doctors and published in medical journals, were more likely to be read by other doctors. Therefore, the attention of doctors and researchers increased with the publication of about a dozen studies examining the association between low literacy and medication-taking, disease management, and hospitalization. A White Paper on health and

literacy published in 1999 in the prestigious *Journal of the American Medical Association* increased awareness among doctors and medical researchers of the potential health consequences of limited literacy.

Reinvention

Rogers also notes that reinvention is part of the diffusion process. As awareness of health and literacy links were disseminated, researchers and practitioners in public health began to expand the definition of health literacy. The idea that health literacy should be defined and measured by what takes place within the doctor's office or within an institutional setting is slowly being replaced by a broader vision that incorporates health promotion and health protection activities that take place where people live and work. Some of these will be included in the 2002 national assessment of adult literacy noted earlier. It will include functional literacy tasks such as finding information in a health article, an insurance plan, or a food label. This broader notion of functional health literacy calls for an additional set of skills related to fact-finding, decision-making, participation, and advocacy. Many of these skills are rooted in a sense of efficacy both for individuals and for people working in groups. This brings us full circle back to the health team activities noted earlier.

Future Efforts

The health team activities and several other examples of innovative practices in adult education can be enhanced or developed through insight from the diffusion of innovation model. The diffusion model supports good curriculum planning. It encourages us to think about what topics and skills are most needed by and fit into the interests of the students, how new ideas and skills are best introduced, what kinds of activities best support learning and adoption, and what activities would best support the further diffusion of ideas and skills beyond the classroom.

Research tells us that the strongest channel of communication is face to face. Of course, the education system is based on this powerful communication channel. Within the adult education classroom, teachers are in the best position to introduce new ideas. They serve well as change agents because of the close contact they have with their students and because they are often well trusted by their students. The educator introducing new ideas and skills to adult learners is a diffusion process. How might this setting support a much wider diffusion effort?

> *"...program design must involve partnerships involving professionals from both fields."*

If adult learners are viewed as possible change agents in their own communities, then lessons can be shaped to help them develop the needed skills to become change agents. Their work in class can increase their reading skills, vocabulary, inquiry skills, ability to read and understand charts, ability to fill out forms, and, of course, their knowledge base. This class work combined with practice opportunities and assignments that take them outside the classroom can enhance their ability to engage with and perhaps teach others. Materials used in class can, if shared with these adult learners, provide them with the tools needed to reach out to others in their family, at work, and in the community. Organized teamwork and opportunities to help others enhance a sense of efficacy and support change as well as the diffusion process.

How else might this model shape future efforts? Increased health literacy must involve educators as well as health professionals. We know that adult educators are more likely to adopt materials developed by experts in their field. Health professionals are likewise more apt to attend to and approve of processes and materials developed by health professionals. Thus, program design must involve partnerships involving professionals from both fields. Furthermore, if educators and health professionals conduct studies and publish together, these results are more likely to draw the attention of researchers in both fields.

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Resources

Many health education textbooks offer discussions of different social and behavioral theories. A small handbook for practitioners offers a good start:

Glanz, K., & Rimer, B.K. (1995). *Theory at a Glance: A Guide for Health Promotion Practice*. Maryland: US Department of Health and Human Services. National Cancer Institute (NCI). NIH Publication No. 95-3896.❖

Struggles: Writing as Healing

A writing program in a prison addresses the violence in participants' lives

by Leslie Ridgway & Dale Griffith

York Correctional Institution (YCI), Connecticut's maximum-security (and only) female prison, is located in the shoreline community of Niantic. The majority of the approximately 1,300 residents are African-American or Hispanic who come largely from the state's cities. Most are incarcerated for crimes related to drug use. Their length of stay varies from one day to life.

Inside the walls of YCI is York School, where a 32-member staff offers adult education services in basic literacy, adult basic education (ABE), general educational development (GED), vocational training, English for speakers of other languages (ESOL), special education, and college courses (available through local community colleges). In addition to the teachers, the school staff includes a librarian, four pupil service counselors, three administrators, two administrative assistants, two correctional officers, and two part-time transitional counselors.

The school, which operates year-round, serves about 400 students daily, ranging in age from 15 to 60, with classes running from 8 am to 11 am and 12:15 pm to 3 pm. College classes and other special programs are conducted in the evenings. Anyone who wants to attend school is eligible; the only requirement is to be discipline-free for 90 days. The school's mission states that York School "will provide a positive learning environment for all students that promotes lifelong learning through academic, vocational, life skills, and college programming." To a large degree, the school fulfills its mission.

The Problem

In the past, Niantic's prison has served as a model for other women's institutions across the country interested in treatment leading to rehabilitation. Since the mid-1990s, however, the political tide has turned. In Connecticut, tougher views on the treatment of convicts have resulted in longer sentences and fewer treatment programs. Custody has become the primary concern, and new staff trainees follow a rigid military model, creating an "us versus them" mentality. Most women are not incarcerated for violent crimes, and, while the prison has always had its share of disruptive inmates, most residents are compliant. Still, under the new system, all YCI inmates receive harsh treatment and few privileges, even when their behavior is exemplary.

Within this climate, the inmates of YCI suffer more humiliation than under the old system. This often awakens old traumas. For example, inmates were once called by their given rather than their last names; now, they are referred to solely by last name. This may seem like a small change, but it symbolizes the increased distance of the present order. In a prison, the staff's authority cannot be questioned, so residents often bury feelings. Some inmates explode either by harming others or themselves. Mental health services, overcrowded and understaffed, provide little help; women dislike being sent there.

Learning had become difficult. Many women had reached the limit of their coping skills. At the school, educational staff worried about the women's mental and physical health and discussed ways to help them cope. A safe port in the emotional storm was needed.

Intervention Strategies: the Process

After a double suicide in the spring of 1999, educators joined forces with custody, medical, and mental health staff to form the Women's Health and Healing Committee. The committee brought in health-care providers and educators, who shared the latest in medical research and treatment options. Throughout the academic year, staff also recruited volunteers (writers, musicians, and artists) to conduct workshops with school students. Staff hoped to provide creative space wherein the students' grief might be expressed safely. As the health and arts programs ended their one-year commitment, it became obvious that the women needed continuing vehicles for expression.

We (Leslie Ridgway, school social worker, and Dale Griffith, teacher) both participated in activities that spring and summer

that inspired us to join forces and form a healing-through-writing group for inmates. Physical, sexual, verbal, and psychological violence had impaired the inmates' academic progress prior to incarceration. In particular, many of the incarcerated women had literacy issues. Reading comprehension and writing skills were areas of real concern. Since trauma contributes to learning problems, would writing about trauma improve literacy (Horsman, 2000), we wondered? Might writing about trauma also heal deep emotional wounds and contribute to rehabilitation?

Writing deeply about painful personal experiences can heal the writers (DeSalvo, 1999). In addition, writing without fear of the red pen or criticism improves writers' basic skills and elevates self-esteem (Schneider, 1993). Yet fear of condemnation keeps many inexperienced writers from taking risks (DeSalvo, 1999; Schneider, 1993; Horsman, 2000). What might happen if students were encouraged to write freely and to talk about their feelings with each other?

In the healing-through-writing group, students would use writing as a way to understand how violence (or other trauma) had affected their ability to learn. We drew upon Pat Schneider's book, *The Writer as an Artist: A New Approach to Writing Alone and with Others* (1994), for suggestions on how to run the group. According to Schneider, each member of the group must write, but only those who want to share their writing do so. All work is treated as fictional (disguising nonfiction as fiction if desired), freeing women to write personal stories yet retain privacy. No one's work is criticized. Responses are limited to what worked well and what might be deepened. Confidentiality is of utmost importance.

For the experimental group, 15 African-American and white participants of all academic levels were selected, based on their interest and teacher recommendation (in subsequent groups, English-speaking Hispanic-Americans were included). Writing ability was not a factor in selection. One student suggested calling the group *Struggles*, and the name stuck. The workshop was originally slotted for an eight-week session, with Leslie and Dale acting as facilitators. Leslie would monitor the clinical process of the group and deal with crisis intervention. Dale would lead the group's writing exercises and record the group's progress.

In Jenny Horsman's groundbreaking book, *Too Scared To Learn* (2000), she indicates that learning difficulties are closely related to trauma. She also emphasizes the

Student Writing

I remember a time when...

I remember a time when I finally fought back to protect myself while my mother was beating me. I was 20 years old and the mother of two, but still the victim of my mother's unhappiness.

As children we're taught to respect and obey our parents. Usually I covered with my hands up protecting my face and head. A reaction that I'm sure is a defense mechanism of survival. I didn't harm my mother, but my physically defensive behavior of pushing her away from me shocked her back into reality. The beatings finally stopped and I was left with the question as to why I hadn't reacted to her actions years earlier. Then again, respect for your parents and the physical abuse from them are a hard combination to explain to a child.

If I could I would...

If I could I would shatter the cycle of abuse, so not one more child, woman or man needs to live in fear. Physical abuse breaks bones, but emotional abuse breaks your soul.

I hoped you wouldn't hurt me...

I hoped you wouldn't hurt me, but I know that I was wrong. I could see the signs in the beginning but I shrugged them off. I thought it would get better, now I know it wasn't right to think that I could change you. The hope that I had was that I could do you some good. Now I see what I didn't see. I wouldn't help myself. I hoped you wouldn't hurt me but I knew that I was wrong but now I see it differently, it wasn't me it was you. Now I hope you find peace the way I have. The hurting is gone. I had hoped you didn't hurt me but through that hurt I've learned I don't have to change anyone else. The change lies within me, and I am in the hands of God.

importance of creating a safe physical space where internal healing and learning can take place. With this in mind, coupled with suggestions Leslie brought back from the training provided by the Women, Violence, and Adult Education Institute, we decorated the classroom with lace tablecloths, pillows and quilts, and fresh flowers. All decorations had to be approved by custody officials. Later, we added a stuffed animal. Following Horsman's model, we arranged chairs in a circle, with one special chair placed outside the circle, in case a woman chose not to actively participate. We never had more than one participant at a time who "needed" the chair.

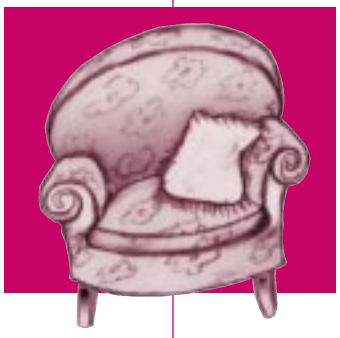
Our first meeting began with a cohesiveness-building exercise, including having the women establish their own guidelines, which were posted at subsequent meetings. Some of them were: no monopolizing, confidentiality, respect, one speaker at a time, and using "I" statements. We issued inexpensive "blue books" for their writing. At the third meeting, when membership had crystallized, cardboard composition books, a treasure in the prison, were distributed. The women decorated and personalized their *Struggles*' journals using fabric, lace and ribbon, and colored paper we provided.

We wrote along with the women and shared our writing. The format developed on a weekly basis, according to trial and error. Dale recorded weekly difficulties, exercises, and triumphs in a journal. In the beginning, we encouraged the women to write directly about violence. As a prompt, we suggested: *Violence means…* The women resisted, writing vague passages with little detail. However, when poems such as Maya Angelou's "Caged Bird" were offered, the women responded readily, identifying with authors' feelings. We decided to use a more indirect approach, using a variety of published work for prompts. The result was positive, as this quote indicates: "The poems were very meaningful — they prompted us to explore our feelings in depth; some of them stay in your mind for a long time."

The women decided to end each session by issuing a wish or a blessing to the person next to her. Mary might turn to Sarah and say, "I wish you peace and serenity for the next week" or "You are a child of God." Group members told us that the closing ritual was a powerful tool for building group cohesiveness. We encouraged the women to change seats weekly to build new relationships. We distributed note cards before the end of each week's session on which members could make private comments or request a session with Leslie. Before each woman left, she received a dab of scented hand lotion. The women looked forward to the lotion and said it made them feel special.

> *"… students would use writing as a way to understand how violence (or other trauma) had affected their ability to learn."*

The women gradually shared more of themselves as trust grew. One woman wrote, "Writing about violence has given me the chance to talk about my family's darkest secrets. It allowed me to get over my fears. As a child growing up I was not allowed to tell anyone that I was being abused mentally and physically. I didn't like opening up to others. I now am able to open up a little because I was able to share my family's darkest secrets. This group has helped me a lot." As the workshop's end neared, the women voted to extend the group for eight more weeks, with the participants taking greater charge. We assumed less active roles, but continued to provide support.



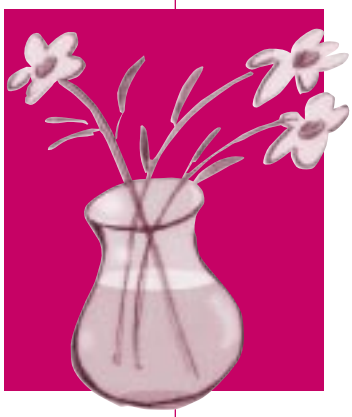
Word of the workshop spread throughout the school, and requests for another session poured in. Group members from the original workshop were invited to become facilitators for a second session of *Struggles*. Four women, not all of whom had displayed leadership qualities during the course of the workshop, volunteered. Two new workshops were formed to run simultaneously. Using our notes and journal records, we created a curriculum guide and trained the new leaders, holding weekly meetings to provide support for the peer facilitators. Leslie continued to provide crisis intervention.

Difficulties

In a maximum-security prison, difficulties are inevitable. In *Struggles*, most of the difficulties were outside the group's control. Physical safety and security are always the prison's top priority, so if an emergency (such as a medical problem, a fight, or a miscount) occurred, the school would close. In addition, vacations, holidays, and staff obligations occasionally interfered with the group's schedule. Finding the physical space to meet also presented problems for our second session. Regular classroom space was juggled to accommodate the group, and, at times, privacy was interrupted. Student members were amazingly flexible.

Student group leaders had little planning time, so lack of communication caused some trouble. For example, as a group leader, Judy

planned each session carefully, while Mary, her partner, preferred improvising. Yolanda had difficulty with reading aloud, so she needed extra support to feel comfortable in her leadership role.



Trust is an important issue in any group. For the women at YCI, trust may be the issue. While confidentially was a firm rule, and generally honored, one member shared another woman's business outside the group, but, rather than ignore the issue, the group managed to resolve the problem through group discussion — without staff intervention.

Successes

One year later, *Struggles* continues to evolve. In the second session, student facilitators selected their own opening and closing exercises, added poems, prose, and prompts — in short, each group built its own identity, establishing a culture specific to its participants. We became advisors, sitting outside the circle, taking attendance, handling any disciplinary problem, and distributing materials.

An advanced *Struggles* group (for those who completed the first workshop and wished to continue) is now in session. According to the students' evaluations and feedback, the group has been a great success. Poor attendance and high drop out rates are chronic problems at York, yet *Struggles*' workshops have claimed near perfect attendance and program completion. Teachers have observed increased confidence and expertise in oral reading, writing, and general literacy from students who have completed *Struggles*. Beyond academics, *Struggles* graduates demonstrate an improved attitude toward school, better coping skills, and elevated self-esteem.

The women from the *Struggles*' group testify to its success: "Seeing our violent experiences in writing is more personal and real — especially when we read them aloud. When I hear myself aloud, I'm relating my experience to someone else, and the emotional feelings, which have often been repressed, hit me." *Struggles* is establishing itself as a regular part of the school's literacy curriculum and adding further evidence to the growing body of research about the healing properties of creative expression.

"Writing helps me to bring out what was inside."

"I think it's a lot easier to express yourself in writing because you don't seem to stumble over the words as much. The pen just flows..."

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About the Authors

Leslie Ridgway, a clinical social worker, has worked at York Correctional Institution in Connecticut for about four years. Ms. Ridgway was a public school social worker in Massachusetts and Connecticut. In her 16 years as a clinician, she has also worked in community mental health and private practice.

Dale Griffith, a state school teacher, has taught at York Correctional Institution, Connecticut, for more than seven years; she has also taught English courses at Middlesex Community College, Middletown, CT. ❖

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Focus on Basics electronic discussion list is a forum for discussion about the articles published in *Focus on Basics*. It is a place to converse with colleagues about the themes examined in the publication; to get questions answered and to pose them; to critique issues raised in the publication; and to share relevant experiences and resources.

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Reflections on the Women, Violence, and Adult Education Project

by Elizabeth Morrish

Quantitative research has established conclusively that domestic violence is a factor in approximately six percent of all US households, and that 20 percent to 30 percent of women receiving welfare are current victims of domestic violence (Raphael, 2000). Fifty-five percent to 65 percent of women receiving welfare have experienced violence sometime in their lives (GAO, 1998). According to statistics reported in the Bureau of Justice Statistics Special Report "Violence against Women," violence occurs more frequently in families with low incomes. Average annual rate of violent victimizations per 1,000 females was 57 for families with incomes below $10,000 and 31 for families with incomes between $30,000 and $50,000. Level of education was also found to correlate with the rate of violence. For victims with less than a high school diploma the average annual rate of violent victimizations per 1,000 females was 48, compared to 28 for female victims who were high school graduates (Bachman & Saltzman, 1995).

Concerned with violence as a barrier to learning in adult basic education, World Education sought funding through the US Department of Education Women's Educational Equity Act that would enable six programs to enhance educational services for women who have or are experiencing violence by exploring changes in practice and policy. Drawing on the work of researcher Jenny Horsman, who participated in the project, we named as violence many forms of oppression and trauma, including domestic violence, violence by institutions of the state, childhood abuse, workplace violence, and rape. Two years later, we articulate these assumptions about violence:

- violence is pervasive and takes many forms;
- different forms of violence are intertwined;
- violence is supported by institutions;
- violence affects all of us; and
- by participating in institutions that perpetrate violence, we all perpetuate the violence our society supports.

We wanted a project that would support adult education practitioners because we saw that teachers know how widespread violence is and yet hesitate to weave their understanding into their practice. The project gave participants the legitimacy and the support needed to explore the complexities of these issues. One teacher described her inability to connect the implications of violence to her teaching before participating in the project:

> I already knew about violence. And I already knew that oppression is a form of violence. I am politically conscious. But before the project, I never put my politics together with my teaching... . The project made me more sensitive in my teaching position. Before, when someone had an attitude or went to sleep in class it would aggravate me. Now it's a red flag for me. Before it was, "Look, if you're not coming here to learn, don't come." Now, I say, "Are you OK?"
>
> Now I have a different mindset. I've seen that there's a connection between counseling and teaching. I wasn't aware of this before… . I will forever be more conscious of the issue as it affects women in the classroom.

Project participants gathered for a photograph during one of a series of workshops. Back, left to right: Tammy Stockman, Katy Chaffee, Janet Smith, Janice Armstrong, Kimberly McCaughey, Nancy Fritz, Gloria Caprio, Margie Parsons, Michele Rajotte. Middle, left to right: Caye Caplan, Char Caver, Bernice Morris, Maria Salgado, Elizabeth Morrish. Bottom, left to right: Anna Yangco, Ruthie Ackerman, Jenny Horsman.

The initial Women, Violence, and Adult Education project event was an introductory institute held in April, 2000. Adult education practitioners gathered from across New England to explore issues of violence and oppression. Programs then

applied to become part of the three-year project that would explore ways to address the implications of violence on learning. Six programs were chosen; teachers from these programs participated in a series of four two-day training workshops to share ideas, discuss research, and create a supportive community of educators. Wherever possible, at least two teachers participated from each program. This group of teachers has developed strategies and materials that now, in the final phase of the project, are being compiled in a *Sourcebook* that will be published in the fall, 2002. (Look for information about it in future issues of *Focus on Basics*.)

In selecting participants, World Education was looking for geographic diversity, a variety of program structures, and a variety of student populations. We chose the York School, described in the article that starts on page 11; Vermont Adult Learning, a welfare-to-work program in a small town; Even Start Learning, Innovation, Nurturing, Knowledge, Success (LINKS), a program in rural Maine that works with families in their homes; Project Hope, located in a shelter for homeless women in Boston; the Community Education Project, based in a community organization in a small town in Massachusetts; and the Genesis Center in Rhode Island, which provides classes in English for speakers of other languages (ESOL). What happened in each of these programs is profound. Working on the project shifted people's thinking: it changed teachers' practices and influenced students to make new decisions about education and work. While all programs will be featured in the *Sourcebook*, in this article, space restricts me to highlighting the work from three programs. I will outline the activities of the programs and share the views of teachers and students. The examples are taken from personal observation, project reports, and interviews.

Vermont Adult Learning

The White River Junction "Getting Ready to Work" is a regional program funded to serve welfare clients, primarily women who are single parents with work mandates. Teacher Katy Chaffee wrote, "Their lives are compromised by very little income. As a result of recent changes in welfare legislation there are enormous pressures and stresses on our participants." She talked more about this when interviewed about why the program joined the project:

> "Poverty itself is an act of violence."

We're in this whole structure of violence at the same time we are trying to acknowledge it in other women's lives. It is sitting here even in how we are being asked to work. I don't want to go there — it hurts. I was living it. I saw the life raft out there, I went "Yeah! Grab it!" And so [one of the teachers] participated in the institute and she talked about there being one violence… . So then you have to look at how you participate in that [violence], too.

The program, housed in a storefront on Main Street, draws people from a wide geographical area. They offer classes and individual help. Both participating teachers saw institutional violence as a reason to join the project. Teacher Tammy Stockman explained:

I have been aware for years that violence in every possible form is a huge part of the women's lives. Poverty itself is an act of violence. Often the women had to leave early to go to court. Our site was right around the corner from the court house, and the women were in and out of there all the time, dealing with custody and child support issues, addiction issues, abuse issues. The violence is systemic, not just episodic. The system is set up to hurt and to continue to hurt poor women.

When asked what she was hoping to gain from joining the project, Tammy replied:

Lately, it seems like the violence has been getting worse, and we needed more support than we were getting. One woman came to class with a loaded pistol because of an abusive partner. There was no place for us to get trained in how to deal with things like this because the people above us didn't want to hear about it. They'd say, "Don't tell us that there are so many women affected. We don't believe you." What can you say to something like that?

Participating in this project enabled us to openly discuss violence as a reality and to ideally come back with a language to describe it and statistics to say, "You're wrong. This is a huge problem." I am hoping that once this project is over, we will be well informed and have strength in numbers. The people above us won't be able to sweep it under the rug so easily.

Inspired by the model of self care provided by the introductory institute, the participating teachers in Vermont decided to begin their project with a staff retreat and invited a therapist to join as a mentor-advisor. Katy said:

We needed no further evidence or proof that our participants had multiple experiences of trauma and violence. Did they also have ideas and experiences of wellness: what it is, what moments of wellness feel like, what it would be like to live well; what words that describe it?

The staff emerged from their retreat determined to focus on wellness and to see if this would change the outcomes in their welfare to work program. They were being pushed to become more focused on getting students out of the education program and into work. Nevertheless, they started a well-being support group that

met once a week as a regular part of the program. They hired outside consultants — "experts" — to teach and joined the courses as participants.

They piloted three consecutive courses consisting of eight to 10 two-and-a-half hour sessions each. The first was on mindfulness, the second on creative writing, and the third on collage, facilitated in turn by a therapist, a high school student, and an artist. A turning point occurred in the mindfulness course when they decided to lock the door. Tammy wrote:

How had we been so blind to the signals of stress that our participants had been giving? We realized at this time that [what] we had come to see as trust and comfort was actually at a rather shallow level and that much of our participants' behavior was a direct result of their fear. When the door was locked and the phones turned off and the fear of being interrupted was eliminated, when the collective act of self-care was given top priority and the rest of the world was sent a clear message that this was our time and space, that was when we felt a sense of well being. And that was when trust was built.

Students' reactions included:

I appreciated the safety of this group, that I could try things. In other groups I have felt that I am not as good as everybody else in the room. Here I am not worried about not being able to do what other people can do.

This laid the groundwork for the writing and collage groups. Again the teachers hired consultants and participated as part of the group. Again they unplugged the phones and locked the door. The collage artist they hired was convinced of the power of healing arts in her own life and others. She says:

The creating of one's own artwork is inherently healing and revealing. It allows access to the deeper parts of the self, and as a consequence, draws on and shares in the humanity of all of us.

Following is Katy's report about the collage process. Her reflections and her interviews with students show what a difference this made in the lives of the students and their ability to imagine themselves changing.

There is a cultural expectation that welfare-to-work training should provide goal-oriented, rational, job related programming. This well-being support group provided a weekly personal space for valuing each other, and ourselves for asking questions, and for exploring who we are and what we are meant to do in this world. The format facilitated clarity about career directions for some or an appreciation of personal strengths.

A student commented:

We also imagined a place of well being, and another time, a challenge in our life and then changed places with someone of our choosing.

The students agreed it was valuable to include collage in the welfare to work program. One in particular articulated what developing a collage meant to her:

...It taught me to be in a classroom situation again. I did get a job. It gave me the confidence that I can focus... . I know that the collage I did about change is very important to me. Because I'm very angry at the world that we live in and the conditions that there are. It [the collage] gave me a place to put it just the way it is now. ...It got it out of me. Because I couldn't put it into words — all these things — but I could put it all on the collage. It worked.

> *"How had we been so blind to the signals of stress that our participants had been giving?"*

Katy and Tammy were pleased with the outcomes.

Participation grew and attendance improved. In our program, which is not mandatory, participants often vote with their feet. Participants' enthusiasm developed quickly. Although initially scheduled for four to six weeks, participants wanted to continue longer. We extended the class to 10 weeks.

Participants gained self-confidence and pride in their work. Collage required a unique process of listening to your inner self through right brain work. One of our satisfied artists commented, "There is nothing quite like discovering that inside of you is an interesting person – worth getting to know."

The exploration of interior personal space informed participants' ideas about work, relationships, and values. Career ideas and job direction were never part of the agenda of the collage group. However, greater personal clarity about future directions was an outcome.

Even Start LINKS, Maine

This rural family literacy program sends tutors to work with women in their homes, where it can be hard to focus on literacy skills. Life intervenes, often in the form of violence. A jealous boyfriend lingered at the door with a gun when the tutor was there. Child sexual abuse was hidden by the community, including the local doctors; even the literacy coordinator had felt powerless to address it. The teachers and the students needed support. Participation in this project enabled them to hire a social worker to meet with the staff every month for discussion, counseling, and clinical advice. The coordinator, Janice Armstrong, says the inclusion of a therapist at the introductory institute inspired her to hire the counselor. Otherwise, she says, "it absolutely would not have occurred to me." She described the role of the social worker:

…She gave us an opportunity to

process our roles with the families, helped me process my role as supervisor of the teachers, and [gave the] teachers an opportunity to save up problems and situations that they were uncomfortable with and needed feedback on. They prioritized the problems and we processed them one by one. She gave very objective feedback... one family had a death in the family. She had very specific suggestions like contacting the death and dying support group at the hospital for support and counseling. She knew specifics and could give the teachers that information. Not only that, she was willing to go on home visits. She did visit this family [and] we were able to get all the children into counseling, and arrange for counseling at school.

There were just so many ways she helped the program. The teachers were sometimes very stressed. She had such a calming way. That is very, very necessary for staff in the type of program we work in. To be able to feel that calm, know that there is hope, [that] everyone will be able to carry on in some way.

As part of the project, one of the teachers was trained by a staff person from a collaborating family service agency to facilitate a support group. Once students were able to address issues in this group, and staff could do the same in their monthly meetings, literacy work could be the focus during tutoring sessions. Janice wrote:

... having a women's support group for learners has opened up time for literacy instruction during home visits because the women have less of a need to talk about their problems to the teachers.

> *"We changed 'self-improvement activities' to 'self-empowerment activities'."*

After participating in the project, Janice realized that the teachers and the students had to feel supported for changes to happen. She says this about the student group:

We tried so many different ways to bring these women together and it just didn't work but this clicked. They got together and planned an end of the year trip to Bangor for all their nine families. [It clicked] because of this women's empowerment group. They were meeting together every Wednesday for an hour and then afterwards would stick around and they started talking about what they could do together.

The project resulted in better attendance than usual, and, for the

"There Will be Change" by Aimee Ferland

first time, student ownership and participation in the program planning process. Janice now feels that a counselor is an essential part of her program that she will work to find funding to continue.

Project Hope, Massachusetts

Project Hope is a homeless shelter that recognizes the role of supports in addressing homelessness. They run adult basic education classes in addition to other programming for women. The ABE teachers knew violence was a part of the women's lives at home, on the streets, and in the institutions governing their lives. What convinced them to join the project was the murder of one of the students.

> In February, 2000, one of my [Anna Yangco] students was killed by her son. As a writing teacher, I get to look at people's innermost thoughts. I thought I knew this woman. But she used religion to mask her problem. She would say "it is in the hands of God." Still, I felt I should have known. In the fall she used to write a lot, but after Christmas break she would hardly write at all. I would ask her "Why aren't you writing anymore?" And she would say "Oh, I don't know. I just can't do it anymore." And then she died, I was so upset. I kept thinking. "What could I have done?" I started wondering what I could do to prevent this from happening again. Then, in March, my boss got a flier about the Women and Violence project and told me I should get involved in it. It was perfect timing. So I went to the first institute and I have been involved ever since.

One of the participating teachers was also coordinator of the Paul and Phyllis Firemen Scholarship, which gave women full scholarships for further education after passing their GED. It seemed that because of the generosity of the scholarship, many of the usual barriers to education would be addressed. For the women at Project Hope, this was not so. Something else held them back. Taking on the work around violence enabled the participating teachers to see if creating the conditions for learning was that something. Anna describes how they began:

> When we got back from the first institute, we were thinking, "How do we create positive conditions for learning?" My partner teacher looked around and said, "Why don't we change the room?" So she held a "visioning day" in her class. She asked her students to draw pictures of what they would like the room to look like. She asked, "If you could have anything you wanted in this room, what would it be? No restrictions!" So the students drew these incredible pictures, and we worked on the room all summer based on what they told us they wanted. We painted the walls, added plants, put a little fountain in, got halogen lights instead of the fluorescent ones, bought new, more comfortable chairs. We hung a stained glass panel in the window… . By the end of the summer, the room looked totally different. And when the year began, we noticed a complete change in people's attitudes. They were much more relaxed, much calmer.

"The staff of the programs changed their practices to allow time for activities and elements that are usually considered luxuries in adult education."

Teacher Char Carver describes what was different about the work they were doing as part of the project:

> We changed "self-improvement" activities to "self-empowerment activities" — so we took them to the library [for] a poetry and writing session. Two women got up and read their poems and they had never written before, so it was wonderful! We went out for dinner with the women and they all got dressed up for the occasion. We used music and writing as healing getting them to think outside of the box… . We had an activity period where every week they had to do an act of self-care.
>
> We put money in the budget into childcare, which we didn't have before…the frivolous thing is difficult. We need to put our resources into the women, if we value their endeavor. It's critical that we don't repeat the oppression of poverty. We need to learn how to budget in a different way. How do you explain to other people what you're doing when you buy flowers? But when the women talked about the flowers, they talked about hope.

Anna says this about what she and the students learned from the project:

> I've seen lots of changes. By the end of the year, the women can say, "I'm important." They tell me that they don't worry so much about what everyone else thinks. They think more positively about themselves. Last year, five people went on to college. There are always changes, and it's hard to isolate it to just this project. But I have seen their willingness to take risks increase. At the end of the year, we had a yoga class. This was a big risk. We moved the tables back so that everyone was sort of exposed. We were on the floor doing stretches. If this had been at the beginning of the year, I'm sure no one would have come. But at the end of the year, everyone went. And they came back for all four sessions.

Conclusion

This project has taught us that addressing violence does not mean inviting everyone to disclose. It does

not mean that we need to address violence directly in curriculum and materials. It means creating the conditions for learning that name and recognize the presence of violence in our lives.

The staff of the programs changed their practices to allow time for activities and elements that are usually considered luxuries in adult education. These included creating safe and beautiful space, doing art, and giving teachers and students time to talk and find ways to reflect. The shift in thinking and programming could not have happened without modeling and encouraging three levels of support: care of self, support from within the program, and support from community counseling and referral resources. The teachers report changes in their students: better attendance, improved writing skills, the willingness to take risks which led to the ability to make changes in their career and educational choices. As Katy Chaffee said, "greater personal clarity about future directions was an outcome." Surely that is what much teaching in adult basic education is all about.

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About the Author

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Literacy, Health, and Health Literacy: State Policy Considerations

by Marcia Drew Hohn

Both the literacy and health care worlds are increasingly coming to see the connection between low literacy and poor health as an issue of social and economic justice, and the two fields are starting to address the problem together. Across the nation, a slow but growing movement is leading to initiatives and programs that use an integrated literacy and health approach. Focus on Basics asked me to review the policies and supports being put into place by state adult basic education (ABE) policy-makers that will enable the ABE field to address this national concern. In this article, I provide an overview of five strategies worth considering when contemplating how to engage with literacy and health issues. The strategies were drawn from a series of interviews with Bob Bickerton, Director of Adult and Community Learning Services in Massachusetts; Cheryl Keenan, Director of Adult Basic and Literacy Education in Pennsylvania; Kim Lee, Director of Assessment, Evaluation, and GED at the Georgia Department of Education; Matthew Scelza, Programs and Advocacy Director at California Literacy; and Yvonne Thayer, Director of Adult Education and Literacy in Virginia, all of whom are responsible for initiating literacy and health activities in their respective states. They were chosen for the diversity of their approaches. I also draw from my work in Massachusetts over the last decade as a researcher, practitioner, and advocate in integrating literacy and health education. By no means was I able to interview all the states, programs, and individuals who have been, and currently are, doing meaningful work in the literacy and health arena. The recounting of selected experiences does, however, provide a broad array of ideas for policy and process.

Leveraging Interagency Cooperation

Cheryl Keenan, director of Adult Basic and Literacy Education in Pennsylvania, explains that 1996 legislation in her state created an Interagency Coordinating Council (ICC), an advisory body charged with improving the delivery and outcomes of basic skill services across four key state agencies. In its first full report, the ICC connected adult literacy to several major policy priorities in Pennsylvania, including economic and workforce development, welfare reform, and school improvement. Legislated membership of the ICC was then expanded to include the

Secretary of the Department of Aging and Pennsylvania's Physician General as a representative of the Department of Public Health. In formulating a plan to expand the scope of interagency collaboration to these two new interagency partners, issues related to health literacy were added to the ICC's agenda.

In July, 2001, the ICC sponsored a special symposium on health literacy. Because of Pennsylvania's large number of older citizens, an emphasis was placed on health literacy issues and aging. In addition to ICC members, special guests with interests and expertise in health and health literacy participated. The symposium raised awareness around literacy and health, and stimulated important dialogue among professionals about how to meet the health needs of certain populations, including those who have diverse cultural or linguistic backgrounds, low literacy, or who are more than 65 years old. Embedding health literacy in the work of the ICC, a well-established and visible organization, helped to bring greater attention to the issue. A proceedings paper is providing a foundation for crafting recommendations for action. The implications of low health literacy and the need for expanded interagency partnership will be a centerpiece of the second ICC report, scheduled for publication in 2002.

California Literacy's Matthew Scelza recounts how members of his agency looked at social issues of importance to ABE and were drawn to the research and writing about low literacy and poor health. California Literacy, a private, non-profit organization, develops organizational capacity and leadership among community-based organizations delivering ABE services. Scelza was particularly startled by the finding that 40 percent of Americans cannot understand medication instructions (Williams et al., 1995). "California," he says, "does not have a coordinated effort to address literacy and health issues although there are many exemplary small programs and individual efforts."

"... when literacy joins other public agencies to address a common social issue ... a greater appreciation for the key role of adult literacy emerges."

In an effort to provide coordination and build critical mass around addressing these issues, California Literacy organized a two day event that brought together people from Health and Human Services, California medical providers and insurance groups, the state Department of Education, nursing associations, and other stakeholders in November, 2001. The purpose of the meeting was to build awareness, develop ideas and broaden involvement, and build an action agenda for working together across agencies.

Bob Bickerton, director of Adult and Community Learning Services in Massachusetts, points out that when literacy joins other public agencies to address a common social issue, in, for example, such endeavors as the Massachusetts Family Literacy Consortium, a greater appreciation for the key role of adult literacy emerges. This gives birth to a new group of literacy advocates, frequently raising unexpected voices for support of ABE overall. Bickerton also points out that many ABE advocates in the United States are currently struggling to be defined not solely by workforce development. While employability is important, it is not the only goal for ABE students. Connecting with health has the potential to position ABE more broadly and to leverage investment in literacy for broader purposes.

Enhancing Current Services and Leveraging Resources

Yvonne Thayer, director of Adult Education and Literacy in Virginia, remembers how her state became aware of the connections between low literacy and poor health at the national Adult Literacy Summit held in Washington, DC, in 2000. Recognizing the importance of taking action, but lacking a dedicated stream of funding, Virginia integrated the concept of health into English language services with an emphasis on technology. Bonus points in a funding process were given to projects that included a health literacy component. The state is initiating two levels of activity: enhancing current services and curriculum development. Results from the first year were encouraging. The importance of health literacy was recognized and teacher-student teams developed projects that were shared electronically across the state. For

In this article, the term ABE (adult basic education) is used interchangeably with adult literacy and is understood to include English for speakers of other languages, General Educational Development (GED) programs, the broad array of basic education from beginning literacy through pre-GED, and specialty programs such as Family Literacy and Correctional Education.

* * *

Health Literacy is understood to mean the ability to obtain, interpret, and understand basic health information as well as the ability to apply skills to health situations at home, at work, and in the community (Rudd, 2000).

example, one team created web-based virtual tours of local hospitals, supported by the state technology component that provided equipment, technical assistance, staff development, and software support.

State plans include providing video conferencing that will enable students to talk to each other about the health projects, general health concerns, and other topics of importance to them. The health literacy curriculum development projects are also showing the potential to energize and catalyze the revision of curricula.

At this time, Yvonne Thayer says they are "testing the waters" to see what will work and then evaluate policy and process for the long term. The state is not letting the dearth of specific funds for health literacy deter them. Dr. Thayer points out that states and state directors need to reflect on what is important to the populations served. When states do not have enough funds, she says, look to leveraging already existing funds, making one initiative interactive with another. States also need to think about issues in the broader public domain and connect with the great social issues of the day. ABE engagement in these issues creates public awareness about what ABE is all about and provides information that others can understand. Echoing Bickerton, she reminds us that it builds support for ABE over the long term.

Promoting Contextualized Education

Massachusetts' Bob Bickerton notes that many state directors believe in the need to have curriculum and instruction embedded and contextualized in learners' lives. They support the views of Malcolm Knowles (1989), known for his clear and coherent voice on honoring adults' "need to know" and using immediate questions as fundamental starting points. Mezirow (1990), Brookfield (1986), and Quigley (1997) also all suggest that adult learning must address immediate needs and concerns. Auerbach (1992) and Fingeret (1990) both promote an approach in which literacy education is understood in the context of adults' lives, rather than separated from it. For Fingeret, the context of adults' lives — their issues, problems, aspirations, skills, cultures, languages — creates the basis for literacy work as well as the tools to engage in it. State directors, however, have a difficult time creating an environment that ensures that this actually happens this in the field. As Bickerton notes, "Health can be a wonderful way to begin a different process. Health is a vitally important topic to the ABE learner and their families and communities. It is a common denominator in multilevel classrooms, illuminates the value of group learning, and can be jet fuel for programs to begin discussions about the how contextualized curriculum and instruction is approached, and how curriculum can be reshaped." More on how this works in practice is covered in the following section.

Building Student Leadership and Enhancing Literacy Education

Building student leadership has been both the foundation and the outcome of the literacy and health work done in Massachusetts over the last decade. The work has emphasized the development of Student Health Teams. These teams are comprised of groups of students who work with facilitators, teachers, community health organizations, and health practitioners. Using teamwork and creative methodologies such as drama, art, and music, these teams employ a peer teaching and learning together approach to engage in a variety of activities. Student Health Team activities may include:

- researching health information,
- teaching other students about health,
- making and distributing brochures,
- developing and conducting surveys,
- participating in or running health fairs,
- arranging for medical screening services at the program site,
- documenting and taking action around community health issues.

The philosophical basis is allied to that of contextualized education and the teachings of Paulo Friere. Friere argued that traditional adult literacy approaches promote literacy as a set of monolithic skills existing independently of how or where they are used and as an individual deficit to be corrected, perpetuating the marginalization and disempowerment of learners (Auerbach, 1992). This leads to the "banking" model of education, in which learners are seen as empty vessels awaiting deposits of knowledge by the teacher, who makes all the decisions and controls the process. According to Freire (1985), the banking model supports the development of individuals who accept the passive role imposed on them and learn, along with a fragmented view of reality, to adapt to the world as it is and not to act upon and change it (Rudd & Comings, 1994).

In Massachusetts, student leadership of the health projects through Student Health Teams has helped programs to move away from the banking model and towards education for transformation. As one member of a student health team put it:

"I saw my opinion was important and it felt good. In Hispanic families, the parents or the husband make all the decisions. I thought, 'oh my God, I have the right to speak and give opinions.' We [the health team] said that HIV/AIDS and drug and alcohol use were the biggest community health problems…and we found that brochures to teach about these problems were too hard. No one understood the words and everything was too crowded, too complicated…so we started with making simpler brochures. Everyone

on the team, my family, and friends like them and it made me so proud."

Students across the state echo feelings of pride in their work, and in being involved with health issues important to everyone in the program, including staff, and in projects that made real changes and have visible results. The personal growth that comes from being involved and being supported has been highly motivating.

The experience of talking in front of many other groups and being heard is also motivating. As one student said, "When I realized that what I had to say was more important than how I said it, I could speak English." Reading, writing, math, and technology skills are pressed into service and enhanced through the literacy and health work. Student teams learn to use the Internet to search for health information, read maps, construct surveys, make presentations, learn how to ask questions, and develop knowledge about the economic and political environment surrounding health issues. One teacher noted, "There is nothing like a small group experience, like the student health team, that arises around purpose and a focus where all the cognitive stuff happens peripherally. When you are not focusing on learning goals, learning sneaks up on you."

Massachusetts' adult basic education learners have been articulate about what they see as the problems with health education for limited-literacy individuals and groups and have developed an array of projects, interventions, and materials to assist in addressing the problems (MA Department of Education, 2000). In the process, they have developed new knowledge, skills, awareness, and vision for social action that promote new images of themselves as people who can help make things change. Learners involved in these activities reported that they did not feel like immigrants or foreigners in their own living place. For the first time, they felt included in and part of the United States (System for Adult Basic Education Support, 2001).

Reaching New Student Groups

Kim Lee, director of Assessment, Evaluation, and GED within Georgia's State Department of Technical and Adult Education, notes that Georgia is experimenting with a new approach to literacy and health. A year ago, they read the symposium proceedings report from the National Health Council (2000) about literacy and health that made them take a closer look what was being done, and not done, in Georgia. A working group of ABE and health education professionals was formed to explore what could be done. The group wanted the work to assist health care providers who identified literacy as an issue and help ABE teachers incorporate health into their classrooms. They decided to break the ABE work into two pieces, both of which will emphasize referrals and collaborations between ABE programs and health care facilities

> *"... health education needs to be more than simply reaching people with a particular health message or a particular piece of health information."*

The first activity was training for ABE teachers on how to modify and incorporate health content into existing ABE programs. The Georgia State Department of Education sponsored a summer curriculum academy for fulltime teachers to review and begin the process of integrating health content literacy into curriculum. To identify top health concerns for integration, panels of physicians, public health specialists, and dentists were brought together with the teachers to speak together about relevant health areas, identify resources, and answer questions in response to the specifically identified health concerns. Through these processes, four broad health areas emerged: diabetes, heart diseases including hypertension, oral health, and HIV/AIDS. A full-time health literacy coordinator with a nursing background has been hired at the state Department of Education to review the results of the academy and work with teachers to use this information as part of curriculum revision and incorporation of health information

The other aspect of the initiative was to create "health literacy" classes to be taught by literacy and health education teachers together in a variety sites such as hospitals, churches, and public health agencies. Such programs may attract groups of learners who often do not seek regular ABE services.

The healthy literacy classes were included because Kim Lee and others in the Literacy and Health Working Group had explored the literature on how limited-literacy adults often feel stigmatized (Beder, 1991; Davis et al., 1996). Many individuals in need of services will not go to a regular ABE program but might attend "health literacy" classes that have a dual agenda — learning about health topics important to you while simultaneously developing literacy skills — and perhaps transition to regular ABE in the future. Health education can thereby become a vehicle for literacy, an approach that the Massachusetts experience supports.

Kim Lee says that Georgia is venturing into uncharted territory; they are not sure where the road will lead them. However, staff in the state think that the junction of literacy and health is a crucial area for ABE to

address that has a natural fit with ABE services overall, and family literacy in particular, and they are committed to its pursuit.

Lifelong Learning Tools

The past decade has provided insights into how best to approach integrated literacy and health education. The following are my perspectives as a researcher, practitioner, and advocate in literacy and health about what has been learned from the Massachusetts' experience, from the work of other states' ABE systems, and through dialogue and collaboration with the professionals in public health and health care. I have learned that health education needs to be more than simply reaching people with a particular health message or a particular piece of health information. The current emphasis on addressing the health education needs of limited-literacy groups through simply rewriting existing materials at an easier language level is exceedingly limited. Information is only one piece of a process that needs to include community context, participation, and support. Adult basic education learners in Massachusetts have, in fact, been very articulate about what they need. Simpler materials are only the tip of the iceberg, they say. A psychologically safe environment in which to learn about health, the opportunity to ask questions and to consider the relevance of the information to everyday life, and the opportunity to talk about different cultural perceptions about health and medical treatment are all vitally important. They also say that many recent immigrants may have little or no experience with concepts of prevention and early detection, rendering many public messages ineffective. Information about and a forum in which to discuss how the American health care system, including public health insurance programs, operate is needed.

A recent series of focus groups with patients at Montreal (Canada) General Hospital found similar views on health education in relation to particular medical conditions. These focus groups articulated a need for small, comfortable settings for patients and their families in which they can learn about their medical conditions and their treatment. They should be designed by patients and families working with medical personnel, using multifaceted approaches to patient information and activities, with an emphasis on participatory group activities (Centre for Literacy of Quebec, 2001).

> *"Creating a climate that supports literacy and health programming is also needed."*

Working towards the integration of literacy and health education has made me confident that ABE programs offer the luxury of time and an appropriate environment, in which adult literacy learners and staff can work together with community health educators to design and implement health teaching and learning programs. The programs can address the health and the language and literacy learning needs of ABE students and can catalyze them in a process of mutual enhancement. ABE can provide tools for lifelong learning about health that can be applied in myriad settings, both within health education and in the broader world.

Conclusions

Enormous opportunities for synergy with the health care field exist. Both ABE (including our learners) and health care need to develop system goals and map strategies together to accomplish these goals. Both sides need to rethink and reshape how we can work together to enhance the health status and literacy level of our country's most vulnerable populations.

In this article, I have presented a number of different approaches that state literacy systems have used to begin their work. These approaches are based on the unique circumstances, needs, and concerns of particular states and, in most cases, are still in the very beginning stages. The ABE system overall needs to think through what policy supports need to be in place to provide a firm foundation on which to rest literacy and health work. Attention also needs to be paid to how states can involve ground level practitioners in developing and shaping the work.

One obvious support needed is financial. Teacher training on integrating health content, revising curriculum, and grappling with work that may throw difficult personal health issues into sharp relief have costs associated with them. Student health teams also need to be supported in their work. Staff need supported time in which to work with their local health care agencies on information sharing, on cross-referrals, and to explore collaborative actions.

Creating a climate that supports literacy and health programming is also needed. Such a climate begins with a long-term commitment to the importance of literacy and health work, and to building the ABE field's capacity to work effectively in a new arena. It also includes time and space to consider crucial questions that arise as the work increases. These questions include such concerns as

- When literacy and health are joined, what comes first, literacy or health?
- Which approaches work best under what circumstances, for example, an empowerment approach that emphasizes student leadership? A disease-specific approach that concentrates health learning in one health topic separated from regular instructions or an integrated

curriculum approach?

- In what ways do the practice of literacy teachers and programs change by being involved in health work?
- What evidence can be produced that documents changes in health knowledge, beliefs, and attitudes — and, ultimately, behavior — through linking literacy and health education?
- What influence does an interagency approach have on the partners involved? These and other crucial questions will need to be addressed through research, thoughtful dialogue, and careful analysis of experience.

None of this will come without financial support, capacity-building, research, and the willingness to rethink and reshape practices in both the literacy and health worlds. However, the reasons to do this work are clear and compelling. Our country's most vulnerable, low-literacy groups, concentrated in minority populations and numbering 90 million people, have poor health (Davis et al., 1996; Kirsch et al., 1993; US DHHS, Public Health Service, 1991). They die sooner than the average population and have a higher incidence of chronic disease (US Bureau of the Census, 1993; Weiss et al., 1992). Many are also our ABE students. Collaborating with the health care world to address their health literacy needs to be one of ABE's priorities in the coming years.

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ESOL Teachers: Helpers in Health Care

Singleton developed methods to help students navigate the health care system

by Kate Singleton

Luz, a 36-year-old mother of seven from El Salvador, was in my adult English for speakers of other languages (ESOL) class in Arlington, VA. After three 3-month terms, she was beginning to sight-read when she started experiencing severe abdominal pains. Her attendance dwindled. At school, her pain distracted her. One day she reported that she had been to the emergency room; her children had been told that their uninsured mother needed an operation very soon. As the operation date approached, Luz said she was very nervous.

Never having studied in her native country, Luz knew nothing of internal organs. She did not know what her diagnosis of uterine fibroid meant. I tried to calm her, saying the surgery was done all the time with no problems. But in her case there were problems; a surgeon slipped and accidentally cut into her bladder. The surgery and recovery suddenly became longer, more traumatic, and more costly to Luz and her family. As she recuperated at home she received piles of medical bills in the mail. Her literate children understood little on the bills, but the whole family understood the large numbers of dollars printed at the bottom. Luz, who had been making long-sought gains in her struggle for literacy, dropped out of school.

Jose, a Bolivian man in his early 30s, stayed after class one night so I could help him understand a hospital bill. He had been having bad headaches for some time. Thinking it was his only option for care, he had gone to the emergency room to get treatment. There he was told the headaches would clear up if he got glasses. He was charged $300 for this diagnosis.

Maria, a Salvadorean woman in her early 40s, came into class pale and panicking. She had gone to the emergency room over the weekend and had had an operation. When asked about the procedure she said hysterically, "Me don't know. They cut me. What they take me don't know!" She had had a hospital interpreter, but she, like Luz, did not have the basic anatomical knowledge to understand what was explained. Unlike Luz, she had no family in the area to intercede for her. I called a social worker, who helped Maria find out that she had had a gallstone removed, and that she needed to follow a specific diet and receive follow-up care. The social worker also helped her negotiate a payment plan for her hospital bills.

I taught these three students and many other beginners like them during my nine years in Arlington County. They are hard working and hungry for education. Most often uninsured, they do not seek preventive care. A health problem arises, or a lingering one worsens, and they are in crisis, immersed in a health care system they do not know how to navigate. They have weak support systems in this country, little English to speak, and no idea how to access helpful services. With poor health and the urgent need to pay large medical bills, their attendance in school suffers and they often drop out to work harder and raise money when they should probably be working less.

Curriculum vs. Life

Based on these experiences, I felt a gap between what I have been teaching (my program's health curriculum) and the health-related situations my students actually encounter. I do not dislike the curriculum: I have taught most of my beginner classes for the Arlington Education and Employment Program (REEP), and know how hard the teachers have worked to make the curriculum practical, needs-based, and learner-centered. The content is simple, it presents basic, important vocabulary on body parts and describing symptoms to the doctor. The simplicity of the language structures and the basic life skills are level-appropriate and necessary for beginner students, designed to be pertinent but not overwhelming. In my experience, however, it is precisely the uninsured beginners who find themselves overwhelmed in the most catastrophic, complicated health situations. Beginning-level students need and want to be able to describe basic symptoms (more often than not it was their first or second choice in class needs assessments) but they also need to understand the comparative financial and health costs of opting for emergency care over preventive care. They can similarly benefit from understanding how to advocate for themselves when or if they suddenly find themselves having to navigate the complexities of the US health care system.

Certainly many people, fluent English speakers among them, are overwhelmed when seeking health care in the United States. Language

and cultural barriers present additional difficulty. It seems that the less language and cultural skill one has, the less the likelihood of having health insurance, access to preventive care, and an understanding of the US health care system. Research indicates that uninsured people who do not get care tend to have more chronic, difficult to treat conditions (Ayanian et al., 2000). Beginning-level ESOL students need the complex health-related material and concepts that often are only taught in higher level classes. These observations led me to explore the following question: What else can ESOL teachers do to prepare our beginning-level students for encounters with the US health care system, especially those who are uninsured?

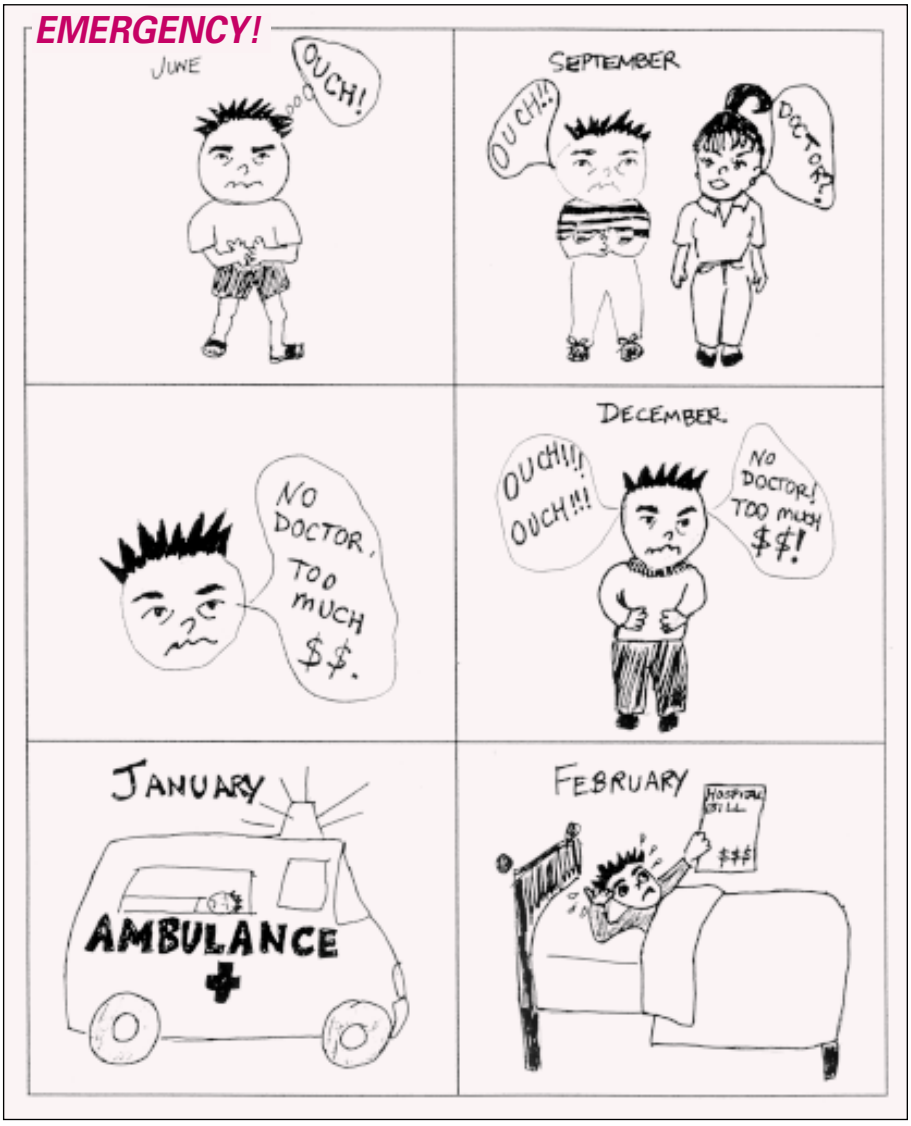
Exploration

I started by exploring the question informally, talking with other teachers in my program and finding that many had made the same observations. Many students who had been here for years, I learned, some with high levels of English competency, were unaware of the availability of low-cost clinics for the uninsured. I educated myself more about community services available to immigrants in the community and read about physical and mental health problems common among low-income immigrants (see the Blackboard on page 35 for recommended resources). I began reading about health beliefs and practices in other cultures, and how those beliefs blend or clash with mainstream US practices.

I also began a Masters degree in social work. My work in ESOL had made me curious about what immigrants go through when they settle in a new country, and social work has allowed me to explore that in more depth. The coursework has helped me understand how truly difficult it is for care providers with the best intentions to suppress their own cultural beliefs when working with clients or patients from other cultures. If we can introduce ESOL students to just a little of the mainstream US medical culture, then they might have more understanding of what is expected of them as patients. With this awareness, they might be able to be more active in their treatment and better advocate for their own needs.

When I started reading on the subject of health literacy as viewed by literacy professionals within the medical field, I detected a general disregard for contributions of adult educators to the discussion and a preoccupation with semantic issues. While the issues deserve some place in discussion, I saw little analysis of the effects of culture on comprehension, or the effect of the context in which a person was being given information. As a literacy instructor, I know that when people are feeling stress, their comprehension decreases. Imagine the stress an immigrant like Maria feels, with scant English and low literacy, having just had emergency surgery, sedatives still blurring the senses, as follow-up care instructions are presented to her.

One person who helped recharge my optimism was Maria Meuse, RN, a community health nurse in Bailey's



The materials that evolved included picture stories about preventive care, asking for clarification from the doctor, handling stress, and domestic violence.

Suggestions for low-income students who do not have health insurance

- Find out if there is a low-cost clinic in your area.
- If you must see a regular doctor, say you are uninsured and ask if you can pay a lower rate.
- If you have a big bill, ask for a payment plan so you can pay a little every month.
- Don't wait until the problem is an emergency. If you go to the doctor early, you will probably pay much less.
- See if your children qualify for free health insurance. Ask at their school or at the health department.

Tips for handling sensitive subjects

Many teachers might be uncomfortable taking on health topics in class that have the potential to bring up very personal experiences for students. They might feel that they don't have enough specific knowledge of US health care practices (or the time to acquire it) to be able to handle students' questions. These concerns and others are addressed in a useful chart by J. LaMachia and E. Morrish entitled "Teachers Concerns about Incorporating Health into Adult Education" in the Spring 2001 edition of Field Notes, available on-line at *http://www. sabes.org/ f04conc.htm.*

Handling language problems at the doctor

- Bring a friend with you who speaks more English than you do. Sometimes it is not comfortable for children to translate their parents' health problems.
- Write down some questions to take with you. This will help you remember to get all the important information.
- Ask someone who speaks English to call the doctor's office before your appointment to say that you will need an interpreter. The doctor may know someone who can interpret for you.
- If you can pay, see if there is a doctor near you who speaks your language.
- Always ask questions! You are the customer and your health is important. In the United States, it is OK to ask the doctor questions until you understand.

Cultural expectations of the US medical system

- Preventive care is seen as the patient's responsibility. US medical culture emphasizes self-care.
- Patients have the responsibility to ask questions in a fast-paced doctor's office or clinic.
- Patients must be clear with their health care provider about any medications they take, even herbs or traditional medicines from another country, to avoid dangerous interactions.
- Patients are expected to find out which side effects of medications are dangerous and which are benign before leaving the doctor's office, clinic, or pharmacy.
- Sometimes payment plans or financial assistance are available in hospitals for uninsured patients, but the patient must ask about them specifically.
- By law (the federal Civil Rights Act of 1964), patients whose first language is not English should be provided with an interpreter. If one is locally unavailable, 24-hour telephonic interpretation services exist for doctors to use (at the doctor's expense). This is not popular among doctors, but it does exist for emergencies.

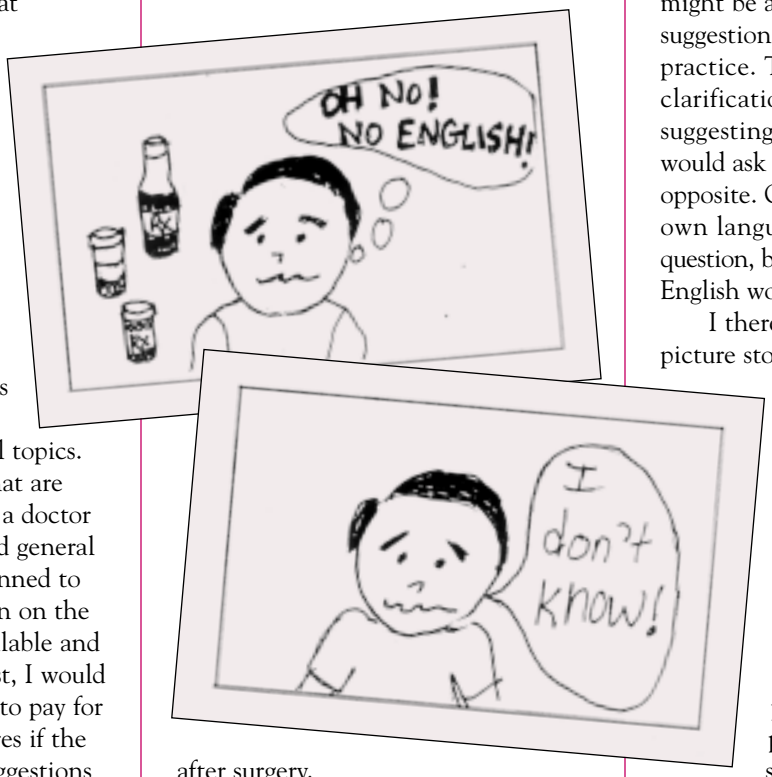
Health Center, a county-run, low-cost clinic in Falls Church, VA. She recognized the cultural variation among the clinic's immigrant patients, and the stresses that illness and seeing a US health care provider create for them. In the box on page 28 is a listing of several cultural expectations of the US medical system that are problematic for many immigrants, as described by Maria.

With Maria's clarification, I decided to design materials that would help teachers convey to students concepts such as preventive care and the need to ask questions of the doctor. The materials needed to enable but not require both students and teachers to discuss difficult, potentially personal topics. I would identify questions that are culturally appropriate to ask a doctor about medicines, surgery, and general treatment. In addition, I planned to collect and share information on the low-cost health services available and how to access them. And last, I would develop suggestions on how to pay for emergency medical procedures if the patient is uninsured. The suggestions would not eliminate the financial burden, but they could give the student more control.

Testing Materials

The materials that evolved included picture stories about preventive care, asking for clarification from the doctor, handling stress, and domestic violence. I also wrote problem-solving stories, for readers at a high beginner level or above, about anxiety and depression. I compiled lists of simple questions to ask the doctor, and a brief list of options for payment after an emergency.

I piloted the picture stories in the Arlington County Community Outreach Program classes held in apartment buildings and community centers around the county: drop-in, multilevel classes that tend toward beginner level but have some higher-level students as well. I started each session with a picture story about a man who ignores pain symptoms until he has to be taken to the emergency room for emergency surgery. In the last frame he is still in bed a month after surgery, looking in terror at a big bill. (See page 27.) We analyzed the situation, then wrote a story about it, with the students dictating and me writing. We discussed alternatives the man might have pursued at the beginning to avoid the catastrophic outcome, and talked about preventive practices, low-cost clinics, requesting payment plans, and what happens if you do not pay the medical bills.



In every group, people had a lot to say or ask. After the first pilot lesson, a young man came up to me and said, "This is my story!" Excited to learn about the clinic, he had thought the emergency room was his only option for treating gastritis, and now was paying the bills. Another man said he had had emergency surgery and had ignored a collection agency's attempts to reach him. That admission led to discussion about the importance of credit records in the United States and what effect nonpayment of bills can have.

In the first pilot class, after developing the story I talked about asking the doctor questions. I thought that the more advanced students might be able to brainstorm some suggestions that other students could practice. The activity needed more clarification: some students were suggesting questions the doctor would ask a patient rather than the opposite. Others had an idea in their own language of an appropriate question, but could not find the right English words.

I therefore created a second picture story, in which a man tells the doctor that he understands everything, but in fact understands nothing. When he gets home, he is thoroughly confused as to how to treat his problem. At another center, I did the same story writing with the first picture story, then presented the second picture story as a conversation topic. As the students looked at the story for the first time, I heard laughter and admissions of "This is me!" Discussion brought out many questions from students: "The doctor knows more. Why should I ask questions?" "The doctor speaks too fast. What can I do?" "All my friends are at work. Who can interpret for me?" The topic is hard, but we did generate some worthwhile suggestions and comparisons between health care here and in the students' native cultures.

I consider the pilot lessons to have been generally successful. Most students, although a little puzzled by the approach to health in the United States, have been inquisitive and enthusiastic. Students occasionally complained that clinics have income restrictions and may charge a small amount to higher-income patients,

but the complaints were easily handled by asking the class to compare the cost of the emergency room with the inconvenience of the clinic qualification requirements. The questions for the doctor are the hardest part with every group, and much more difficult for the very beginners. I usually try to dissuade translation among students during class, but in these lessons I sometimes encouraged it because I thought that the information was so important. I urged participants to share the information with their families and read the list of questions at home with someone who could explain it in their language.

I was able to share what I had learned from my research and pilot lessons at the Virginia Institute for Lifelong Learning ESOL Conference in Arlington in July, 2001. Comments from participants indicated that the session was "much needed" and that "curiosity has been sparked." I hope that ESOL instructors will continue to explore ways to empower the neediest students for inevitable encounters with the complexity of the US health care system.

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About the Author

Kate Singleton is an ESOL teacher and curriculum writer for the Fairfax County Adult and Community Education program in Virginia. She has been teaching adult ESOL for 14 years, during which her special interests have been literacy instruction, working with students perceived to have learning disabilities, and health education. She is also pursuing a Masters in Clinical Social Work at Virginia Commonwealth University, for which she works as a case manager of HIV-positive clients at Whitman Walker Clinic of Northern Virginia. ❖

The Elizabeth West Project: A Health Professional Joins a Literacy Program in Downeast Maine

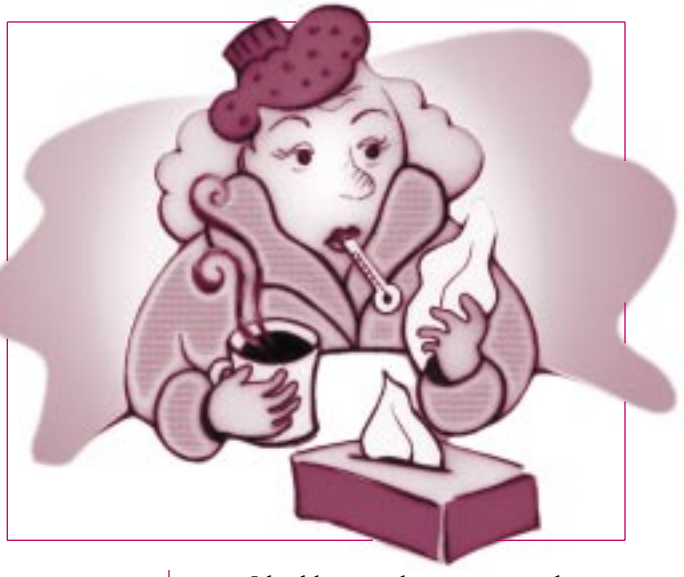
by Beth Russett

The Elizabeth West Health Literacy Project was named for Elizabeth West, a student at the Sumner Adult Learning Center, who died shortly after the program began. Her friend and teacher, Marty Duncan, wrote the poem in the adjacent box.

*

The staff of the Sumner Adult Learning Center had concerns that health-related issues were interfering with students' learning. The Center's coordinator, Ann Sargent Slayton, noted that, "health problems contribute to frequent cancellations, decreased energy levels, interrupted learning plans and an overall disruption of education goals. Family health concerns prevent women from being able to focus on their own learning needs." With the help of a grant from Laubach Literacy Action: Women in Literacy, the Center set out to address some of these roadblocks.

The Adult Learning Center is housed in a community center in rural, downeast Maine. Open enrollment services include basic literacy, English for speakers of other languages (ESOL), family literacy, preparation for the tests of General Educational Development (GED) or an adult diploma, and employability and computer training provided on site, at area schools, in homes, and at various community sites. Of the 93 participants who enrolled in the center last year, 73 were women. Close to half of the women who come to the center are unemployed. Those who are employed work in seasonal positions in the fishing, seafood processing, and tourist industries, or in other service jobs.



I had been volunteering at the center with ESOL students for close to a year. I am trained as a family nurse practitioner with a focus on women's health. My previous clinical experience was at a migrant/rural health center where literacy issues (inability to read or write, and language barriers) interfered with

people's ability to access health services. The Laubach grant enabled the Center to hire me to work three days a month for a school year, during which time we planned to use health issues as a means of improving learning and literacy skills to improve health. While the staff at the center realized that men's health issues are also important, the program focused on women, as required by the grant.

We had decided that it would be most effective for health education to be offered in a number of settings geared toward different styles of learning and participation. In the course of the 10 months, I surveyed students' health needs, met individually with women for health education appointments, organized a health committee called the Health Action Team, and offered three separate health workshops. I also promoted collaboration between Sumner Adult Education and local health care providers. What follows is a description of the Elizabeth West Health Literacy Project, its impact, and its limitations.

To Elizabeth West (1943-1999)

I keep thinking you're going to
come around the corner
from the hallway and walk
- no strut, almost swagger -
through the door and look around,
then say something about
how you're late, though you're not.
You'll sit across the table
from me and in a few
minutes something will make us
laugh; nobody would think
grocery ads could be funny.
"Ham shank" means something I can't
explain to anyone else.

You'll tell me which grandchild
you've come from or will go to
whose bus , whose game, whose birthday.
At least six times you'll yell
at yourself in a whisper
("Lib, now pay attention")
roll your eyes at the letter
on the printed page and say,
"Oh boy, that one again!"
and today you'll get it right,
though last week it stumped you.
We'll talk about your checkbook,
make some more stationery,
email your brother down South
then we'll add some more words
to this week's grocery list,
practice the word searches,
and I promise I'll find you
another Hurston tape;
you like the stories so much.

We have so much to do.
It can't be three already.

Health Survey

The first step in the project was to identify the students' specific health concerns as well as to measure their general interest in health information. The staff developed a simple, three-question survey. The teachers asked 36 women who were currently enrolled at the center:

- Do health problems sometimes make it difficult for you to come to school? What kinds of problems?
- Do you need information and/or resources to better take care of your health? What kind would be helpful?
- Would knowing more about your health/your body help you? How?

We learned that the women were concerned with mental and emotional stress, colds, and digestive problems. They were interested in information on issues such as childhood illness, depression, pregnancy, nutrition, and exercise. One woman said, "Women are not informed enough about ways to help them feel better and they are socialized to take care of everyone else besides themselves." The needs and concerns expressed in the survey confirmed the initial concern and laid the foundation for the project.

Health Education Appointments

Every female student at the center was told about the availability of health education appointments. Any interested student could fill out a brief form — by herself or with the aid of her teacher — stating her health concern and the best time and place to meet. While teachers had previously included general health information in their classes, many found that students had specific and serious health issues that required a more trained interaction. The ability to refer students to me, an onsite health educator, was noted by staff as one of the most significant benefits of the health literacy project.

During the project, I had the opportunity to meet with 11 women one-on-one to discuss their specific concerns. The nature of each interaction was as varied as the participants. I conducted two of the meetings in Spanish and the rest in English. Each interaction confirmed the powerful link between health and literacy, as well as the broad definition of both. I worked with women to find creative and realistic solutions to health concerns that were interfering with their learning.

Health Action Team

One of most exciting parts of the project for me was the creation of the Health Action Team, which was designed to bring together any students interested in talking about health. We would also work as a group to put together a presentation for a local health center and two health workshops. The grant included money for stipends for the team.

Four women joined the Health Action Team: Mary, Elaine, Juana, and Gabi. Given my limited schedule, and transportation issues and personal commitments of every student, the staff and I were grateful to have a group of this size. The group was uniquely multicultural; in

an area that is more than 97 percent white and English-speaking, two of the four women are Spanish-speaking: one from Honduras and one from Mexico.

The Students' List of How to Make Patients Feel More Comfortable

- offer translation services
- wash your hands
- listen
- take them seriously
- provide services at an affordable cost
- provide a children's room with a sitter
- ensure that patients spend less time waiting naked
- provide health education material that uses bigger writing [font size] and is easier to understand

Juana and Gabi are advocates for their community: bringing people to the center, helping others with license exams, filling out forms, making telephone calls. Mary and Elaine are also strong advocates for themselves and their families. They both have children with special needs and have years of experience with the medical community. The size and makeup of the team presented certain challenges and infinite possibilities.

In the few months we had, we were able to meet three times. For half of the group, it was a new experience to be in a bilingual activity. Both Juana and Gabi were ESOL students who spoke varying amounts of English. Juana or I translated any conversation that Gabi did not understand.

Mary called me following our first meeting. She felt left out, suspicious that we were talking about her, and uncomfortable with the amount of Spanish I had used in our discussion. Elaine felt the same way, she told me. This provided an opportunity for us to begin to talk about our own bias and the challenges faced by ESOL students everyday. She considered leaving the group, but voicing her discomfort made it easier for her to stay.

Many of the activities in our meetings were adapted from *Beyond Prescriptions — Meeting Your Health Needs — A Plain Language Workbook About Health*. This is an excellent resource that addresses the personal and political aspects of health literacy. We focused on the discussion of health rights and responsibilities. It was much more difficult for team members to voice health rights than responsibilities, but we came up with a good working list. The group also shared ideas about barriers and resources. The participants had all experienced some common barriers to health care. Elaine was able to inform Juana and Gabi about free transportation services, which are a valuable resource in a rural area. These group discussions provided the framework for our clinic presentation.

Mary, Elaine, and I went to the local health clinic to talk to the staff about health literacy. I talked about the need to link health and literacy work. Mary shared our list of health rights and responsibilities. Elaine shared a list of recommendations that the team felt would improve access and make patients feel more comfortable seeking care at the clinic. These lists are in boxes on this page and the next.

After the talk, the staff completed evaluations. They all expressed appreciation. Some stated that it was the first time they had the opportunity to hear from the people who use the clinic, in a non-clinical setting. The clinic manager said, "These are voices we do not generally hear. We need to pay attention to them." She also talked about ways to start a child care morning so that women could visit with their health care provider alone. It seemed to be a positive experience for everyone.

The Health Action Team was the part of the Elizabeth West Project most directly affected by the temporary nature of the grant. The team had the potential to have a more significant impact on each individual member and the broader community, but could not be sustained without the initial effort of a designated staff member for a longer period of time.

Health Workshops

The workshops were prepared with help from the four members of the Health Action Team. They chose the topic most interesting to them, worked on the agenda, and prepared class materials. My goal was to have them co-facilitate each workshop. This only happened once, in part because of the limited time and flexibility inherent in short-term funding.

The first in the series of health workshops, "It's Cold Season Again!" looked at what does and does not work to cure the common cold. It was one session and five people attended.

Homemade Cold Syrup

Mix:
- 1/2 cup lemon juice
- 4 cloves of garlic, chopped
- 1/2 cup water

Let this sit for four hours, then strain and add:
- 1/2 cup brandy (or water)
- 1 cup honey
- Take 2 tablespoons every four hours. Keep refrigerated.

We waded through the myriad over-the-counter medications, discussed the need for antibiotics, shared home remedies, and made cough syrup (see recipe above).

"Stress Management for Women"

Health Rights

- clean water and good housing
- to be listened to and believed
- to not have to pay too much
- to feel safe in our homes and communities
- to be treated with respect

Health Responsibilities

- to speak up and ask questions
- to learn about things ourselves
- to follow through or get a second opinion
- to eat healthy and exercise
- to take care of ourselves

was a three-part class that relied heavily on the *Deep Breathing while Doing it All* curriculum developed by the Tobacco Free Greater Franklin County Coalition's Stress Management Task Force (turn to the Blackboard for information on how to get this curriculum). I also invited a local massage therapist and yoga instructor to share techniques with the class. Participants left with practical skills to use to deal with tension. In the evaluations, written or discussed with their teachers, one participant expressed a commen theme: "Just having the chance to spend time with other women talking about stress was a stress relief itself. When can we do it again?"

The final workshop was on "Domestic Violence: How to Help a Friend." Although violence was not explicitly mentioned as a concern in the initial survey, we felt it to be a contributing factor in many health problems. Juana co-facilitated this session with me. All of the material was provided in Spanish and English, although Juana was the only ESOL student in attendance. There were nine other participants. This workshop was unique in that both staff and students attended it. Months later a participant called to talk about a new relationship. She recognized some of the behaviors we had discussed in her new partner. With courage and support, she ended the relationship.

Afterwards

Close to a year after the Elizabeth West Health Literacy Project ended, I returned to the Sumner Adult Learning Center. Two of the women I worked with have since received their GEDs, and one is home full-time caring for her new baby. The ESOL students are taking classes closer to home. Many of the women continue to come to the Center for help with reading, parenting, and college preparation. There are no workshops on health issues and no Health Action Team.

The connection with the local clinic has weakened. During the course of the grant, 12 referrals were made to the health clinic and six referrals were made from the clinic to us. This was evidence of a heightened awareness of community resources on the part of the clinic. However, without continuing personal interaction — a face and a name — these have dropped off in the last year. Lacking the funds for a coordinator, no one is right there to turn to with questions or referrals, which is most difficult for the staff.

In all the areas where students work are brochures on stress management, childhood illnesses, exercise, pregnancy, high blood pressure, and other health issues. An entire bookshelf is dedicated to in-depth health material. These references are a reminder of the Elizabeth West Project. They are not interactive, they are not personal, they are not bilingual. They are evidence of the staff's continuing commitment to keeping health issues a visible part of their literacy work and of the difficulties in doing so without adequate support.

About the Author

Beth Russet lives on the coast of downeast Maine with her husband and two boys. She worked as a family nurse practitioner with a focus on women's health in a migrant/community clinic in North Carolina. ❖

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- For resources on trauma and learning, go to **http://www.jennyhorsman.com.**

Books used by Beth Russett in Maine (see page 30)

- *The Deep Breathing While Doing it All* curriculum, developed by the Tobacco Free Greater Franklin County Coalition's Stress Management Task Force, produced by The Literacy Project, Greenfield, MA. Telephone: 1-413-774-3934.
- *Beyond Prescriptions — Meeting Your Health Needs — A Plain Language Workbook About Health* by the Women's Network Inc., Prince Edward Island, was published by Literacy Services of Canada. Telephone: 1-780-413-6491. The book addresses the personal and political aspects of health literacy.

Resources on Immigrant Health Concerns

- Ayanian, J. Z., Weissman, J. S., Schneider, E. C., Ginsburg, J. A., & Zaslavsky, A. M. (2000). "Unmet health needs of uninsured adults in the United States." *Journal of the American Medical Association*, 284, 2061-2078.
- EthnoMed, at **http://healthlinks.washington.edu/clinical/ethnomed/** Contains in-depth profiles of various ethnic communities' cultures and health concerns. Maintained by the University of Washington.
- McGoldrick, M., Giordano, J., & Pearce, J. (1996). *Ethnicity and Family Therapy*. New York City: Guilford Press. Also reader-friendly, this book describes family interaction and mental health issues for more than 40 cultures.

Resources on Culture and Health Care in the United States

- Galanti, G. (1997). *Caring for Patients from Different Cultures*. Philadelphia: University of Pennsylvania Press. A clear and sometimes entertaining text written for nursing students, it gives 172 case studies of cultural conflicts that occurred in US hospitals.
- U.S. Department of Health and Human Services. (2001). *Mental Health: Culture, Race, and Ethnicity — A Supplement to Mental Health: a Report of the Surgeon General*. Rockville, MD: US Department of Health and Human Services. (available on-line: **http://www.surgeongeneral.gov/library/mentalhealth/cre/sma-01-3613.pdf)**.
- **http://www.healthfinder.gov/justforyou/** links with many health-related sites, and has a Spanish version.

Resources on Writing as Healing

- Anderson, C., & McCurdy, M. (eds.) (2000). *Writing and Healing: Toward An Informed Practice*. Urbana Illinois: National Council of Teachers of English.
- Cameron, J. (1992). *The Artist's Way*. New York: G.P. Putnam's Sons.
- DeSalvo, L. (1999). *Writing as a Way of Healing: How Telling Stories Transforms our Lives*. San Francisco: Harper.
- Fox, J. (1995). *Finding What You Didn't Lose*. New York: Penguin Putnam.
- Fox, J. (1997). *Poetic Medicine*. New York: Penguin Putnam.
- Horsman, J, (2000). *Too Scared To Learn: Women, Violence, and Education*. New Jersey: Lawrence Erlbaum Associates.
- Lamott, A. (1995). *Bird by Bird*. New York: Anchor Books, Doubleday.
- May, G. (1988). *Addiction and Grace*. New York: Harper Collins.
- Miller, J. (2001). "Goddard's transformative language arts program." *Poets and Writers*. 66-68.
- Mitchell, F. (2001). "Frances Driscoll and The Rape Poems." *Poets and Writers*. 43-46.
- Otis, L. (2001). "Poetry in prisons: Part two." *Poets and Writers*. 58-62.
- Petersen, S. & Straub, R. (1992) *School Crisis Survival Guide*. New York: The Center for Applied Research in Education.
- Prevallet, K. (2001). "Creativity and the Importance of Fourth Grade." *Poets and Writers*. 51-54.
- Rierden, A. (1997). *The Farm: Life Inside a Women's Prison*. Amherst, MA: University of Massachusetts Press.
- Schneider, P. (1994). *The Writer as an Artist: A New Approach to Writing Alone and with Others*. Amherst, MA: Amherst Writers and Artists Press.
- Therrien, R. (1999). *Voices From the Hood*. Amherst, MA: Amherst Writers and Artists Press.
- Tietjen, J., & Pugh, D. (eds.) (1997). *I Have Arrived Before My Words*. Alexandria, VA: Charles River Press.
- Vega, J. (2001) "Poetry in prisons: Part one." *Poets and Writers*. 56-58.

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