

J. Marion Sims Foundation

ADULT LITERACY & BASIC SKILLS INITIATIVE

PROMOTING

health literacy

LANCASTER COUNTY | FORT LAWN | GREAT FALLS

South Carolina

A *What Works* REPORT OF THE INSTITUTE ON FAMILY AND NEIGHBORHOOD LIFE, CLEMSON UNIVERSITY

AND THE J. MARION SIMS FOUNDATION, INC.

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J. Marion Sims Foundation

ADULT LITERACY & BASIC SKILLS INITIATIVE

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ADULT LITERACY & BASIC SKILLS INITIATIVE

INTRODUCTION

The purpose of this report is to promote increases in health literacy among all residents in Lancaster County and the Great Falls and Fort Lawn communities of Chester County, South Carolina, the funding area for the J. Marion Sims Foundation, Inc. This report is written for those who wish to create caring communities that support health literacy skill development so that everyday healthy living is enhanced. It is particularly focused on literacy development for adults in their role as health care consumer and provider, and in their efforts to maintain their own health and the health of those they love. Other reports are available that discuss literacy skill development related to being an effective worker, citizen, parent and family member.

Having low health literacy is extremely costly. It is an insidious barrier to being healthy. The lack of general literacy in a large portion of the population of the United States, including South Carolina, means many are unable to effectively access and use health care services. The high rate of low health literacy among the adult population is estimated to have cost \$73 billion dollars in 1998.¹ If there is one area of community improvement that could decrease the cost of government and community expenditures yet increase the quality of life in America, it would be to tackle our health literacy issues in America and create effective health literacy learning and communication systems. Community leaders who improve health literacy levels are involved in two primary literacy education tasks: improving literacy skills in general and health literacy skills in particular. They are related skill sets but are not the same thing. Therefore, we begin with a review of literacy skill development in general and how these skills have been measured. This discussion is followed by a description of what health literacy skills are and how they are measured.

Engaged community leaders also understand how to build a seamless health literacy system that supports health providers and adults who wish to increase their health literacy skills, knowledge and communication practices. Therefore, model efforts are reviewed. Help is provided on how to start health literacy initiatives. Resources are reviewed to assist readers in quickly accessing needed resources.

Since health promotion efforts might be confused with health literacy efforts, this report begins by defining what literacy is so that readers can understand the differences between a health literacy initiative and a health promotion initiative in general.

What is Literacy?

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The National Institute on Literacy defines literacy as the ability to read, write and speak English proficiently, to compute and solve problems, and to use technology in order to become a life-long learner and to be effective in the family, in the workplace and in the community.²

The ability to read, to write, to understand and to be understood are critical to personal freedom, to the maintenance of a democratic society and to the broader goals of economic opportunity and security, social justice, human dignity and personal well-being. Approximately half of America's adults were not functionally literate in 1993, the last time a national survey was conducted. That percentage equals approximately 90 million adults. Very few adults in the U.S. are truly illiterate. Rather, there are many adults with low literacy skills who lack the foundation they need to find and keep a decent-paying job, support their children's education, maintain their health and actively participate in civic life.

In Lancaster and Chester counties it is estimated that 68% of the Chester County population has level 1 or 2 literacy proficiency and that 60% of Lancaster County's population is at this same level. These levels are explained below but, for now, the point is that both counties are above national and state averages in low literacy rates. We shall see as we go along that this current situation is having many costly effects.

All adults need four literacy skill sets. These four categories of skills are used in combination in order to effectively carry out everyday activities as a parent, worker, citizen and health care consumer/provider.³ The health care consumer and provider make four categories of skills; particularly when as they are later in the document. They are reviewed in **TABLE 1**.

TABLE 1 | Basic Literacy Skills Needed by All People

Communication Skills

- | Read with understanding
- | Convey ideas in writing
- | Speak so others can understand
- | Listen actively
- | Observe critically

Interpersonal Skills

- | Cooperate with others
- | Guide others
- | Advocate and influence
- | Resolve conflict and negotiate

Decision-Making Skills

- | Solve problems and make decisions
- | Plan
- | Use math to solve problems and communicate

Lifelong Learning Skills

- | Take responsibility for learning
- | Learn through research
- | Reflect and evaluate
- | Use information and communications technology

The implications and impacts of such staggering numbers of low literacy rates in the U.S. population are many. Forty-three percent of people with the lowest literacy skills live in poverty. More than 75% of current welfare recipients have very low or low reading skills. Only 30% of adults with very low literacy skills have full-time jobs. Some have part-time jobs, but over half of these adults no longer look for work. Nearly one-third of prison inmates have very low literacy skills. Another 40% are barely able to read. Every aspect of life is affected by such high rates of low literacy skills. Forty million adults find it a struggle to read to their children or to help with their homework. They cannot understand health instructions.⁴ Everyday tasks are beyond their skill levels.

How Is Adult Literacy Measured?

When literacy was simply thought of as reading, it was typically measured in grade-level equivalents. An adult's literacy skill was said to be at a first grade or fifth grade level, for example. A more complex, more realistic conception of literacy emphasizes its use in adult activities. To determine literacy skills in American adults ages 16 and older, the 1992 National Adult Literacy Survey (NALS) used test items that resembled everyday life tasks. It involved the use of prose, document and quantitative skills. The NALS classified the results in five levels of proficiency, with level one being the lowest level of proficiency and level five being the highest. These levels are now commonly used to describe adult literacy skill levels.

The prose literacy items assessed the adults' ability to handle written text such as editorials, news stories, poems and fiction. It assessed the ability to handle both expository and narrative prose. Expository prose involved printed information that defines, describes or informs, such as newspaper stories or written instructions. Narrative prose assessed the adults' ability to understand a story. Prose literacy tasks included locating all the information requested, integrating information from various parts of a passage of text and writing new information related to the text.

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How Is Adult Literacy Measured?

Document literacy items assessed the adults' ability to understand short forms or graphically displayed information found in everyday life, including job applications, payroll forms, transportation schedules, maps, tables and graphs. Document literacy tasks included locating a particular intersection on a street map, using a schedule to choose the appropriate bus and entering information on an application form.

Quantitative literacy information was displayed visually in graphs or charts or in numerical form using whole numbers, fractions, decimals, percentages or time units. These quantities appeared in both prose and document form. Quantitative literacy referred to locating quantities, integrating information from various parts of a document, determining the necessary arithmetic operation and performing that operation. Quantitative literacy tasks included balancing a checkbook, completing an order form and determining the amount of interest paid on a loan.

The National Adult Literacy Survey (NALS) captures well the printed and written information dimensions and related reasoning skills, but is not as complete as the National Institute for Literacy's **Equipped for the Future** competency standards for adult literacy. These standards also include the communication, interpersonal relationship and life-long learning dimensions to literacy development. **Equipped for the Future** standards are reviewed later in this report.

Almost all adults in Level 1 can read a little, but not well enough to fill out an application, read a food or medicine label, read a simple story to a child or fill out a deposit slip correctly. Adults in level 2 usually can perform more complex tasks such as comparing, contrasting or integrating pieces of information, but usually not higher-level reading and problem-solving skills. For example, those at level 2 could correctly write their signature on a social security card and fill out a simple job application. However, they could not correctly read a sales graph or figure out what the gross pay was on a paycheck stub or add correctly the cost of a meal. Adults in levels 3 through 5 usually can perform the same types of more complex tasks on increasingly lengthy and dense texts and documents. These levels use a broad range of information processing skills in various combinations. For example, people at level 3 could figure out bar charts and graphs but could not correctly read a bus schedule. They could not figure out the correct number of minutes that it would take to get from one location to another. People at level 4 could read the bus schedule but not summarize the views of parents and teachers found on a summary chart which involved comparing parent and teacher data across four questions and across three levels of schools. They could not correctly estimate the cost per ounce of a food product when given a food store shelf label with this information on it, or figure out interest charges on a home loan.

In summary, each scale was divided into five levels that reflect the progression of information-processing skills and strategies. These levels were determined, not as a result of any statistical property of the scales, but rather as a result of shifts in the skills and strategies required to succeed in various tasks along the scales, from simple to complex.

For a review of the levels of literacy found in the National Adult Literacy Survey see <http://nces.ed.gov/naal/>. This site also contains samples from the survey instruments.

Many factors explain the relatively high number of adults in the lowest level of literacy. Twenty-two percent of adults in Level 1 were immigrants who may have just been learning to speak English. More than 60% didn't complete high school. More than 30% were over 65. More than 25% had physical or mental conditions that kept them from fully participating in work, school, housework or other activities, and almost 20% had vision problems that affected their ability to read print.⁵

What is Health Literacy?

Health literacy is “the capacity of an individual to obtain, interpret and understand basic health information and services, and the competence to use such information and services in ways which are health-enhancing.”⁶

Patients are often faced with complex information and treatment decisions. They are asked to evaluate information for credibility and quality. They must analyze relative risks and benefits, calculate dosages, interpret test results and locate health information to make wise decisions. In order to do so, an adult must be visually literate (able to understand graphs or other visual information), computer literate (able to operate a computer to search for information), information literate (able to obtain and apply relevant information) and numerically or computationally literate (able to calculate or reason numerically). Oral language skills are important as well. They have to be able to articulate health concerns and describe symptoms accurately. They need to ask pertinent questions. They need to understand spoken medical advice or treatment directions. In an age of shared responsibility between health providers and patients for health care, patients need strong decision-making skills. Even those highly literate in other areas of life face challenges in the health literacy area.

Both health care providers and consumers are responsible for having functional health literacy competencies. Each has important roles and responsibilities. As consumers, we all must learn to be health literate. And given certain circumstances, our health literacy skills may be too low or we may not know how to use them. Some situations will require more learning in order to function adequately, thus testing our lifelong learning literacy skills. We can be literate in all other aspects but still not be functionally health literate. However, those with low literacy levels are particularly vulnerable to also having low health literacy. **In Lancaster and Chester counties more than half of the adult population is expected to have inadequate health literacy competencies, based on national averages.**

Health care providers also have roles and responsibilities for ensuring a health literate population and in dealing with those who are not health literate. There are professional and volunteer providers. Family members, friends, nurses, doctors, health educators, pharmacists and public health practitioners also play a role in health literacy practice. So the health literacy field has created help for consumers and caregivers. Some resources listed in this report are aimed at consumers and others are aimed at health care providers in public and private settings.

What is Health Literacy? CONTINUED

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The National Institute for Literacy is charged by the U.S. Congress to develop standards for leaders to use to equip adults with literacy skills needed to effectively carry out primary adult roles of parent, worker, citizen and health consumer/provider. When the National Institute produced the Equipped for the Future (EFF) standards report for literacy, a role map for health literacy competencies was not done.⁷ Health literacy professionals developed this area after the EFF standards were produced. Since then, the Eastern LINCS system, managed by the National Institute for Literacy, has adopted health literacy as a special focus of their development work on behalf of the national literacy system. Their work has helped communities add the health literacy area of concentration to their efforts. In the future, there will probably be a role map for health care providers and consumers. In the meantime, health maintenance tasks are found in all three current role maps (i.e. parent, citizen and worker) found in the Equipped for the Future report.

For each role, key everyday living tasks common across these roles were identified. These tasks were seen as ones that endured through time and across the various roles. They are the building blocks of being a literate adult as parent, as worker, as citizen, as health care consumer and as provider. The 13 everyday activities related to being health literate are found in Table 2. These 13 activities are primary competencies used to effectively consume health information and services and provide effective health care for one's self and others.

TABLE 2 | 13 Everyday Literacy-related Health Care Consumer and Provider Activities

Gather, analyze and use health information

Find and analyze information from diverse sources. Use it to form opinions, make decisions and take action.

- | Monitor and gather information from a variety of sources
- | Establish criteria for the quality and appropriateness of the information
- | Assess the value of the information
- | Use the information to make informed decisions

Manage resources

Find, manage, share and allocate time, money and material resources in a way that supports your own health needs, goals and priorities, and those of your family, community and workplace.

- | Identify those resources you have and those you need
- | Determine where they are and how they can be obtained
- | Use the resources in an efficient and effective manner
- | Balance resources effectively for family, work, community and self

Work within the big picture

Look beyond the immediate situation. Take into account the structures, culture, practices and formal and informal rules and expectations of the health care systems that influence and shape your health care actions.

- | Gather information about a system and how it works
- | Determine your relationship to the system and the roles you and others have within it
- | Monitor the system and predict changes
- | Base your efforts to influence the system on your knowledge of how it works

TABLE 2 | CONTINUED

Work together

Cooperate with others to learn, accomplish tasks and pursue common health-related goals.

- | Identify what needs to be done and plan how to do it
- | Pay attention to the relationships within the group as well as to completing the task
- | Identify and draw upon everyone's strengths in carrying out the work of the group
- | Recognize and deal with conflict in a productive manner

Provide leadership

Inspire and direct others in shaping and achieving a common health goal.

- | Institute and manage plans for action and change based on an understanding of the big picture
- | Organize and motivate others to act
- | Guide sound problem solving and decision making
- | Assure consistent monitoring and evaluation of performance

Guide and support others

Help others succeed by setting an example of healthy living, providing opportunities for learning or giving other types of assistance.

- | Acknowledge and reward others' strengths and accomplishments
- | Contribute to creating supportive learning environments and experiences
- | Empower others through mentoring, coaching and being a role model

Seek guidance and support from others

Help yourself succeed by asking for information, advice and assistance.

- | Recognize when you need help and know where to go for it
- | Seek out relationships with people whose judgment is trusted
- | Create and make use of networks of personal and professional contacts
- | Be responsive to new ideas and accept and use constructive criticism and feedback

Develop and express sense of self

Create your own personal voice in healthy living. Use your understanding of self to guide your health care actions.

- | Examine and clarify your own values and beliefs, recognizing the role your cultural heritage and personal history play in shaping these and in determining the possibilities of expression
- | Maintain standards of integrity
- | Consider the constraints of the situation as well as your own strengths and weaknesses when choosing a course of action
- | Pursue outlets for interests and talents to maintain emotional and physical health

TABLE 2 | 13 Everyday Literacy-related Health Care Consumer and Provider Activities CONTINUED

Respect others and value diversity

Respect and appreciate the values, beliefs, cultures and history of others. Use this understanding to counteract prejudice and stereotypes.

- | Create an environment where others feel welcome, are included and thrive
- | Encourage and carefully consider a wide range of opinion and beliefs
- | Educate yourself about other cultures
- | Challenge the beliefs that a person's inherent capacity is limited by background or group membership

Exercise rights and responsibilities

Act and advocate on behalf of yourself and others, taking into account laws, social standards and cultural traditions.

- | Recognize and assume your share of family, civic and work responsibilities
- | Monitor and keep up-to-date on federal, state and local laws and regulations
- | Make sure your own behavior is just and responsible
- | Take personal responsibility to bring about change or resolve problems to achieve a common good

Create and pursue vision and goals

Dare to dream. Be clear about where you want to go to maintain health and well-being, and how to get there.

- | Articulate a vision that embodies your values and goals or those of your family, community or work group
- | Establish attainable goals that are compatible with that vision
- | Develop a realistic plan to move toward the vision and goals
- | Create alternative means of meeting your goals that anticipate the effects of change

Use technology and other tools to accomplish goals

Be familiar with a variety of tools and technologies that can make it easier to achieve your health goals.

- | Keep up-to-date on developments in tools and technologies that may be useful for communicating, managing information, solving problems and carrying out daily tasks
- | Determine which tools are most useful for the purpose and context at hand
- | Use complex tools, machines and equipment to solve problems

Keep pace with change

Anticipate, manage and adapt to change in health conditions and systems that affect your life.

- | Adjust your goals and plans over time to take into account actual or prospective changes in health
- | Keep abreast of and evaluate trends in the health care industry and community, as well as the nation and world
- | Determine what skills and knowledge are needed to meet emerging health needs or new situations
- | Create opportunities to expand your own skills and knowledge, as well as those of your family, community and work group

How Is Health Literacy Measured?

Health literacy levels are determined by using the Test of Functional Health Literacy in Adults (TOFHLA). The TOFHLA enables health professionals to determine patients' general level of health literacy in numeracy and reading comprehension. These skills are necessary for patients to understand and follow healthcare providers' instructions. Without these skills, patients have difficulty following instructions accompanying medications, reading reminder cards for clinic appointments and understanding issues involved in signing informed consent documents. TOFHLA is available in both English and Spanish versions, regular and large print, and in a short version. It is the most widely used way of determining health literacy levels.⁸

There were also health-related questions found in the National Adult Literacy Survey. The 2002 survey will contain an entire section on health literacy. In addition, the Comprehensive Assessment and Accountability System, (CASAS) is an assessment which measures health literacy. The CASAS assessment correlates highly with NALS results. In other words, whether one uses CASAS or NALS, the health literacy rates will be comparable. Health professionals and health care facilities most often use the TOFHLA survey to determine health literacy rates.

What Issues Are Connected with Health Literacy?

Several critical issues are related to having a significant portion of the adult population with low health literacy skills. Some of the frequently reported statistics and facts related to these issues are reviewed in the Appendix. Sources upon which this section is based are identified in the endnotes.

Low health literacy contributes to higher use of health care and related services.

When people do not understand health care instructions or live a healthy lifestyle, they are more at risk for adverse health consequences. This results in an increased use of health care services. In addition, there is higher risk of becoming ill more often and more acutely, placing people at higher risk for unemployment, which in turn relates to a higher risk of substance abuse and domestic violence, all of which require even more services—expensive services.

Economies can become dependent on low literacy rates, including low health literacy rates. The market place can become organized to survive off the ills of low literacy people. Such economic growth is not the best way to grow the economy or create communities with attractive quality of life features.

Counties with low health literacy populations have an added and unnecessary economic burden.

Everyone pays an increased cost for low literacy skills within a community. Taxpayers pay more taxes to fund services. Businesses pay more for health insurance premiums and experience less productivity. Consumers pay more for health care. More of limited state and county government resources are diverted to serving the consequences of low literacy behaviors. Hospitals and insurance companies pay more for services and thus charge more. Businesses are more at-risk for malpractice claims. For example, national studies have shown a great deal of Medicaid costs for children and youth are associated with low literacy rates of parents and other health care providers.

What Issues Are Connected with Health Literacy? CONTINUED

Low health literacy disproportionately affects the most vulnerable populations.

People with disabilities, those living in poverty conditions, those speaking English as another language and seniors have special health literacy issues and challenges. These groups, on average, have higher rates of low health literacy than the general population.

Learning a new culture is always challenging. Adults whose first language is not English must become literate about a health care system that is both new and complicated. They must try to understand what is being said and learn how to solve problems in ways that are strange, unfamiliar or contrary to practices back home. Additionally, seniors with multiple medical conditions and slowing cognitive processes are similarly challenged.

The disproportionate effect of low literacy rates can be seen in the emergency room visits and in hospitalization of seniors and low-income families in Lancaster and Chester counties.

One can be literate in all other aspects and still have low health literacy skills.

To be functional implies that information and services are used so that one's health is maintained and enhanced. However, what we know may not affect what we do to be healthy. To compound the issue, the health care system is sufficiently complex that at times it baffles most of us. When emotional trauma is present during life-threatening situations, one's abilities to be a self-learner, and to put together, retain and use information correctly are greatly challenged.

To summarize, low health literacy skills:

- | exist among the educated and uneducated;
- | exist among the rich and poor;
- | are dangerous to one's health;
- | threaten the health and well-being of children;
- | sabotage appropriate medical treatment;
- | undermine health promotion efforts that rely on printed communication;
- | reduce one's ability to access health care and get insurance;
- | result in poor health behaviors;
- | have a severe economic consequence to society;
- | add to everyone's state and federal tax burden.

While some do, community leaders cannot afford to ignore high rates of low health literacy and low literacy skills in general. It simply costs us all too much, both personally and collectively.

What do health literacy initiatives look like?

In the health literacy field there are several different types of health literacy models from which to learn. Some target the health professional. Others target the population at large. Some incorporate health content into general literacy learning contexts. Others help health providers and agency leaders effectively communicate health content to adults with low literacy. Still other programs effectively apply functional literacy skill development to health maintenance behavioral learning and to situations where literacy skills are needed to cope with disease and illness.

Health literacy initiatives are led by public agencies and private for-profit and non-profit agencies. Some of each is reviewed in the following section. Still others are good examples of partnerships of various types in which scarce resources are shared and leveraged.

The purpose of this section is to provide a menu of possibilities for leaders to learn from and to enhance the number and effectiveness of health literacy education efforts in their community.

Examples of Public Agency Partnerships

The Massachusetts State Adult Basic Education Services (SABES) Health Literacy Initiative

Five years of innovative and creative work done by the Massachusetts Department of Health integrated health education into Adult Basic Education (ABE) and English for speakers of other languages (ESOL) activities throughout the state. As a result, Massachusetts is considered the national leader in the development of organizational mechanisms, programs and resources on health literacy. They have created the necessary help for directors of adult learning centers and teachers in ABE/ESOL settings to effectively incorporate health literacy learning experiences into what they do. Curriculum materials are available online. Assistance in fostering health collaborations in communities so that health literacy issues are addressed is also available online. They have created 10 regional centers that are collaborative partnerships among public agencies and non-profits. It is the most well-developed example of good articulation between the departments of health, education, labor, the technical colleges, non-profits and private health care providers. The state's literacy councils are also involved with these centers. This initiative provides a good model of what could be done at the county, as well as the state level. With the support and understanding of each center director, teachers use health as a content area in all the center's programs—family literacy, ESOL, workplace education, pre-GED and GED, skills training, parenting. (See <http://www.sabes.org/>. The SABES Health Page is particularly rich with idea and resources.)

Local Health Literacy Collaborations

Adult, health and workforce educators understand the need to communicate and collaborate so that community health resources, services and information are available to adult learners. These educators tend to target the same populations. As mentioned above, Massachusetts organized their efforts around 10 prevention centers located throughout the state. Each provides consultation, training and education in the areas of public health, literacy and community development. They house extensive resource collections and services.

Other communities incorporate health literacy initiatives as a part of their healthy community initiatives. Still others have taken the National Literacy Volunteer Model and created a community volunteer system to organize resources and support needed for all adults in the community to have the type of help they need.

Georgia's Certified Literate Community Program (CLCP)

Georgia's Department of Technical and Adult Education has developed a Certified Literate Community Program with the goal of improving the literacy levels of half of the adult population in each Georgia community during a 10-year time frame. While this is a new initiative, it looks very promising. The idea is simple but one that community leaders can get behind. They are targeting communities with the capacity to initiate programs to help low literacy individuals. (That is, this initiative is aimed at communities having enough social capital present so that leaders effectively work with one another, share resources and enhance a variety of settings.) The program is working to bring business, health, education and community leaders together. See their site at <http://www.dtae.org>. While the model is aimed at increasing general literacy competencies of the adult population, one can see the possibilities for a certified health literate community program.

Examples of Public Agency Partnerships CONTINUED

The National Network of Libraries of Medicine

The National Network of Libraries of Medicine promotes the role of consumer health librarians and provides help to encourage librarians' active involvement in health literacy efforts at the community level. They find that many consumer health literacy initiatives are geared toward technological access to health information or rewriting existing health materials at a simpler language level. They suggest these approaches are important but limited in result and are only pieces of a process that must be placed in a larger community context. They suggest that consumer health librarians can actively develop partnerships between literacy groups, community organizations and health care associations. They can provide space for meetings or health literacy materials, or actively develop health literacy programs. They can promote awareness of health literacy among health professionals by creating clearinghouses of health literacy information, sponsoring health literacy seminars and encouraging multi-organizational collaborations. The National Network of Libraries of Medicine, South Central Region, which is part of the Houston Academy of Medicine, Texas Medical Center Library, is leading the way and has good information for those librarians who want to become actively involved in health literacy efforts. (See <http://www.nnlm.nlm.nih.gov/scr/conhlth/hlthlit.htm> for further suggestions and resources.)

Health Literacy Information Models

The Eastern LINCS Special Health Collection

As explained elsewhere in this report, the United States' literacy resource system is now organized at the state, regional and national levels. At the regional level, there are regional literacy information service centers called LINCS. (See <http://www.nifl.gov> for details.) The Eastern LINCS center is known for its health literacy development. There are online lesson plans and student project ideas. For community leaders just getting underway with health literacy instruction, this will be a very important resource for you.

Also see the World Education's **Health and Literacy Compendium** described below in the "national efforts supporting local efforts" section.

Nonprofit Examples

Infant Welfare Society of Chicago

Infant Welfare Society of Chicago is a nonprofit primary health service center mainly for indigent Hispanic women and children. The clinic provides pediatric care, pediatric dental care, women's health care (including reproductive health and well woman care), health education and mental health services. All services are on a sliding fee scale; no one is denied service. They are involved in providing plain language materials to their participants as well as increasing reading levels of children and parents. This clinic introduced a reading program that provides bilingual books for parents of children when they come in for their physical exams. Volunteers are in the waiting rooms to model effective reading and listening times. Reading is approached as a story-telling session and parents are encouraged to talk about the pictures in the books with their children. They established a book club for the older children and each year the clinic holds a Reading Fiesta. This event keeps families reading over the summer. They also host a street fair, which provides opportunities to get out a variety of health messages. The clinic also collaborates with the City of Chicago's Bookmobile program. The bookmobile goes to the neighborhoods in which the clinic's patients live. As well, they have a partnership with an adult literacy provider, Literacy Chicago, and the West Town Public Library. This partnership offers an ESOL class on-site during clinic hours and provides family literacy and library literacy activities. The ESOL curriculum contains health literacy modules, how to interact with the public schools, how to access medical services, how to go to the store and how to take public transportation. Parenting and nutrition information is the content around which ESOL instruction is done. (See <http://www.infantwelfare.org>.)

The Gathering Place and Navajo Co-op Store

The Gathering Place and Navajo Co-op Store is a good example of creating a health literacy program that meets the needs of a specific cultural group. The Gathering Place is a nonprofit family center that focuses on family literacy, health awareness and economic development in the Eastern Agency of the Navajo Nation. Local women who are peers of the participants served by the center offer services. They share their language, culture and reality, and thereby bring culturally sensitive compassion and insight into the health literacy learning experiences. There are several literacy emphases. One emphasis is on literacy learning through sharing cultural traditions. Another is on learning English as a second language. Another stresses Parents as First Teachers (which is a key component of effective family literacy programs) and aims to increase the reading skills and education of participating parents and to increase the time parents spend with their children. The ultimate goal is to end the intergenerational cycle of under-education and poverty prevalent in their service area.

They also have WIC clinics, pre-schools, battered women's shelters and tribal houses. Their wellness programs combine literacy development with health, safety, mental and physical wellness, and preventive health maintenance measures. You can visit their site at <http://www.navajo-coop.org/>.

Nonprofit Examples CONTINUED

Avance, Inc.

Avance, Inc. is a leading nonprofit model that combines worker, family and health literacy efforts into an integrated family center. AVANCE started out in San Antonio, Texas and is now a recognized pioneer in the field of comprehensive, community-based services for very high-risk Spanish-speaking families. It is one of the country's oldest and largest programs supporting and educating parents of children under 3 years of age. It has centers all over Texas and now, with the help of funding from the Kellogg and Casey Foundations, the model is being replicated in other communities throughout the United States. This is one of the most comprehensive program models available to follow. See <http://www.avance.org/> for a description of their entire literacy emphasis including health literacy. See <http://www.latino-net.org/avance/history.htm> for the AVANCE Kansas City model.

Bethel New Life

Bethel New Life is a model for several effective practices, including health literacy. It is an example of a church-based effort that saw a vision as to how to transform their neighborhood surroundings on the West Side of Chicago. It now has a national reputation for innovative approaches to community economic development in a predominately low-resourced African-American community. One of their efforts was to engage local neighborhood residents in a discussion process through which they identified key indicators of what they thought was related to helping them become healthier. In this case, health literacy learning opportunities are seen in the larger context of creating healthy, sustainable communities. (See http://www.healthforum.com/hfcomhealth/asp/act_summary.asp for a description of some of their work.) While this is an urban model, for all practical purposes what they have accomplished could be done in a rural setting. When they started out, they had virtually few resources at their disposal. The story of how they organized is both inspiring and instructive. Creating and sharing a plan of action is key to the success and the involvement of local residents. See their latest strategic plan and more about all they are doing at <http://www.bethelnewlife.org/>.

Nonprofit Examples CONTINUED

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Healthwise Communities

Healthwise Communities is a partnership model that was started in Boise, Idaho but several states have used their work as a base to begin their own. Anderson, Oconee and Pickens counties in South Carolina and Hart County, Georgia drew from the Boise model to develop a similar effort. The Partners for a Healthy Community in Anderson received grants that allowed them to mail each household in four counties a **Healthwise Handbook**. This handbook deals with more than 180 health topics and is designed to help adults think through health questions. The handbook coaches people on how to connect with the health care community in effective ways. The handbook, however, is written for a fairly high reading level, which limits its audience and its usefulness. Where reading literacy is higher, even though other health literacy skills may be lower, the handbook will be useful. The Partners also have a 1-800-phone line managed by nurses, called Partners Nursewise Line, so that those who need health-related information and advice might access a nurse. This oral communication mechanism helps reach out to those who might not be able to read the handbook. They also have a **Healthwise Knowledgebase** that is accessible through their web site. (See www.healthwise-community.org and click on the **Healthwise Knowledgebase** icon.) This obviously is for adults with higher literacy skills. Topics included deal with questions frequently asked by local adults, such as what to do if you have insomnia, how to be good to your back (which is one of the top reasons why people visit the hospital in the area), communicating with your doctor, depression and avoiding diabetes. Through this same effort, the Partners offer community workshops on a variety of topics.

Healthwise, Inc., the parent company that started all these resources, is now a nonprofit organization committed to creating self-care and shared decision-making tools from technical medical information. Their mission is to help people do a better job of staying healthy and taking care of their health problems. They believe that wise health decisions involve three things: a mindset to take an active role in one's own health; a skill set to do self-care and shared decision-making; and a toolset of information to understand health options.

What do health literacy initiatives look like?

Health Literacy Volunteer Efforts

In some communities, the resources may be scarce enough to only be able to think about what to do without the benefit of any additional financial resources or paid staff. In such cases, consider a volunteer health literacy project. Churches can partner with the local literacy council on such efforts. Using volunteers helps lower costs of services, provides more flexibility in providing services and instruction, is more personalized, is less threatening and provides more opportunities for mentoring and individualized instruction. The pace of learning can be more flexible and a greater range of services is possible for those requiring non-traditional education.

Several organizations provide volunteers. It may be that your leadership could develop a partnership with one or more of these organizations. They include the Corporation for National Service (<http://www.cns.gov>), AmeriCorps (<http://www.americorps.org>), Learn and Serve America (<http://www.cns.gov/learn/>), National Senior Service Corps (<http://www.fostergrandparents.org/>), The President's Service Student Challenge (<http://www.cns.gov>), Laubach Literacy Action (<http://www.laubach.org/home.html>) and Literacy Volunteers of America (www.literacyvolunteers.org). For those wanting to use youth as volunteers, consult the Family Literacy Foundation for resources. Their Youth Reading Role Models, while geared to youth reading to children, could be adapted to encourage youth reading health-related information to adults in various health care settings. (See <http://www.read2kids.org/programs.htm>.)

In recent studies on the effects of using volunteers, rather dramatic gains were found. For example, the Literacy Volunteers of America found that, on average, student reading scores improve more than one grade level with 35 to 40 hours of tutoring by a trained volunteer. The Literacy Volunteers of America is recognized among many as a very effective training program available for volunteers interested in literacy development.

Community Health Adviser Network Program was created by the Center for Sustainable Health Outreach in Hattiesburg, Mississippi. This center is a collaboration between the University of Southern Mississippi and the Harrison Institute for Public Law of Georgetown University. A full-time, paid facilitator is linked with a network of natural helper volunteers at the neighborhood level. The volunteers receive training and mentoring, then help their neighbors and friends with their health-related needs. The volunteers link with public health services, when needed, through the facilitator. The volunteers seek to improve individual and community health by identifying perceived health problems, organizing self-help action in their neighborhoods and community areas, linking people in need with available health services, and giving advice and assistance to neighbors, friends and families. This network provides the missing catalyst link between public health services and community members, particularly for those with low health literacy. It is a program that is being replicated in several states, including Georgia, Alabama and Mississippi.¹⁰

National Efforts that Support Local Efforts

World Education works all over the world.

In the United States, two projects are currently promoting health literacy. **Health Education and Adult Literacy: Breast and Cervical Cancer (HEAL:BCC)** is a partnership between World Education and the Centers for Disease Control and Prevention. The project builds on the three-year CDC-funded Health Education and Adult Literacy (HEAL) project. HEAL:BCC promotes the spread of information about breast and cervical cancer to women who do not have a high school education. The model supports adult basic education and English for speakers of other languages classes as the location for in-depth health education. Materials and technical supports include a comprehensive curriculum, a center-wide orientation and teacher training, materials for learners, linkages with local health care providers, and ongoing support and training. World Education will partner with adult learning centers to pilot the model in three states. Evaluation results will be incorporated before moving on to implementation nationwide.

World Education's Health and Literacy Compendium project provides a unique resource for both health and literacy educators. This annotated bibliography is designed to help literacy teachers find and use health information and to provide health professionals with literacy information and easy-to-read health materials. It presently contains a collection of more than 70 citations to both print and web-based materials. The compendium itself is available on the web at <http://www.worlded.org/us/health/docs/comp/> and is linked to actual materials on-line. The project's greatest potential lies in the dynamic nature of the web document, which can be continually updated and expanded. The Health and Literacy Compendium represents a collaborative effort between World Education and the National Institute for Literacy.

Health Literacy Month

This is a grassroots campaign to promote understandable health communication across the world. The first event was held in October 2000. During that month, community leaders across the world were encouraged to raise awareness of health literacy in their own communities. This event is expected to grow each year. More resources and lessons learned will be available for local community leaders to draw on. If you are interested in hosting a Health Literacy Month in your community, contact Helen Osborn at Health Literacy Consulting to get connected with the latest resources and information available. (Helen@healthliteracy.com or see <http://www.prenataled.com/> for suggestions on how to organize such an event in your community.)

National Efforts that Support Local Efforts CONTINUED

The National Alliance of Urban Literacy Coalitions

The National Alliance of Urban Literacy Coalitions addresses literacy needs in more than 30 major metropolitan areas across the United States. The Coalition represents thousands of literacy service providers in workplace, family and community-based settings and encourages system-wide cooperation. For those wanting to start a coalition, refer to their site for further help at <http://www.naulc.org>.

Verizon Sponsors Literacy Champions

Verizon Sponsors Literacy Champions is a public awareness campaign strategy. This strategy could be applied to all aspects of literacy, including health literacy efforts. Verizon partners with local celebrities in communities to connect literacy to a familiar face, bring attention to this critical issue and raise awareness and funding for the cause. Verizon promotes literacy awareness through a media campaign that includes posters in Verizon stores, bill inserts, calling cards and newspaper inserts, as well as marketing activities and community literacy-awareness events. See <http://www.gtereads.com/champions/default.asp> for more details.

Early Start, Even Start, Head Start

Early Start, Even Start, Head Start efforts are beginning to recognize the importance of health literacy learning opportunities for adults involved in their programs. Home visitors are encouraged to add health literacy learning events as part of the home visit. Childcare providers and educators are encouraged to add health literacy learning experiences for children and their parents. Head Start and Early Start providers are encouraged to add health services, thereby adding health literacy learning opportunities to their efforts. (See <http://www.ed.gov/pubs/biennial/104.html> for further descriptions of Even Start efforts. See <http://www.acf.dhhs.gov/programs/hsb> for Head Start program efforts. See the National Center on Family Literacy for involvement of these national programs related to health and family literacy <http://www.famlit.org>.)

Private Health Care Provider Settings

Reach Out and Read

This is a pediatric, clinic-based literacy program that seeks to make books and literacy “as common a part of pediatric primary care as immunizations.” Volunteer opportunities include reading to children in the waiting room and organizing a book drive. The program is currently in 50 states, including South Carolina. It annually serves 1.3 million kids and yearly distributes more than 2.5 million books to families. They have trained over 10,000 pediatricians and nurse practitioners. Visit their web site at <http://www.reachoutandread.org>. The aim of this program in most places is to develop parents’ general literacy skills. A few program sites also are sensitive to providing health literacy learning experiences as well.

An example of a nonprofit pediatric clinic model is The Infant Welfare Society of Chicago (reviewed above). The Greenwood Community Children’s Center in Greenwood, South Carolina is another example providing similar services.

Hospitals

Hospitals increasingly understand their role in preventive health care. Through their volunteer systems, they are enhancing their services to support adults who have trouble reading, understanding health instructions, or need a listening ear to figure out what to do given their complex medical conditions. Some have expanded their healthy living programs. Health literacy efforts could be an additional component to such programs.

Hospital auxiliary units are a great place to begin health literacy initiatives. Auxiliary members can be trained to help low literate adults read and understand medical consent forms, medical instructions and medicine labels, for starters.

International Efforts that Support Local Efforts

The University of Pennsylvania’s School of Education hosts the International Literacy Institute. This institute is the link between the national literacy system’s efforts and the international efforts of the United Nations and OECD’s Center for Educational Research and Innovation (CERI). This Institute has summer literacy training programs, hosts regional forums and engages in a variety of research and development projects. Their emphasis is on professional development of literacy providers, including health literacy providers. See <http://ncal.literacy.upenn.edu/>.

Sometimes looking at what is being done around the world is a good way to stimulate creative thinking at home. Readers are encouraged to discover what the **United Nation’s World Health Organization** is doing on health literacy. You can access their work through the University of Pennsylvania’s web site (url provided above).

Models for Increasing Readability and Understandability of Health Messages

Maine's Health Literacy Center at the University of New England

Maine's Health Literacy Center at the University of New England specializes in helping professionals learn to plan and create attention-getting communications that are clear and simple. They have a full-service package to help health organizations revise their written communications and review all oral instructions. They have assisted national health agencies, insurance companies, community health organizations, and private industry and health education professionals. They offer a summer institute each year that is a highly recognized program. Visit their site at <http://www.une.edu/com/othrdept/hlit/index.htm>. (It provides a model for South Carolina to follow in having a source for private providers to use) written and oral instructions as well as health education materials are being understood by all adults—those who are literate and those who have low reading and comprehension skills.

Canada's "plain language" movement in health care

Canada's "plain language" movement in health care is changing communications between patients and professionals. The leaders believe that simple instructions and easy-to-read health information will help to improve health care in Canada. A well-organized movement to foster plain language in healthcare materials is underway which emphasizes short, simple sentences with common words and practical information. The Canadian Public Health Association has sponsored the National Literacy and Health Program. This program is a working partnership of 26 national health associations to raise awareness about literacy and health. They have found that materials should cover only 3 to 5 points, use simple graphics and techniques, such as bullet formatting and bold type, and use common words instead of technical terms. The program has developed an information kit for providers so that they can develop plain language materials. See <http://www.hsph.harvard.edu/healthliteracy> and <http://www.sabes.org/f04resou.htm> and the Canadian Public Health Associations web site for resources on plain language initiative (<http://www.pls.cpha.ca/>).

Higher Education Models

There are higher education models in other states that model possibilities for South Carolina's higher education system and its role in improving health literacy skills of its residents.

There are at least 13 colleges and universities within a 60-mile radius of most towns in Chester and Lancaster counties. At least part of the answer to the low literacy rates in these two counties involves getting higher education focused on literacy development in general and health literacy as it relates to this report's focus. Faculty and students from these and other colleges and universities are encouraged to join community leaders in creating a strong literacy education system in these two counties.

A few models of what higher education is doing elsewhere are given to stimulate thinking about what could be done in Lancaster and Chester counties through higher education involvement with county literacy providers.

Georgia State University, Center for the Study of Adult Literacy

Georgia State University, Center for the Study of Adult Literacy has led the way in developing measurement tools to measure rates of health literacy. Their staff, working with faculty from Emory University, developed the most widely used health literacy measurement instrument reviewed in a previous section of this report. They are particularly interested currently in women's and health literacy issues and research. See <http://education.gsu.edu/csal/>.

The University of Maine's Health Literacy Center

The University of Maine's Health Literacy Center is a good example of one institution that has consciously organized its public service functions so that private health organizations have help available to take a look at their materials and communication systems so that they promote effective health literacy standards.

Harvard University's School of Public Health

Harvard University's School of Public Health is the home of the National Center for the Study of Adult Learning and Literacy that is connected with the national literacy system. They have created a practitioner research network that is a model for what could be done within South Carolina. They link practitioners with researchers for information-sharing purposes. They help identify practitioner sites that would be willing to be research sites. They keep abreast of what various researchers are doing and bring practitioners together with researchers to discuss topics of common interest. They share results of research in useful ways. This center is also a model of the types of studies that could be done in South Carolina so that the outcomes and effects of health literacy education in communities throughout South Carolina are better understood. See <http://gseweb.harvard.edu/-ncsall/>.

Higher Education Models CONTINUED

Brown University

Brown University has developed a model web-based online resource for literacy educators. It is called the Knowledge Loom. (See <http://www.knowledgeloom.org>.) It presents principles of best practice for teaching and learning in various subject areas, including literacy. The early literacy best practices section is already developed. During 2002, the adolescent and adult literacy best practices will also be online. The way in which this site is structured is a model from which other higher education units could learn. (See <http://www.lab.brown.edu/public/literacy/implementationq.shtml>.)

The Student Coalition for Action in Literacy Education (SCALE) at the University of North Carolina

The Student Coalition for Action in Literacy Education (SCALE) at the University of North Carolina at Chapel Hill is a model of what a network of college students, adult learners, administrators, literacy practitioners and community partners can do to implement and support participatory education and social change work in campus-based literacy programs. It also hosts a consortium of campus-based literacy programs implementing and expanding a service-learning initiative related to literacy. Each network partner conducts a seminar and initiates an action project. This consortium involves colleges in Georgia, Ohio, Minnesota, South Carolina (Benedict College), New York, Washington, D.C., Pennsylvania, as well as North Carolina. (<http://www.unc.edu/depts/scale/mission.html>.)

Several other universities are affiliated with the LINC system and are strategically helping to create parts of the literacy system as described in the National Literacy Act. A similar higher education system is needed in South Carolina to support the technical centers now being developed by the South Carolina Literacy Resource Center and local literacy providers.

initiatives look like?

What Can We Learn From These Efforts?

About The Need for Collaboration

| The most comprehensive impact on health literacy is made through the formation of a partnership of public and private agencies working together, sharing resources, and each improving their own health literacy services, information and communication practices.

About Who Is Responsible for Ensuring a Health Literate Adult Population

| Becoming a health literate county is just as much the responsibility of the health care provider as it is the health care consumer.

| Higher education institutions have a vital role to play in supporting local efforts and helping state, county and community leaders meet the challenges described elsewhere in this report. Professional development of health literacy providers is needed throughout the United States, including South Carolina. We need to advance our understanding of the impact of health literacy and how best to increase the rate of health literacy. A strong, practical research program is needed in South Carolina on literacy in general and on health literacy, in particular. Higher education faculty members must be linked in intentional ways with literacy providers in order to increase literacy rates. Students as well as faculty have important roles to play in providing literacy services in low resourced communities.

About the Need for Integration

| Adult education programs can integrate health literacy learning experiences into all areas of their curriculum and connect to other initiatives, such as family literacy, adult basic skills education (ABE), ESOL classes, worker literacy and citizen literacy efforts.

| Family literacy and health literacy efforts go together very well. Think of ways to integrate health literacy into programs offered routinely by state government and the nonprofit sector in your area. There is a particularly good fit with family literacy efforts. Find ways to integrate health literacy into state and county departments of health, education and social service family-focused programs. For example, many of the public health departments, including those in South Carolina, promote the use of the Parent and Child Together time (PACT). This is a necessary component of effective family literacy programs. The SABES program in Massachusetts promotes incorporating appropriate health activities into the PACT program. Discussions about appropriate health activities (e.g., importance of washing hands or eating nutritious meals), healthy eating habits, exercising tips, how best to talk with the pediatrician or where to access medical help at reasonable costs can be incorporated easily into PACT program activities. Home visitor programs done by the Department of Education, the Department of Health and Environmental Control, and the Department of Social Services, or by various non-profits, can easily incorporate health literacy teaching and learning efforts into a home visit. In some places home visitors bring backpacks of health-related activities to do as a family (e.g., home safety; street safety, dealing with conflict; communicating how one feels physically). Early childhood development programs, such as those launched under the First Steps initiative, can promote health literacy in their efforts. Adult education programs in every county can be encouraged to incorporate health content for reading, writing, speaking, listening and problem solving activities per learner choice and interest. Special health-related projects might form the basis of learning literacy skills for adults. Obviously, the health literacy initiative need not be seen as a stand-alone effort in communities.

What Can We Learn From These Efforts? CONTINUED

About the Need for Integration

| Those working in health clinics and pediatric offices that have incorporated health literacy learning opportunities through their practices have learned the following things:¹¹

- | It helps to personalize health information by putting the patient's name on it.
- | It helps to review the content with the patient to see how well they comprehend messages and to allow opportunities to reinforce important information and instructions.
- | It helps to highlight or circle the important information.
- | It helps to ask questions that require the patient to find information on the paper.
- | It helps to repeat the most important points as needed.
- | It helps, if you believe the patient cannot read, and you know the information is vital, to audio tape the highlights for them. Some provide inexpensive tape recorders to their patients for this purpose.

| Adequate understanding of health literacy skills should shape the way health promotion happens. It should affect what is said, how it is said and what types of communication processes are used. Health literacy education is not the same as health promotion education. In order for health promoters to truly begin health literacy efforts, they must consciously be thinking about health literacy and basic literacy skill development. In addition, an adequate understanding of health literacy should make health promoters understand that given the right set of circumstances anyone's literacy skills may be inadequate. This understanding should re-shape health settings so that they are active learning settings and provide every adult with resources to make learning possible and understandable so that wise health behavior choices can be made.

| Health literacy initiatives need to pay attention to the literacy levels of learners and where they get health information.

What Can We Learn From These Efforts? CONTINUED

About the Need for a Clearly Defined Leader

| The Massachusetts' initiative teaches us that communities need resources and technical assistance to get health literacy efforts well incorporated into community educational opportunities. They created a health and literacy liaison system. Someone has to intentionally lead the effort, even though partnerships are needed.

About Costs

| The cost of integrating health literacy efforts into community-based organizations is actually fairly reasonable. On average, the cost is approximately \$22,000 per year for those wishing to follow Massachusetts' lead. This includes hiring five health facilitators at five hours per week for 42 weeks at \$25 an hour; paying a health team of five members \$10 an hour for four hours of work per week for 42 weeks; and allowing \$2,000 for materials and software, approximately \$300 for travel and \$4,200 for curriculum development. During the initial phase when the health team needs mentoring, an additional \$1,200 is reserved to train the team.

This five-member health team becomes responsible for conducting health fairs, gathering resources, preparing materials and events, developing collaborations with local health and allied organizations such as family centers, human service non-profits and churches. A complete job description for this model is found on the SABES web site. It might be a good place to start before resources are appropriated for a larger initiative or as a complement for a staff-led initiative, such as is the case in Massachusetts.

About Cultural Compatibility

| Communities with low levels of functional literacy need to generate their own informed health messages that best fit their local situation.

| With ESOL learners, health messages cannot only be translated from English into their native language, but also need to be developed with the cultural context in mind. Often this translation is best done by involving local ESOL instructors who know the area and the particular cultural beliefs and practices of local ESOL learners.

The next section of this report identifies the components of a successful health literacy initiative.

What will help us be successful?

This section of the report identifies a variety of ways to get started. While leaders are encouraged to think about a collaborative effort to build a strong health literacy system, we encourage leaders to also think about what they can do to improve their individual efforts.

Leaders can do the following things in order to ensure a successful health literacy initiative:

- | Ground health literacy issues within their specific context;
- | Envision what an effective health literacy system would look like given their specific context;
- | Identify, based on their vision, what outcomes they intend to reach with their efforts;
- | Create efforts that will best ensure they reach their intended outcomes;
- | Find partners willing to share resources and work load;
- | Use effective adult teaching and learning principles to guide educational and communication behaviors;
- | Design and implement an evaluation program;
- | Communicate through a mass communication campaign what health literacy is all about and its importance to individuals, families and the economy.

A few pointers on each of these tasks are given on the following page.

Start by determining your community's health literacy issues in context

In order to tackle issues one must ground them. Grounding an issue means to describe and address the features of a specific context or situation that make it an issue in order to clarify what is at stake. Otherwise, the solutions suggested are typically off base or too general to gain people's attention. No two communities have the same contextual features to their health literacy issues (or any issue, for that matter). So it is important to understand the specific features of the health literacy issues in your community and area. Why are so many testing so low? What are health providers doing to improve literacy rates? What are people's values and beliefs about health practices? What are the general population's beliefs about what literacy is and is not? Who is doing what regarding health literacy?

Two different kinds of community dialogue processes work well in helping community leaders ground health literacy issues. Choose one and conduct an issue-framing dialogue process so that you know the specific features and characteristics that must be addressed to effectively tackle health literacy development in your area.

One community dialogue process is the Study Circle Resource Center model. Study circles can have any discussion topic community leaders or members want. Health literacy issues and why health literacy is an issue could be a discussion topic. Study circles are small group, democratic, peer-led discussions. The Study Circle Resource Center has created a variety of support materials and services to help interested groups get started and conduct study circles. See their web site for guidebooks that can be downloaded (<http://www.studycircle.org/>). Sometimes the name "study circle" is not appropriate. For example, the Anderson Healthy Partners groups named their effort "neighborhood chats."

A second community dialogue process is an issue forum as developed by the National Issue Forums (NIF) network. It is a nationwide network of educational and community organizations that discuss issues of major significance. NIF forums provide a way for citizens to exchange ideas and experiences with one another to make more thoughtful and informed decisions. Typically, a critical issue is identified (for example, low health literacy rates and their effects on county or community residents and businesses), then a non-partisan issue book is written based on local ideas, varying perspectives and options for taking action. Local forums and study circles are conducted using the issue booklet. A community-wide forum is conducted to share the results of the forums, and study circles and action plans are created. See <http://www.nifi.org/> for details. One key distinction of this group's approach is that citizens are asked to think about and consider the value of opposing and alternative perspectives on an issue. This thinking process helps build literacy skills that can contribute to the development of citizen literacy. Notions such as tolerance and cultural diversity cannot be developed until people learn to think and appreciate the wisdom found in multiple perspectives.

Visioning: What are the components of an effective health literacy system?

Grounding health literacy issues provides part of the information needed to develop an effective vision. A strong vision guides and grounds effective practice. Visions are developed based on participants' understanding of issues, assets and effective practices.

Massachusetts models what an effective health literacy system might look like. While it is suggested that community leaders develop their own vision for what an effective health literacy system would look like in both Lancaster and Chester counties, one possible vision is included here. It draws from Massachusetts' work. An effective health literacy system in Lancaster and Chester counties might function as described in TABLE 3 .

The functions identified in Table 3 are the system components found most often throughout the United States. Leaders in Lancaster and Chester counties may want to use the sample vision statement to begin thinking about what type of health literacy system they want, what types of partnerships are needed, and who will do what on behalf of the partnerships. Other system components might be needed based on discussions. Use the model program and resource sections of this report to identify and draw on resources that might help you develop health literacy system components.

TABLE 3 | A possible vision statement of an effective health literacy system in Lancaster and Chester Counties

An information creation and dissemination system

| Plain language health materials are available to any adult and professional needing them. Services are accessible to help health professionals assess the readability and understandability of the health information materials they use with their patients. Adults, irrespective of literacy levels, can access health information that is understandable. This information is available through sources they trust. Information is found in many forms (e.g., written, audio, audiovisual, visual, in a variety of languages). It is sensitive to a variety of cultural needs. There is a place where health professionals can go to have their materials checked for readability and understandability. The higher education system within the state is connected with literacy practitioners in the community. Professional enrichment is available. Practical research is done which improves health literacy programs, health professional practice and learner health literacy skills. Information is shared among researchers and practitioners. Adult learners are empowered to be a part of this information, creation and dissemination system. Elementary, middle and high school, technical college, college and university faculties and students are involved in health literacy service learning projects in every community within both counties.

TABLE 3 | A possible vision statement of an effective health literacy system in Lancaster and Chester Counties CONTINUED

A coordinated health literacy learning system

| Existing learning opportunities include health literacy content in their instructional plans. Educators know and plan their instruction around what the 13 common everyday literacy-related activities are in order to be an effective health care consumer and provider. They plan instruction around the four literacy skills sets. They make applications to learners' everyday needs as health care consumers and providers. Every learning opportunity present in each community includes health literacy activities as part of its overall learning package. Family and senior centers include health literacy training with their family literacy efforts. Health literacy efforts are found in all the schools, public agency programs, in family and neighborhood center programs and in healthy community efforts. There is a self-learning system, such as the Healthwise movement, that allows adults to learn about health issues when they are ready and want to learn. The learning system is non-stigmatized, easily accessible, and reinforced with a formal and informal health advisement system such as the Mississippi community health adviser network initiative.

A health literacy measurement and assessment system

| County leaders know their population's health literacy rates. They measure these rates periodically using TOFHLA. They ensure that South Carolina is a part of the 2003 National Adult Literacy Survey so that South Carolina has a robust statewide sample and clear picture of its literacy situation. They target services and supports for health literacy education where there is the most need. They assess current health literacy development efforts for the presence and effectiveness of current health literacy education. They measure important indicators that tell whether increasing health literacy rates is having a positive effect on the economic, business, and human growth and development outcomes often associated with low health literacy rates.

A formal and informal health decision-making advice system

| There is a phone number any adult can call anytime to help them make wise decisions about health-related issues. Health literacy volunteers are organized at the local level through church networks, through higher education service learning projects, through neighborhood associations and other locally based civic groups. These volunteers are available to any individual in the community to help them solve health-related problems. Each household has a Healthwise Handbook, or other plain language health decision-making materials, which helps everyone take charge of health care decisions. Each household can access a Nursewise hotline. Each household can access a health educator who can provide understandable information. Computerized health decision support aids on health topics are available through all the public libraries. There is a health consumer librarian available within the county that helps organize library resources related to health literacy.

A professional health provider learning system

| There are opportunities organized for all professional doctors, nurses and health educators to learn how to speak and write in plain language. On-the-job seminars are offered. On-site coaching is done based on observation of the health professional's interaction with low literate adults.

Determine Outcomes Based on Vision

Once a vision is created, then outcomes can be developed for each part of the vision. Two different levels of outcomes might be created: health literacy system level outcomes and program level outcomes. The system level outcomes state positively what various organizations are doing to provide health literacy services to learners in an improved situation. The program level outcomes express what learning outcomes in adults are desired in an improved situation.

At the learner level, the National Institute for Literacy has defined the primary literacy outcomes sought for the roles of worker, parent and citizen. The Equipped for the Future standards report provides learning objectives related to each outcome statement.¹² The Joint Committee on National Health Education standards forms the basis for the health literacy consumer and provider outcome. At the systems level, the National Literacy Summit provides the basis for a system-wide outcome statement. Using these sources as a base, possible system-wide and learner level outcomes for a health literacy initiative are given in TABLE 4 on the following page.

The next section begins to address competency level objectives for health literacy learning opportunities. The learning objectives need to be based on enhancing competence in performing enduring adult everyday activities related to the role of health care provider and consumer.

What will help us
be successful?

TABLE 4 | Possible outcomes for a health literacy effort in Lancaster and Chester Counties

Possible health literacy system level outcome

| By 2010 there is a coordinated system of health literacy services that connect public and private agencies so that any adult wanting to improve their health literacy skills can do so in a timely, cost-effective manner, free from stigma and in a useable form. A system of health literacy services and supports is available so that all willing individuals are able to achieve their health learning, health maintenance and health provider goals.

Health Care consumer and provider learner outcomes

| Health consumers and providers in Lancaster and Chester counties can obtain, interpret and understand basic health information and services and have the competence to use such information and services in health-enhancing ways.¹³ They obtain and manage information by proficiently using the 4 Equipped for the Future literacy skills sets across 13 everyday health literacy-related activities.

Frame learning outcomes around 13 core health care consumer and provider literacy-related everyday activities.¹⁴

| What daily activities do people do related to being a consumer and provider of health care? What do they do to become healthy and maintain health? The National Institute for Literacy identified 13 core activities that are common to all the major roles adults tend to play. Three roles (parent, worker and citizen) were emphasized in the EFF standards. These same activities are also common to adults who personally maintain their health and are consumers and providers of health care. These 13 core activities are integrative cognitive, social and behavioral processes that endure over time, even in the face of changes in technology, health care system changes, work processes and societal demands.

Creating learning experiences around these 13 core activities is central to health literacy program development. Creating health care environments in which people can gain these skills is at the heart of creating an effective health literacy system. Health literacy learning, advisement and tutoring efforts address one or more of the skill-based, health consumer and provider role-related activities found in Table 2 of this report. These 13 core activities are part of consuming health information and services effectively, and providing effective health care for oneself and others.

TABLE 4 | CONTINUED

Back to Addressing Literacy Skill Development within the Framework of Health Literacy Education.

There may be a tendency for some professionals to start calling everything health literacy education when, in fact, it is not. One cannot address health literacy education without developing instruction on basic literacy skill development. Healthy living is the content of health literacy education. The development of literacy skills so that people can obtain, interpret and understand basic health information and services, and have the competence to use such information and services in health-enhancing ways, is at the heart of health literacy education.

As mentioned in the first section of this report, adults need four fundamental types of literacy skills to draw from in order to carry out the key activities that are central to their primary role as health consumer and provider. They need communication, decision-making, interpersonal and lifelong learning literacy skills. In the past, literacy was often thought of as only those skills found in the first category: communication skills. Some even tend to think of literacy only as being able to read and write. See Table 1 for a reminder of what these 4 basic literacy skills sets are. In order to have an effective health literacy effort, leaders must consciously address the development of one or more of these four literacy skill areas.¹⁵

In summary, effective health literacy efforts identify system level changes needed and health literacy learning outcomes. An evaluation program cannot be designed until intended outcomes are known. Effective efforts start by articulating outcomes and then choosing strategies that have the best possible chance of reaching those outcomes. This may sound logical, but it is rarely done. People sometimes get caught up in implementing a favorite solution or program without clarifying what outcomes are sought and why. Declare health literacy outcomes first and then determine what to do to ensure that those outcomes are obtained.

What outcomes should be achieved? Effective outcome statements are linked conceptually to visions for improvement. They are based on trying to improve the basic literacy skills mentioned in Table 1 and the 13 common role-related behavior sets mentioned in Table 2. The outcomes should also be patterned after effective health literacy efforts elsewhere. In other words, draw on your own vision for improvement based on your understanding of your particular context, on nationally recognized practices and the thoughtful work of scholars and practitioners across the U.S. Much of this wisdom is summarized in this report.

Once outcomes are identified, selecting appropriate ways to measure these outcomes becomes possible.

Build Necessary Partnerships

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An effective way to ensure a health literate population that can take charge of health decisions and reduce costs is to form a partnership. Leaders from limited-resource communities particularly may need partnerships so assets can be leveraged and enhanced. Partners may include leaders from hospitals, businesses, insurance companies, local governments, physicians, nurses, health educators, librarians and nonprofit organizations – leaders who care about the importance of having a health literate population.

A partnership functions best when every partner has a responsibility and knows what is expected of them. Each partner should have the resources necessary to accomplish their responsibilities. Local resources are leveraged so that those who are willing to lead have the resources necessary to do a good job on behalf of the partners. The partnership has a coordinating center of operation. In many places this coordinating center is a health district office, a private nonprofit formed through healthy community deliberations or a literacy council. Partnerships take hard work to form and even harder work to keep going. Therefore, good leadership is required in order to build a strong health literacy system.¹⁶ Effective leadership is intentional, visionary and continually communicates and leads.

Use effective adult teaching and learning principles to guide instructional development and communication practices

Sometimes teaching behaviors are shaped by what has been seen in school settings. For low literate adults (as well as children and youth), schooling models of teaching are not valued. While some of the model efforts described elsewhere in this report are more schooling oriented in approach, we encourage leaders (e.g., doctors, nurses, health educators, adult educators, school teachers, family center program officers, family members, friends, volunteers) to think about effective moments when they teach. Traditional schooling approaches to teaching adults do not tend to work well, particularly with level 1 and 2 literate adults. Think about how adults learn and therefore how to effectively teach them by framing your teaching around what they do in their role as health consumer and provider. Effective adult educators of health literacy efforts do the following things (a fuller description of these educational principles is found in the Appendix):

What will help us
be successful?

Use effective adult teaching and learning principles to guide instructional development and communication practices CONTINUED

- | Link new literacy learning to an adult's prior health care consumer experience.
- | Help adults meet specific health literacy learning goals related to their own health literacy needs.
- | Help adults meet specific health literacy learning goals related to their role as educator of their children's and other family members' health literacy needs.
- | Experientially base their health literacy instruction.
- | Assess various learning styles of adults and communicate new health literacy information and skills to their audience in ways easily understood.
- | Contextualize their literacy learning experiences.
- | Communicate effectively with adults who have differing ways in which they think about and take action on health consumer situations.
- | Are able to work in a variety of health consumer and provider settings with a variety of different types of community leaders.
- | Effectively involve adults in planning their own health literacy learning.
- | Market their health literacy learning offerings effectively.
- | Understand that retention of adults in health literacy programs is a problem and act accordingly.
- | Reward adults who have successfully completed a health literacy learning program or correctly accomplished a health maintenance or decision-making task.

Applying these principles is hard work. We are all health literacy educators either formally or informally.

It takes thinking and acting outside the “schooling” instructional box. In situations where programs are offered, recruitment and retention rates often directly correlate to how successful one is in applying these principles of teaching and communicating. Reaching learning outcomes such as those mentioned elsewhere in this report are conditioned on effectively using these principles.

Design and implement a health literacy evaluation program

Evaluation cannot occur unless there are clearly articulated outcomes and related literacy development strategies present. These should be defined early in the development effort. In addition, a clear profile of targeted learners should be developed. Strategies employed should fit logically with the outcomes sought and be based on what is known to work. Once the audience is specified, and outcomes and strategies are determined, then the needed information is available to guide the evaluation design.

An entire book could be written on evaluation.¹⁷ That isn't the purpose of this report. Involve community members who know how to do evaluation in your community's health literacy initiative development. Engage them during the planning process because, if you answer the questions they need for the evaluation design, you will have what is needed to develop the initiative in a sound manner.

Build a health literacy public awareness campaign

The final section on how to get started deals with building the public's awareness of health literacy issues and system development challenges. In the model program section of this report, the Verizon Literacy Champions model is given. Sprint also has a program. The Success by Six initiatives provide another useful model to examine.

Creating awareness of the issues is part of the process of helping all residents begin to increase their own competence. Resources will be more easily harnessed if word gets out about what is at stake. An effective public awareness campaign is a necessary component to a functioning health literacy system. The more the public addresses local specifics of health literacy, the better chances of securing attention and action.



What health literacy resources are available?

Many resources were identified throughout this report. Some additional key resources are cited below. By going to these web sites an entire resource collection on health literacy is available to you. This listing is selective, but by accessing these sites other resource agencies can be identified and their resources accessed.

National Organization Resources

The key national organizations that promote literacy development in general and also related to health literacy are reviewed below:

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National Institute for Literacy
800 Connecticut Avenue, N.W.
Washington, DC 20202-7560
call (202) 632-1500
www.nifl.gov

NIFL was created as a result of the National Literacy Act. It is the national hub through which the literacy system in the United States is to be built. NIFL is the primary source to turn to for finding out about literacy organizations and initiatives at the state and national level. NIFL's web site includes an online directory of literacy resources across the nation. A complete description of the regional resource center system is also there. These regional centers are called LINC'S (Literacy Information and Communication System). Use the LINC'S connections to access region- and state-specific resources. NIFL's Eastern LINC'S web site is home to a special collection of literacy and health information.

World Education
Health and Literacy Initiative
44 Farnsworth Street
Boston, MA 02111-1211
call (617) 482-9485
fax (617) 482-0617
www.worlded.org

The Eastern LINC'S health literacy emphasis was developed by World Education. World Education is known for excellence in its work all over the globe with low literate communities. The Health and Literacy Initiative of the Eastern LINC'S has developed a Health Compendium. The Health Compendium is a special web-based collection of health and literacy resources. World Education, through various literacy projects, provides technical assistance with materials assessment and development, and participatory health education program development. They are currently providing technical assistance to ABE and ESOL programs that are integrating health into existing curricula; implementing the HEAL:BCC Project, a national demonstration project that brings breast and cervical cancer information into literacy and high school equivalency programs. They also coordinate the Massachusetts Health Team, a collaboration of health educators and literacy practitioners.

The Midwest LINC'S
Kent State University
Access site through the NIFL web site
www.nifl.gov

The Midwest LINC'S has a helpful guide to establish program quality indicators (called the Indicators of Program Quality Resource Guide). While it is written to address program quality indicators for literacy programs in general, it will be useful to those groups wishing to create a health literacy program. With slight modifications, it will help form a good basis for a rigorous program evaluation.

U.S. Department of Education
Office of Vocational and Adult Education (OVAE)
Division of Adult Education and Literacy
400 Maryland Avenue, SW
Washington, DC 20202-7240
fax (202) 205-8973
www.ed.gov/offices/OVAE/AdultEd

The Division of Adult Education and Literacy, in the Office of Vocational and Adult Education (OVAE), administers the Adult Education and Family Literacy Act, Title II of the Workforce Investment Act of 1998 (Public Law 105-220). The Adult Education and Family Literacy Act is the department's major program that supports and promotes services to adults who are educationally disadvantaged. The division maintains cooperative and consultative relations with Federal, State and local agencies that provide basic skills services. It maintains a clearinghouse that offers national information resources on issues and trends in adult education and literacy, publishes a newsletter (A.L.L. Points Bulletin), and reports on promising practices in adult education. It has fact sheets and online resources related to health literacy. Consulting these fact sheets will allow the reader to easily access most of the resources available online. Their web site contains links to most of the major web sites connected with literacy education. Readers are encouraged to start there to quickly link to all major sites. (Click on "Related Links.")

National Organization Resources CONTINUED

National Center for the Study of Adult Learning and Literacy (NCSALL)
Health and Literacy Studies
Harvard School of Public Health
Department of Health and Social Behavior
677 Huntington Avenue
Boston, MA 02115-6096
www.hsph.harvard.edu/healthliteracy/

This site is designed for professionals in health and education who are interested in the issue of health literacy. It contains materials you may find useful for your work:

- | A PowerPoint overview of health literacy
- | A video entitled In Plain Language
- | A literature review and annotated bibliography of published research in medicine and public health
- | Research reports from the Health Literacy Study Group
- | Innovative materials
- | Health Literacy and Health Communication Curricula
- | Links to a variety of web sites related to health and to literacy

For those interested in starting research projects, this site will be particularly helpful and instructive.

The National Center for Family Literacy
Research: Literacy Facts and Figures
www.famlit.org/research/research.html

This is the best compendium of statistical indicators and research findings that relate to literacy as well as other educational and social conditions that were found. It covers statistics related to the scope of adult literacy in the U.S.; literacy and welfare; literacy and crime; education and voting behavior; literacy, families and children; schools, teachers and learning; reading and the home; children learning to read: success vs. failure; television and literacy; homework; absence from school; parental involvement; fatherhood; the impact of welfare reform; technology, early childhood intervention; and research reports.

Health Promotion Council of Southeastern Pennsylvania
311 South Juniper Street, Suite 308
Philadelphia, PA 19107-5803
call (215) 546-1276
fax (215) 545-1395
www.hpcpa.org/

The Health Promotion Council promotes health to those at greatest risk through publications and training. They have a multi-cultural, multi-lingual staff and an emphasis on culturally competent health communications. Their pamphlets and audiovisuals for African Americans, Latinos and Asians, written at or below a sixth grade reading level, currently cover blood pressure, diabetes, smoking, stress, nutrition and use of the health care system. The Council has materials in Spanish, Cambodian, Chinese and Vietnamese. They have a seven-to-eight-week training and curriculum for community-based hypertension and diabetes control, offered in both Spanish and English. They have a Community Healthcare Interpreter Training project, which provides high quality and standardized training programs for interpreters who work in health care settings in order to improve the quality of health care for limited-English-speaking consumers. They have a health literacy technical assistance service to help health care professionals learn to communicate effectively with low literate consumers.

National Organization Resources CONTINUED

The key national organizations that promote literacy development in general and also related to health literacy are reviewed below:

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National Assessment for Adult Literacy
National Center for Educational Statistics
Washington DC
<http://nces.ed.gov/help/sitemap.asp>

This site will give you the facts related to which states participated in the 1992 national literacy survey. (South Carolina did not participate.) The site contains definitions of each type of literacy skill tested and definitions of the levels for each of the three areas tested (prose, document and quantitative literacy levels). It provides samples of test items. This site will be useful to those who need to educate boards, staff and community leaders about literacy issues and skills. It will help make sense out of what it means to have 56% and 60% of the adult populations in Lancaster and Chester counties, respectively, at level one and two literacy proficiency.

Alpha Plus Centre
21 Park Road
Toronto, Ontario M4W 2N1 Canada
Phone: (416) 397-5900
Fax: (416) 397-5915
<http://alphaplus.ca/indexl.htm>

The Alpha Plus Centre provides resources for adult learning. The web site houses the online catalog of the center's adult literacy library that includes a large selection of health education materials. While only citations are available online, the center is willing to lend publications, for a fee. They distribute a "mini-bibliography" of information about health and literacy. They provide information for the Anglophone, Francophone, Native and Deaf communities of Canada.

American Association for Advancement of Science
1200 New York Avenue, N.W.
Washington, DC 20005-3920
Phone: (800) 229-7809
Fax: (202) 371-9849
<http://www.aaas.org>

The AAAS is home to the Science + Literacy for Health program which aims to help people understand concepts in biology and health. Click on Science and Education. They have produced a number of short readers on health and science topics at a GED level. Some of these are now available online. See their web site to view Your Genes, Your Choices about the Human Genome Project.

Canadian Public Health Association
National Literacy and Health Program
1565 Carling, Suite 400
Ottawa, Ontario K1Z 8R1 CANADA
Phone: (613) 725-3769
Fax: (613) 725-9826
E-mail: hrc/cds@chpa.ca
<http://www.nlhp.cpha.ca>

The National Literacy and Health Program of the Canadian Public Health Association promotes awareness among health professionals of the links between literacy and health. It produces an information kit on Literacy and Health for Life that covers the scope of literacy issues in Canada; links between literacy status and health status; and plain language philosophy and techniques. By the end of 1999, they plan to publish the North American Plain Language Health Information Resource List. Their Easy Does It health communication training package is very good. There is a training manual, CD-ROM plain language game and a video. A companion to Easy Does It is a guide with practical strategies for working with low literacy seniors. Easy Does It is frequently referred to on most health literacy web sites.

National Organization Resources CONTINUED

Laubach Literacy Action (LLA)
1320 Jamesville Avenue
Box 131
Syracuse, New York 13210-0131
Phone: 315-442-9121
Fax: 315-422-6369
<http://www.laubach.org/home.html>
For information only: 1-800-Laubach

LLA is a leading nonprofit organization established in 1955 to train volunteer tutors to help adults and older youth improve their lives and communities by learning to read, write, do math and learn problem-solving skills. It has now gone international and is in more than 36 countries. They have a very extensive publishing house, called Grass Roots Press, with materials very useful to those involved in all aspects of literacy training—health, family, workforce and citizenship. The web site for the press is <http://www.literacyservices.com/healthandlit.htm>.

Literacy Volunteers of America
635 James Street
Syracuse, New York 13214
<http://www.literacyvolunteers.org>

LVA is a national nonprofit founded to combat problems of adult literacy in America. Its primary premise is that well-trained and supported volunteers can be effective tutors of adults. It is currently under negotiation with Laubach Literacy Action and may well merge with that group.

Institute for the Study of Adult Literacy
Penn State University
102 Rackley Building
University Park, PA 16802-3202
Phone: (814) 863-3777
Fax: (814) 863-6108
isal@psu.edu

The Institute for the Study of Adult Literacy has a number of ongoing, collaborative, health-related research and curriculum development projects. Examples include working with Howard University on CARDES (CARDiovascular Dietary Education System), a project to develop nutrition educational materials for limited-literacy, urban African Americans; working with the American Cancer Society, the Pittsburgh Cancer Institute, and the Cooperative Extension Service on the Northern Appalachian Leadership Initiative on Cancer; and working with the National Health and Education Consortium on developing Rosalie's Neighborhood, a curriculum that is part of a parent information project on health.

Office of Minority Health
P.O. Box 37337
Washington, DC 20013-773
Phone: (800) 444-6472
<http://www.omhrc.gov>

The Office of Minority Health provides print and online information and resource contacts about minority health issues. The Office's online database of organizations, programs and documents includes contact information. The Office's resource persons network sets up health professional volunteers to provide technical assistance to community-based organizations regarding minority health issues. The newsletters are distributed free to interested parties.

National Organization Resources CONTINUED

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Washington DC
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<http://www.alphaont.ca>

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P.O. Box 37337
Washington, DC 20013-773
Phone: (800) 444-6472
<http://www.omhrc.gov>

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National Organization Resources CONTINUED

The key national organizations that promote literacy development in general and also related to health literacy are reviewed below:

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Health Literacy Consulting
31 Highland Street Suite 201
Natick, MA 01760
<http://www.healthliteracy.com>

This consulting firm is considered a national leader in assisting health professionals develop clear communication and written material for low literate populations. They also conduct training sessions for health professionals on a variety of health literacy topics, and consult with healthcare organizations and professionals.

AMC Cancer Research Center
1600 Pierce Street
Denver, CO 80214
Phone: (303) 239-3405
<http://www.amc.org>

The AMC Cancer Research Center is one of the founding member organizations of the National Work Group on Cancer and Literacy. People at the center have created materials appropriate for use in adult literacy classes about breast and cervical cancer early detection. There is hope that the materials will be funded for national distribution in the near future. The Research Center has also created how-to materials about health and literacy agency collaborations, focus groups for planning cancer education programs and more.

Regional Resources

System for Adult Basic Education Support (SABES)
Northern Essex Community College
45 Franklin Street
Lawrence, MA 01840
<http://sabes.necc.mass.edu>

See a review of this model statewide health literacy initiative in the model programs section of this report. It is considered the best-developed statewide health literacy system in the United States.

Health Literacy Center, University of New England
Area Health Education Center Program
Hills Beach Road
Biddeford, ME 04005
Phone: (207) 283-0171
<http://www.une.edu/com/othrdept/hlit/index.htm>

The Health Literacy Center provides consulting services, workshops and publications. They help health organizations write easy-to-read documents and train health workers in communication skills. They do an annual workshop on low literacy communication skills for health professionals. Their products include Write it Easy to Read: A Guide to Creating Plain English Materials, multicultural clip art and easy-to-read pamphlets. Current pamphlet topics include nutrition, tobacco, alcohol, heart disease, diabetes, HIV, women's health, mental health, family planning, injury prevention, oral health, immunizations, occupational safety, sexual harassment and more.

Health Literacy Bibliography Resources

The National Library of Medicine
Health Literacy Bibliography
<http://www.nlm.nih.gov/pubs/cbm/hliteracy.html>

This is one of the best bibliographies on health literacy available online. The bibliography helps define and describe the evidence base for advancing health literacy programs. It examines theories, strategies and tactics found in the published literature. It will be useful to directors of center programs and to teachers who want program ideas, measurements and assessment instruments, resources, readability scales, and materials for special populations and cultural groups.

The National Network of Libraries of Medicine
South Central Region
<http://www.nnlm.nlm.nih.gov/scr/conhlth/read.htm>

This site has a very good readability analysis of consumer health materials listing for those wanting to know at what grade level their materials read.

American Academy of Family Physicians
Information from Your Doctor
<http://familydoctor.org/>

This site provides links to easy-to-read patient information from the American Academy of Family Physicians.

American Self-Help Clearinghouse
St. Clare's Health Services
25 Pocono Road
Denville, NJ 07834
Phone: (973) 625-3037
<http://www.mentalhelp.net/selfhelp.php?id=859>

The American Self-Help Clearinghouse publishes a free online directory and a reasonably priced print version to more than 800 national and international self-help support groups that cover a broad range of health concerns.

Michigan Adult Learning and Technology Center
Health Literacy Online Bibliography
<http://www.malt.cmich.edu/healthlit.htm>

While they say they are a repeat of the Maine AHEC health literacy center bibliography, this particular source is well-organized. The descriptions are useful to those looking for resources on easy-to-ready materials, health literacy problems and solutions, legal writing in plain English, the impact of marginal literacy on health and healthcare, communications planning and sources for clip art.

Limited English Language Speaker Resources

The key national organizations that promote literacy development in general and also related to health literacy are reviewed below:

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Latino Health Institute
95 Berkeley Street
Boston, MA 02116
Phone: (617) 350-6900
Fax: (617) 350-6901
TTY: (617) 350-6914
<http://www.Lhi.org/>

The Latino Health Institute researches, assesses and documents the health conditions of the Latino community. They develop, deliver, evaluate and disseminate culturally competent health promotion and protection programs. They encourage and enable pertinent components of the health care and social service systems to coalesce and coordinate efforts and effectively advocate on behalf of Latino residents of Massachusetts on public health issues, in close contact and collaboration with other health and human service organizations.

National Center for ESL Literacy Education
4646 40th Street, NW
Washington, DC 20016-1859
202-362-0700
ncl@cal.org
<http://www.cal.org/ncl/>

This is the national center for English literacy resources. Books, resource compilations, major publications, list servers and many more resources are available through this site. Health literacy is one emphasis.

National Clearinghouse for ESOL Literacy Education (NCLE)
Center for Applied Linguistics
4646 40th Street, NW
Washington DC 20014
<http://www.cal.org/ncl/>

As the name implies, NCLE has most of the major resources related to English literacy education organized for easy access. ESOL health literacy-related resources are also a part of the collection.

Teachers of English to Speakers of Other Languages
700 South Washington Street, Suite 200
Alexandria, VA 22314
703-836-0774
info@tesol.org
<http://www.tesol.edu/>

TESOL's mission is to develop the expertise of its members and others involved in teaching English to speakers of other languages to help them foster effective communication in diverse settings while respecting individuals' language rights. To this end, TESOL articulates and advances standards for professional preparation and employment, continuing education and student programs. TESOL links groups worldwide to enhance communication among language specialists. TESOL produces high-quality programs, services and products. TESOL promotes advocacy to further the profession.

Adults with Disabilities Resources

See the U.S. DOE's Office of Vocational and Adult Education site for resources related to disabilities and adult basic education.

National Adult Literacy and Learning Disabilities Center
Academy for Educational Development
1875 Connecticut Avenue, NW, 8th Floor
Washington, DC 20009
<http://www.nifl.gov/>

This is a program of the National Institute for Literacy. See their web site to review the resources available through this center.

National Center for Learning Disabilities
<http://www.nclld.org>

This center provides national leadership in support of children and adults with learning disabilities by offering information, resources and referral services. They also develop and support innovative educational programs, including health literacy programs. They promote public awareness and advocate for more effective policies and legislation to help individuals with learning disabilities.

Publications

In addition to the hundreds of publications found on the sites mentioned above, the following are noteworthy.

Directory of National and State Literacy Contacts, December 1997. ED Pubs document EX0017P. Available in print and online at <http://www.literacydirectory.org/>

Contact information for national and state adult education, family literacy, job training and other offices is listed in this 241-page report. The online version is continuously updated.

Culture, Health and Literacy: A Guide to Health Education Materials for Adults with Limited English Literacy Skills, November 2000. Julie McKinney and Sabrina Kurtz-Rossi. ED Pubs document EX0129P. Available in print. This guide is designed as an addendum to the Health and Literacy Compendium and specifically contains descriptions of health education materials in English and other languages, as well as ordering information. It also addresses issues of culture and low literacy. Culture, Health and Literacy is intended to help health care practitioners working with patients with limited English literacy skills and adult literacy practitioners interested in incorporating health topics into adult education classrooms.

Health and Literacy Compendium, 1999. World Education and the National Institute for Literacy. ED Pubs document EX0012P. Available in print and online at <http://www.worlded.org/us/health/docs/comp/>. An annotated bibliography of print and web-based materials on various health-related topics for use with limited literacy adults is provided in this 80-page publication. Some materials are available in Spanish. Organizational resources are also listed.

Empowerment Health Education in Adult Literacy: A Guide for Public Health Education in Adult Literacy Practitioners, Policy Makers and Funders, Vol. 3 No.4, Part A, 1998, Marcia Drew Hohn, Ed.D. ED Pubs document EX0028P. Available in print and online at <http://www.nifl.gov/hohn/HOHN.HTM>. An example of how adult learners can be engaged in defining and addressing their own health care needs. The author worked with a group of women at a Massachusetts literacy center to develop student-led approaches to earlier detection of breast, cervical and testicular cancers, and prevention of family violence. Background information about the relationship between literacy and health is provided.

Resource NO WEB SITE LISTED

The key national organizations that promote literacy development in general and also related to health literacy are reviewed below:

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Education Program Associates
1 West Campbell Avenue, Suite 40
Campbell, CA 95008-1039
Phone: (408) 374-3720
Fax: (408) 374-7385

EPA includes a publications department, consulting services and a Resource Center about health. Their publications include easy-to-read (third grade reading level and up) and culturally sensitive print and audiovisual materials about family health and multicultural health. Family health topics include family planning, sexuality, STDs, substance abuse and childbearing. EPA's consulting services provide training in culturally and linguistically appropriate health education materials development. EPA's Health Resource Center, a membership service, provides access to more than 7,000 health education materials in English, Spanish and Asian languages that have been evaluated for reading level, audience, cultural appropriateness, translation quality and content.

Conclusion

Promoting health literacy by increasing literacy skills related to maintaining individual, family and friends' health care is an important task for both counties given the current population statistics and costs associated with low literacy rates. Literally millions of dollars per year could be applied elsewhere if health literacy rates were increased in both counties. And, more importantly, the quality of life of more adults in both counties and across South Carolina would be significantly enhanced.

We hope that by 2010 there is a coordinated system of health literacy services that connects public and private agencies so that any adult wanting to improve their health literacy skills can do so in a timely, cost-effective manner, free from stigma and in a useable form. We hope that leaders will move toward the development of a system of health literacy services and supports to be made available so that all willing individuals in both counties are able to achieve their health learning, health maintenance and health care provider goals. Chester and Lancaster counties will be better places to live if these outcomes are realized.

If these system outcomes are achieved, then health care consumers and providers in Lancaster and Chester counties will be able to obtain, interpret and understand basic health information and services, and have the competence to use such information and services in health-enhancing ways.¹⁸ They will be able to obtain and manage information by proficiently using the 4 Equipped for the Future literacy skills sets across 13 everyday health literacy-related activities.

The challenges of building such a health literacy system are difficult. It will take leaders from both counties working together in concerted ways on behalf of all residents.

The impacts nationally and locally of low health literacy¹⁹

Low Health Literacy Skills Affect Health Status

People with low literacy are apt to: (Journal of the American Medical Association, 1995)

- die younger.
- have more health complications.
- sign medical consent forms without understanding them or being able to read them.
- not understand health providers' instructions for health care and therefore not follow instructions properly.
- be involved in workplace accidents and use unsafe practices.
- give birth to low birth weight children.
- misuse chemical applications at home and on the job.
- see a doctor one visit more than adults with high health literacy skills (even though they self-report fewer visits).

People with low literacy are twice as likely to: (Archives of Family Medicine, 1996)

- be hospitalized,
- report poor health;

and more likely to:

- smoke;
- improperly read medicine labels and therefore improperly use medication.

People with low literacy are less likely to: (Kilker, 2000)

- have ever had their blood pressure checked.
- engage in regular physical activity.

People with low literacy on average: (Journal of American Medical Association, 1995)

- have 6% more hospital visits.
- stay 2 days longer in the hospital.
- report fewer doctor visits but use substantially more hospital resources.
- are subjected to more medical tests.
- have extended treatment times.
- have delayed diagnosis.
- may not know why mammograms are done or what a lump in the breast may mean. (American Medical Association, 1999)
- For those who have diabetes, hypertension and asthma, health literacy skills are the strongest link to whether or not the health information received is understood and to whether or not the way one manages the disease is adequate to maintain the best health possible. This is true even if they are highly educated or low educated, rich or poor. (American Medical Association, 1999)

Low Health Literacy Affects Family Living and Child Well-being (Archives of Family Medicine, 1996)

- Family and friends may interpret medical instructions erroneously to the low literate member. They may be prone to omit information, add information that was not given by the doctor or nurse, substitute information, volunteer opinions that aren't medically sound or may introduce semantic errors that distort care. Relying on family and friends rather than becoming literate has consequences.
- Patients don't always speak freely when family members, especially children, interpret health information.
- Family interpreters might not translate accurately out of fear of the impact on the patient (family member).
- Parents with low health literacy skills are more apt to have children with low birth weight. Children who are born at a low birth weight are more likely to be enrolled in special education classes, to repeat a grade or to fail in school. Low birth weight is a condition that may increase a child's risk of developing health, learning and behavioral problems.
- Family members can be highly educated and have a decent income, yet have low health literacy skills. Health information may not be understood in a way that promotes effective health practices. The ability to reason and solve problems relative to health issues in the family may be low, even though they can read and write at level three or higher.
- Family members who are caring for parents with low health literacy skills will experience more problems in providing needed care, care will more than likely be more expensive and they will more than likely have greater problems in overseeing proper use of medicines and diet.

The impacts nationally and locally of low health literacy CONTINUED

Low Health Literacy Affects Health Care Providers' Effectiveness (Kilker, 2000)

- | Most health education and promotion materials read at or above 10th grade level. This means that well over half of South Carolina's population cannot read them effectively. In Lancaster County over 56% of the population probably cannot read them effectively. In Chester County well over 60% of the population probably cannot read them effectively.
- | The average reading level of parents with young children is seventh or eighth grade, but 80% of the pediatric materials given to them are written at a tenth grade reading level.
- | Clinicians who fail to overcome language barriers run the risk of malpractice claims arising from injuries suffered as a result of miscommunication.
- | Providers also face potential claims that failure to ensure their understanding of the patient's complaints breaches professional standard of care.
- | Failure to ensure that the patient understands treatment options, risks and benefits breaches informed consent requirements.
- | Health care professionals receiving any kind of federal funds are legally responsible to bridge the communication gaps between themselves and their patients. (Title VI of the 1964 Civil Rights Action states: No person in the United States shall, on the grounds of race, color or national origin, be excluded from participation in, be denied benefits of or be subjected to discrimination under any program or activity receiving Federal financial assistance.)
- | 39% of women polled in one study (in two Atlanta GA hospitals) read below a fourth-grade level and didn't know why women are given mammograms (compared to 12% of those reading at or above a 9th grade level). (Gazmararian, et al In the Journal of American Medical Association, 1999)
- | Patients who had inadequate reading skills did not know that mammography was associated with cancer, looking for a lump or an examination of the breast. The public education announcements had completely escaped their understanding and attention.

Low Health Literacy is Particularly Present Among the Poor (National Network of Libraries of Medicine)

- | Poverty is significantly linked to low literacy levels. If a person has low literacy levels they often can't do what is required to get out of poverty level conditions. Their world of opportunity is significantly limited.
- | Low literacy skills are highly linked with the inability to access health care. Health care may be present but literacy levels may rob the person of the ability to access care, to understand health information, be able to operate within the health system, or to understand lifestyle choices that affect health and well-being. While people who are poor experience problems with attending appointments due to child care, transportation and/or minimum payment issues, literacy levels are an underlying reason why all these complex issues exist.

Low Health Literacy Is an Unnecessary Economic Burden (National Academy on an Aging Society)

- | Low health literacy skills increase the annual health care expenditures in the U.S. by \$73 billion dollars.
- | Another \$11 billion is unnecessarily spent by people with low health literacy skills, primarily due to longer hospital stays (i.e., if you have low literacy skills you are probably spending 16% more on health care than you need to for your limited income).
- | Hospitalization linked to limited literacy skills may be costing as much as \$8 to \$15 billion a year.
- | Low literacy often leads to higher rates of re-hospitalization.
- | Incurable cancers, such as breast and cervical cancer, may be detected earlier if the patient has the ability to understand their seriousness and implications.
- | Birth defects in children are significantly higher for low literate parents and some of these could have been avoided.
- | Over one-third of English-speaking patients at two public hospitals in the South, in a recent study, showed inadequate functional health literacy. They were unable to understand information regarding medication, appointments and informed consent. Eighty percent (80%) of those 60 years old and above in the study had poor health literacy knowledge.
- | In a study of patients in public and private substance abuse treatment centers, more than half of the public and more than a third of the private patients read below a ninth grade level.
- | The Test of Functional Health Literacy in 1995 showed that 42.9% of hospital patients could not understand a tenth-grade reading level Medicaid application.

Health Literacy is Important to People with Disabilities and Their Family Members (National Center for Learning Disabilities)

- | Many people with disabilities are at a higher risk for health problems. This makes understanding health and wellness information critical. Higher skills are needed to make wise health care decisions.
- | A large number of people with disabilities experience difficulty reading and understanding typical consumer health information.
- | Approximately 75% of American adults who report having a physical or mental health condition scored in the two lowest literacy levels of the National Adult Literacy Survey.

The impacts nationally and locally of low health literacy CONTINUED

Health Literacy is a Problem Connected with Seniors and Aging (National Academy on An Aging Society)

- | Older adults face multiple obstacles to learning. To maintain independence and functioning, older adults have to be very good learners.
- | Learning new health care information requires strong reading skills as well as strong math and problem-solving skills. Studies show that older adults often have difficulty in these three areas.
- | Older adults have high rates of low health literacy because they often went to school for fewer years and, consequently, many never have acquired strong reading skills. While their oral and retention skills may be higher, they often get health-related information from TV or listening to radio sources that might not be accurate.
- | Older adults are experiencing changes in sensory and cognitive functions. This may be a result of aging or a side effect of the medications that can impair cognitive processing and problem-solving abilities.
- | Older adults are often faced with multiple illnesses and health problems. Treating and handling these conditions are extremely complicated.
- | In one study of Medicare patients in a national managed care organization, 33.9% of English-speaking and 53.9% of Spanish speaking respondents had poor health literacy knowledge. (Gazmararian, et al Journal of American Medical Association, 1999)
- | In 1990 approximately 22% of the adults 60 years of age and over had 8 years of schooling or less. That is 8.9 million people. This figure increased from the 1980 census. (2000 figures were not yet available at the time this report was written.) (As reported in SC Mature Adult Count)
- | South Carolina is one of the six states (along with California, Florida, Texas, New York and Hawaii) with the most significant number of older persons. Many of the rural areas of South Carolina are aging. In 1999 South Carolina had 473,400 residents 65+. The number has increased by 100,000 each decade since 1950. 27% of the population is 55+. There has been a 100% increase of 55+ residents since 1970.

One Can Be Health Literate in One Language and Culture and Not in Another (National Institute for Literacy, Eastern LINC)

- | Individuals with limited English proficiency have cultural and language barriers that hinder understanding of South Carolina's healthcare system.
- | Adults from other cultures often practice both western medical advice as well as their own cultural practices. These practices may conflict and reduce health status.
- | Managing the organizational culture of the health system can be foreign to both native speakers and English as other language speakers (ESOL). The health system is a culture all its own. People with low literacy levels have a harder time learning how to maneuver the health care system found in the U.S., in South Carolina and in Lancaster and Chester counties.
- | Unless health literature, instructions and labels are in plain language, they are not apt to be understood by ESOL or low literate English-speaking adults.
- | Some health care providers lack necessary cross-cultural communication skills to effectively care for ESOL speakers, thus adding unnecessary obstacles to low literate adults' ability to follow directions and understand health issues.

Principles of Effective Educational Practice

Adults involved in helping others learn health literacy skills are effective when they do the following things:

They link new literacy learning to an adult's prior health consumer experience.

Adults learn more quickly if they can start with what they know and apply new learning to what they already know and can do. Educators must spend time with each adult so that they really know how they think about making health decisions, how they act as consumers and providers of health care, where they feel strong and weak in accessing the health care system and in making wise health decisions for themselves and others. That's one of the reasons why using volunteers is helpful — so that one thinks beyond the traditional classroom approach with one teacher and several students. Educators need to see adults actually making health decisions, trying to access health care, trying to read health instructions and follow them. Adults tend to attach more meaning to the learning that is gained when it happens connected to their own actual health decision-making experiences. Adults tend to learn more quickly if they can use their own life experiences when they are literacy learners and teachers.

They help adults meet specific health literacy learning goals related to their own health literacy needs.

Educators must understand each adult's own health literacy levels. Learning activities that combine basic literacy skills with practical use will enhance the adult's overall ability to become more literate. Instruction should therefore be reality-based and start by meeting immediate-felt health needs and goals. Adults are ready to learn when they need to learn in order to cope with real-life health decision-making tasks or situations. There should be ample opportunity for the learners to practice their newly acquired health literacy skills. In other words, adults need to see models of health consumer acts related to health literacy skill development. They need practice in actually performing health literacy level tasks.

They help adults meet specific health literacy learning goals related to their role as educator of their children's and other family members' health literacy needs.

Adults are not only learners; they are teachers, too. Educators must observe the adult as teacher and coach them to educate their children and other family members to perform health literacy tasks proficiently. Learning experiences must allow adults to interact with children and family members under supervision so that adults can see other adults model effective health literacy instructional behaviors to children and family members. Adults need opportunities to be coached on how to act as educator of their children, family members and friends.

Their health literacy instruction is experientially based.

Adults learn best when they can learn by doing and then discuss what they did and how to do it better. This is called experiential learning. The educational format designed by adult literacy educators should not appear schooling-oriented in approach or style. Most schooling experiences are content-oriented rather than experientially based. And the content taught in school settings often wasn't seen as relevant by the student. In addition, schooling experiences for many level one and level two literate adults were negative experiences because failure was more their experience than success. Therefore, learning experiences for health literacy programs need to be experiential and designed to feel and look different from schooling. Instruction that uses experiential techniques, such as discussion, problem solving, simulation exercises and field experiences are more effective than lectures and rote memorization. Effective health literacy volunteers take the time to assist learning while a person is trying to understand information and learn new behaviors to tackle current health issues. Modeling desired behavior and discussing it is very important, so concrete examples should be available.

Principles of effective educational practice

CONTINUED

They are able to assess various learning styles of adults and communicate new health literacy information and skills to them in ways they can understand.

They need practice in actually teaching health literacy skills to their children, friends and family members. They need to receive the necessary feedback on how to do it better. It means that the instructor must know the material well enough to go where the adult wants to go with health literacy learning rather than following the more traditional lesson plan format which follows the educator's logic but not the learner's needs or logic. Why? Because adults tend to be goal-oriented in their learning—they want to see results immediately. This is particularly true with health literacy learning. It is immediate because the situation is usually immediate. They want new knowledge and skill learning applied directly to their immediate health decision-making needs as parents, workers, citizens and health care consumers. Learning must be practical and address immediate health needs that tend to be more skill-based and decision-oriented.

Their literacy learning experiences are contextual.

Often the health issue present provides the context for teaching. However, health literacy education also occurs within general discussions of skill improvement. To contextualize instruction means that the educator must learn about actual health consumer situations related to the adult's efforts to gain literacy skills and act as educator of their children's and family members health literacy learning. The educator must use those situations as a base for conversations and practice. Adult learners are situation solvers. (Some call these problem solvers but not all situations are seen as problems to adults, but in fact, do demand new learning.) Once actual situations are known, then teaching has a context that is seen as relevant to the adult learner. That is one reason why volunteer and natural helper advice systems and hotlines work well as part of effective health literacy education efforts.

They communicate effectively with adults who have differing ways in which they think about and take action on health consumer situations.

Adults have different learning styles and, therefore, the way they are taught needs to be different. Learning styles affect how we go about making sense out of information received and how we begin taking action on what we hear. It's our own thinking-action process. Some want to understand the overview first before getting to the particulars of a health situation. Others want the particulars first and then the overview. Some want as much information as they can about a health matter before they act. Others want to act or decide and then get information only relevant to what they are specifically doing. Others want to think it through completely before acting. Others want to think while acting. Some have a hard time thinking conceptually about a piece of health information. Others immediately put the information into a context based on their current health maintenance understandings and practices. Some are only comfortable hearing about it and not doing it (this seems particularly true for proper eating habits and exercise or avoiding unhealthy behaviors such as smoking). Others only want to do it and not think much about what it all means to them and others. These are all characteristics of different learning styles. Effective educators are able to adjust personal communications to match what they hear expressed in their adult learner's discussions. So instruction has to be flexible in order to pitch the health literacy message correctly. Because of this demand to meet multiple learning styles, having lots of volunteers to mentor learners one-on-one helps.

They are able to work in a variety of health care consumer and provider settings with a variety of different types of community leaders.

They must partner with leaders from hospitals, clinics, nonprofit agencies, departments of health, education, social services, literacy councils, community coalition groups, churches, media outlets, the public schools, technical colleges, and four-year colleges and universities to develop health literacy learning sequences that can be of benefit to a greater number of adult learners. Effective adult educators can communicate with a variety of different types of people who possess differing levels of communication literacy skills.

Principles of Effective Educational Practice

CONTINUED

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They effectively involve adults in planning their own health literacy learning.

Learning is enhanced when there is buy-in from the learners themselves. Despite more and more training and educational mandates from employers, adult learning remains primarily a voluntary exercise. Strategies, such as the development of a learning contract, seem to work well with adults. Retention is higher when adults are involved in planning their own learning.

They market their health literacy learning offerings in effective ways.

Recruitment is a problem for some. Many adult education programs run through the department of education are low in attendance because mass communication is used rather than a personal touch. Effective educators tend to set up systems so adults are personally invited. Mass communication advertising doesn't seem to work as well. One-on-one invitations given out by an effective volunteer system, or neighbor inviting neighbor, church member inviting church member, or work colleague inviting a work colleague tend to work better. Just think about why you choose to attend or participate in various events and functions. You are more apt to attend things when there is a personal invitation and you feel someone really cares whether or not you are there.

Another method that tends to work is building in some sort of award system. Promising a computer to any adult who comes and goes through the health literacy program has worked in some settings. Giving out books that they can use to read to their kids works for some. Providing a free office visit works. It is estimated that current literacy programs reach only about 8% of the target population.

They understand that retention of adults in health literacy programs is a problem and act accordingly.

Retention is higher in health literacy programs that have a personal touch. Adults should not feel like a faceless number. Needs have to be addressed. They have to feel comfortable and safe to communicate where they really are and what they really want to learn. They have to be given encouragement continuously. They have to experience some gains in their learning. Effective educators know this and act accordingly. Populations needing health literacy the most (ESOL, seniors, families with disabled members, low literacy individuals, those in poverty) are particularly sensitive in these regards.

They reward adults who have successfully completed the program or accomplished correctly a health maintenance or decision-making task.

In private patient care settings, the rewards need to be immediate. If wiser decision making occurs, it needs to be rewarded. If health instructions are understood and followed more accurately, it needs to be rewarded. If family members counsel seniors wisely, it needs to be recognized. If medications are taken properly, it needs to be acknowledged. Immediate feedback and corrective steps are also needed.

In nonprofit settings where health education is being done there may be a longer time between the learning-reward cycle. While rewards must be ever-present throughout the program, a defined end and a reward of some valued kind needs to be present. Educators therefore define the program's goals and objectives. These are obtainable and tailored to the specific group of adults with whom they are working. There are built in small "wins" to learning. These are recognized in legitimate ways. The benefit of the health literacy program should be evident to the adults.

Applying these principles is hard work. It takes thinking and acting outside the "schooling" instructional box. Recruitment and retention rates will directly correlate to how successful one is in applying these principles of teaching and communicating. Reaching learning outcomes such as those mentioned elsewhere in this report are conditioned on using these principles effectively.

J. Marion Sims Foundation

ADULT LITERACY & BASIC SKILLS INITIATIVE

NOTES & REFERENCES

¹ This figure is reported in most statistical reports. See the Center for Health Care Strategies and National Academy on an Aging Society at <http://www.agingociety.org/healthlit.htm> as one example. This is the source used to quote.

² This is the definition found in the 1991 National Literacy Act. See <http://nifl.gov/public-law.html> section three.

³ See the **Equipped for the Future** (EFF) report on the National Institute for Literacy site at <http://www.nifl.gov/>. These skills are not explained in detail within this report. Each skill listed is further defined.

⁴ These figures are based on the Literacy fact sheets found online at <http://www.nifl.gov/>

⁵ Information courtesy of the National Institute for Literacy (NIL).

⁶ This is the Joint Committee on National Health Education Standards' definition of health literacy. Their definition is the most commonly used. Joint Committee on National Health Education Standards. (1995)

⁷ See <http://www.nifl.gov/> for the full **Equipped for the Future** report, including a review of the role maps and literacy skills connected to everyday activities needed to perform effectively the role of parent, worker, citizen, and health care provider and consumer.

⁸ A copy of the **Test of Functional Health Literacy in Adults** can be obtained by writing to Joanne Nurss, Ph.D., Research, Center for the Study of Adult Literacy, Georgia State University, University Plaza, Atlanta, GA 30303-308, phone: 404-651-2405, fax: 404-651-1415. Several versions are available: English and Spanish; short and long; large print and regular print versions. A complete guide to use is available, along with test validation and reliability information.

⁹ This section, including Table 3, is based on the following references: American Medical Association, Council on Scientific Affairs, Ad Hoc Committee on Literacy. (1999). Health literacy: Report of the Council on Scientific Affairs. **The Journal of the American Medical Association**, 281, (6), 552–7; Gazmararian, J.A., Baker, D.W., Williams, M.V., Parker, R.M., Scott, T.L., Green, D.C., Fehrenbach, S.N., Ren, J. & Koplan, J.P. (1999). Health literacy among Medicare enrollees in a managed care organization. *Journal of the American Medical Association*, 281, 545-51; Hohn, M.D. (1998). Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders. Retrieved September 20, 2000 from the World Wide Web: <http://www.nifl.gov/>; Jacobson, T.A., Thomas, D.M., Morton, F.J., Offutt, G., Shevlin, J. & Ray, S. (1999). Use of a low-literacy tool to enhance pneumococcal vaccination rates: a randomized controlled trial. **Journal of the American Medical Association**, 282, (7), 646–650; Kefalides, P.T. (1999). Illiteracy: The silent barrier to health care. *Annals of Internal Medicine*, 130, (4), 333-336; Kilker, K. (2000) Costs of low health literacy. Health Literacy Toolbox. Retrieved September 20, 2000 from the World Wide Web: <http://www.prenataled.com/healthlit/default.asp>; Kirsch, I., Jungeblut, A., Jenkins, L. & Kolstad, A. (1993). Adult literacy in America: A first look at the findings of the national adult literacy survey. Washington DC: National Center for Education Statistics, United States Department of Education; Lee, P.P. (1999). Why literacy matters: links between reading ability and health. *Archives of Ophthalmology*, 117, 100–103; McIntosh, L. (2000) An overview of regulations addressing health literacy. Health Literacy Toolbox. Retrieved September 20, 2000 from the World Wide Web: <http://www.prenataled.com/healthlit/default.asp>; Nordenberg, T. (1999) New drug labels spell it out simply. *Food and drug administration consumer magazine*, 99–3232 Retrieved October 7, 2000 from the World Wide Web: http://www.fda.gov/fdac/features/1999/499_otc.html; United States Department of Health and Human Service. (2000) Healthy people 2010. Retrieved October 8, 2000 from the World Wide Web: <http://www.health.gov/healthypeople/default.htm>; Williams, M.V., Nurss, J.R., Parker, R.M. & Baker, D.W. (1998) Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension and diabetes. *Archives of Internal Medicine*, 158, 166–172; Williams, M.V., Parker, R.M., Baker, D.W., Parikh, N.S., Pitkin, K., Coates, W.C. & Nurss, J.R. (1995). Inadequate functional health literacy among patients at two public hospitals. **Journal of the American Medical Association**, 274, 1677–82; Williams, M.V., Baker, D.W., Honig, E., Lee, T. & Nowlen, A. (1998). Inadequate literacy is a barrier to asthma knowledge and self care. *The American College of Chest Physicians*, 114, 1008–1015.

¹⁰ If interested contact Nedra Lisovicz, CHAN Director, The Community Health Adviser Network (CHAN), University of Southern Mississippi, Box 10015 Hattiesburg, MS 39406-0015; chan@usm.edu.

NOTES & REFERENCES

¹¹ Taken from the National Center for the Study of Adult Learning and Literacy web site
<http://www.gse.harvard.edu/-ncsall/>

¹² See <http://www.nifl.gov/> for the full Equipped for the Future report

¹³ Based on the Joint Committee on National Health Education Standards definition of health literacy. (1995)

¹⁴ This section is focused on the health literacy learning outcomes of the resident population of both counties. For those who plan to target the professional development needs of professional health providers we suggest referring to the following site for the National Health Education Standards, recommended to improve student learning by providing a foundation for curriculum development, instruction and assessment of student performance.
See <http://www.ocps.k12.fl.us/framework/hl/strands/5.htm>

¹⁵ For a complete explanation of each of these literacy skill sets see the Equipped for the Future report at <http://www.nifl.gov/>.

¹⁶ See Clemson University, Institute on Family and Neighborhood Life's report on Creating Supportive Communities for Families with Young Children for a review of the basics on how to form effective collaborative efforts. It reviews the phases of community work required and the three key leadership activities that are ongoing in order to have effective partnerships.
<http://virtual.clemson.edu/groups/ifnl/cnd.htm>

¹⁷ Sisters of Charity Foundation of South Carolina developed a self-learning booklet on how to develop an evaluation that you might find useful. In addition, check the resources available through Amazon.

¹⁸ Based on the Joint Committee on National Health Education Standards definition of health literacy. (1995)

¹⁹ See endnote 9 for the references on which this table is based.