



HEALTHY RELATIONSHIPS

A Guide to Forming Partnerships between Health Care Providers
and Adult Education Programs



What is health literacy?

Simply stated, health literacy is the ability to obtain, understand, and effectively use health-related information. In a recent report entitled “Health Literacy: A Prescription to End Confusion,” the Institute of Medicine estimated that 90 million adults may lack the needed literacy skills to effectively use the U.S. health care system. Extrapolating from the National Adult Literacy Survey, approximately 36 percent of New York City adults would not be able to identify the name of a hospital in a short article; an additional 27 percent would not be able to fill out a standard health insurance form.

Health care providers and patients typically do not identify low health literacy as a major issue, but both groups are well aware of its

consequences. Health care professionals know they need improved communication with their patients so that they can better understand patient concerns and priorities, engage them as active partners in their care, improve their grasp of protocols for care management and the need for preventive care and screening, and ensure that they know when and where to seek care and how to navigate the health care system. Conversely, adults with low literacy skills often feel intimidated by the complexity of the health care system, by the forms and instructions, and by medical terminology. To avoid appearing ignorant, they may be hesitant to ask questions or express concerns, thereby compounding the problem. All of these difficulties are exacerbated when patients do not speak English well and are unfamiliar with the U.S. health care system.

Consequences of low health literacy

A growing body of evidence has revealed the consequences of this mismatch between literacy-related demands of the health care system and reading levels of many adults, including:

- > Lack of knowledge of basic self-care
- > Lack of awareness of preventive health measures
- > Inability to understand appointment slips, discharge instructions, and other written instructions
- > Inability to read the labels of prescription and over-the-counter medications
- > Misunderstanding of medical forms (e.g., informed consent, patient history, and health insurance applications)
- > Inability to understand health education materials
- > Uncertainty over how to use the health care system effectively
- > Inability to effectively advocate for self and family
- > Inability to participate in two-way communications with clinicians, impeding proper diagnosis and treatment
- > Lower levels of patient satisfaction

Compounded by other socio-economic factors, the accumulated ill effects of these literacy-related barriers are severe. Compared with individuals who have stronger literacy skills, individuals with low levels of literacy are less likely to obtain preventive health services, more likely to be hospitalized and rely on the emergency department for care, and more likely to experience poor health outcomes.

The Literacy Assistance Center initiative

How the initiative began

Many adult literacy classes have included health education. Typically, the focus has been on specific diseases and basic health topics such as nutrition, and has not covered the workings of the health care system—vital information such as how to obtain health insurance and find appropriate care in a large hospital. The possibility of a broader approach emerged when city officials began looking for ways to strengthen health care system participation among low income and immigrant New Yorkers, many of whom attend adult literacy classes. Anthony Tassi, Health Policy Advisor in the New York City Mayor's Office, approached the Literacy Assistance Center with a request that it devise a more comprehensive, cooperative, and experiential approach to health literacy that would include bringing health care providers together with literacy programs. He suggested that the resulting partnership could introduce students to the health care system while deepening provider understanding of student needs.

The health literacy study circle

The LAC accepted this challenge, with generous funding from the Altman Foundation, and contacted Dr. Rima Rudd, a professor at the Harvard School of Public Health who was developing a skills-based approach to health literacy. She welcomed LAC interest in trying out her group's initial series of study circles for literacy educators, on navigating the healthcare system, and

readily modified their content in response to LAC suggestions. Aided by a grant from the Guttman Foundation, the LAC recruited four literacy programs with very different constituencies to participate in a pilot project in the fall of 2004 and winter of 2005.

Thirteen instructors and program managers participated in the initial navigation study circles. By the end of the year, an independent evaluator concluded that the classes taught by these instructors gave students a better understanding of the health care system, developed their confidence in asking questions during visits with physicians and nurses, and encouraged them to share health-related information with their families. In addition, these students registered significant gains in general literacy—speaking, reading, writing, vocabulary, and spelling. By the end of 2004, the LAC had offered three more series on navigation to accommodate additional literacy providers; a total of 60 literacy instructors, program directors, and other personnel have been through the program.

In the fall of 2004, 17 of them participated in a pilot series on chronic disease management. The Harvard School of Public Health group incorporated further changes recommended by the LAC into its curricular framework for navigation and will publish an initial version in mid-2005.

Health literacy conferences

In the summer of 2004, Anthony Tassi and the LAC, supported by the Altman Foundation and United Way, organized a series of three health literacy summits that brought together more than 75 leading health care providers, adult educators, policy makers, and funders to get to know each other, explore common concerns, create a common base of knowledge, and develop a shared sense of mission.

The first summit included a talk by Dr. Rima Rudd on critical issues in health literacy, as well as a panel discussion with representatives from the NYC Department of Education, the Health and Hospitals Corporation, and adult education programs. The second featured a presentation by Dr. Emilio Carrillo, Chief Medical Officer of the New York-Presbyterian Community Health Plan. The third included talks on improving health literacy by Professor Victoria Purcell-Gates of the University of British Columbia and Anthony Tassi.

Conference outcomes

Participating adult educators and health care providers now recognize that they share the same client population and both benefit when these clients enhance their reading skills and their ability to take a more active role in their own care. As a result, both sectors have begun to identify areas where their interests overlap and they might be able to apply one another's knowledge and tools. They have also been introduced to potential collaborators: The conferences have given them access to more than 100 other

professionals in health care, adult education, the public sector, and private foundations who share their interest in promoting health literacy.

The conferences also helped the organizers develop an agenda for next steps, which include:

- > Deepening understanding of health literacy
- > Raising health literacy awareness among colleagues
- > Integrating health literacy into existing structures (e.g., quality assurance and forms committees)
- > Identifying and contributing to existing efforts
- > Developing and implementing new interventions (e.g., improving written materials)
- > Creating new partnerships

Partnerships

Like many other complex problems, low health literacy is most likely to be ameliorated through collaborations across disciplines, areas of expertise, and experience. Neither health care professionals nor educators acting alone can improve health literacy and adapt the health care system to meet the needs of the large percentage of patients who have difficulty understanding health information.

Based on this premise, each of the four literacy programs in the pilot project was paired with a nearby health care provider. These collaborations are revealing how much can be accomplished when community partners join together across sectors and share knowledge and tools in the interest of patients. Each of these linkages has taken

a different form, though some similar programs have emerged in all, including student visits to health care facilities and health care provider visits to classrooms.

Partnership activities

Harlem Hospital and the Mid Manhattan Learning Center forged a particularly successful link that worked well from its inception. One of the highlights was a class visit to the hospital. Both groups prepared carefully. Literacy students submitted questions to the hospital ahead of time to ensure that the staff was ready to answer them. Teachers and program managers from the learning center joined the hospital's training director in briefing the speakers on how to communicate effectively with students who have limited English-language literacy skills. The actual hospital visits included presentations by department heads, after which the visiting literacy students broke up into several sections for a tour of the facilities. The visit was so successful that the president of Harlem Hospital screened an LAC video of it at a managers meeting.

Lutheran Community Health Center hosted a class from the Sunset Park Adult and Family Education Center for an entire morning. Literacy classroom preparation for the visit included mock telephone conversations with a registration clerk and a review of hospital registration forms. The class invited the hospital to participate in mock consultations at the family education center; physicians agreed to go after obtaining a promise that they would have communications training first. The manager of community-based programs at Lutheran

Medical Center grew increasingly enthusiastic as she became more familiar with the project. Within a few months she encouraged Sunset Park participants in the pilot project to provide health literacy study circles for new staff members at the medical center's affiliated senior housing and senior center programs; she facilitated links between these programs and Lutheran's ambulatory care center.

Elmhurst Hospital uses a videotape of a visit to a Queens Borough Public Library ESOL literacy program by one of its emergency room doctors to train professional staff members in how to communicate effectively with patients who have low levels of literacy.

It took some months for the partnership between Carroll Gardens Neighborhood Women and the Brooklyn Hospital to develop. Although new to his position, the hospital's community relations director kept after department heads to enlist their cooperation. His persistence paid off when the hospital and the literacy program set up a joint table at a neighborhood street fair.

Partnership benefits

Partnerships have helped adult educators to:

- > Engage their class by using material (e.g., registration forms) that all the students consider relevant to their lives
- > Bring health-related content and skills into the classroom (e.g., visiting speakers on health navigation topics)
- > Familiarize instructors and students with the health care system, increasing the likelihood that they will seek and obtain appropriate care

- > Get a clearer sense of the challenges that their students face in the real world

Partnerships have helped health care providers to:

- > Raise awareness of communication and literacy issues that may affect their interactions with patients, particularly by revealing common gaps between what doctors and other health care professionals and administrators think they have communicated and what patients have understood
- > Expand the conception of health literacy at their institution to include clinical communication as well as low patient literacy levels
- > See their own system through the eyes of community residents
- > Interact with the population they serve in a new context, rather than simply as "patients"

Applying skills and techniques developed in these initial efforts, the LAC has begun providing health literacy training to programs that offer a variety of health education services. Collaborators include Columbia-Presbyterian Medical Center, Community Service Society, Primary Care Development Corporation, United Way, and What to Expect Foundation.

Keys to successful partnerships

> *Creating a shared base of knowledge.* In the initial stages, prospective partners lacked familiarity with basic concepts of health literacy, as well as with their partner's system. Both the conferences and the partnership meetings were structured to deepen mutual understanding.

> *Identifying shared goals and problems.* Prospective partners were surprisingly unaware of how much their work with the same constituencies overlapped. The conferences opened the door to cooperation in these areas.

> *Addressing specific needs of both entities.* Health care providers participated more enthusiastically and energetically once they recognized that inadequate understanding of target population needs was a major obstacle to achieving many of their own goals. Typically, these goals include remediation of health disparities, quality improvement, “appropriate” utilization of the health care system, informed decision-making, disease self-management, and greater patient satisfaction. Several health care providers used the relationship to showcase new services or to pilot test re-engineered programs. Literacy providers benefited from higher student retention and performance, improved student health, new career opportunities for their students, and the extension of adult literacy to new audiences.

> *Securing support from the executive level.* Enthusiastic participation by health care providers is essential but not sufficient. Partnership success requires a considerable

investment of resources by the health care provider, which is only possible when management is behind the partnership.

> *Collecting evidence to measure progress.* Health care providers want to measure the impact of the program on health utilization and access (e.g., insurance enrollment, use of primary care and preventive services, use of the emergency department). This requires baseline data. Adult education programs already collect pre-test and post-test data on enrolled students, and want to know whether incorporating health literacy in their program accelerates general literacy progress.

> *Using pre-existing relationships wherever possible.* Building a partnership from the ground up takes a great deal of time, energy, and commitment. Mutual trust must be established. Representatives from both sides must become familiar with a system they have only viewed from the outside. Quite a few literacy programs have at least a tangential relationship with a health care provider—for example, through a job training program. This can become the springboard to a full partnership.

> *Creating a sense of trust.* When providers and literacy programs enter into a partnership, both sides feel vulnerable. Teachers as well as students often feel intimidated by health care institutions. Many providers feel their training in patient communication has been inadequate. Developing trust and a willingness to adapt to the other partner's needs is essential and requires conscious preparation, as well as joint learning and planning.

> *Preparing partners for a lot of work.* Even relatively straightforward joint activities such as a visit to a hospital require hours of planning and preparation. Everyone involved will have many other responsibilities and pressing work. Unless each meeting ends with specific objectives and a timetable, tasks crucial to the project's success are likely to remain uncompleted.

> *Launching the project with an event.* Organizing a joint event is an easier way to begin a partnership than attempting to integrate health literacy into an already established structure or program. An event such as a health fair at the adult education site creates visibility and buzz, and shows everyone concerned that the partnership has leadership support.

> *Seizing the opportunity to focus on systemic issues.* Both educators and health care providers are accustomed to serving individuals and meeting individual needs, yet both encounter the same problems over and over: Why don't patients take their medicines as prescribed? Why don't they use primary or preventive services? Why is it so hard to gain access to the system? Partnerships between health care providers and adult education centers offer an excellent opportunity to identify recurring problems and seek systemic solutions. For example, counselors at one adult education program had continually encountered difficulties in getting students in the door of the health center and spent many hours solving each case individually. The partnership led to a reorganization of the registration

system, as well as the development of a literacy program lesson on making a health care appointment.

> *Engaging in joint planning and goal setting.* Once the relationship has proven its value, both partners are usually open to integrating health literacy concerns and, in some cases, representatives from the partner into relevant institutional structures, such as cultural competence programs, forms committees, compliance reviews, residency training, and curriculum development.

This guide was written for the Literacy Assistance Center by Sue Kaplan, Clinical Associate Professor of Public Policy at the Robert F. Wagner Graduate School of Public Service, New York University. Funding was provided by the United Hospital Fund. The Altman Foundation has provided major funding for the Literacy Assistance Center's Health Literacy Resource Center since its inception.

Health literacy resources

Audio/written/multimedia materials

Video of Mid Manhattan visit to Harlem Hospital, available from Literacy Assistance Center

www.noah-health.org/

New York Online Access to Health (NOAH)—developed by several agencies in New York to provide access to high quality, free consumer health information in English and Spanish

www.healthyroadsmedia.org/

Contains free audio, written, and multimedia health information in several languages

www.mcedservices.com/online.html

Another multimedia site, with presentations in four languages

Data

www.cbcs.org/

Center for Health Care Strategies—has many fact sheets, as well as information on to how to develop simple and attractive patient education material

www.cssny.org/pubs/issuebrief/no17.htm

This report from the Community Service Society of New York discusses the lack of health care in New York's low income communities

<http://ncsall.gse.harvard.edu/research/report14.pdf>

An annotated bibliography that summarizes much of the research on links between health and literacy

www.ets.org/research/pic/literacy&health.pdf

This publication analyzes the NALS findings from the perspective of literacy and health

Preparing plain language materials

www.cancer.gov/

National Cancer Institute— includes information on how to produce clear, accessible print materials, as well as an alphabetical glossary

<http://cpen.nci.nih.gov/>

Cancer Patient Education Network—provides guidelines for assessing print materials to ensure that they are clearly written.

<http://library.ucbc.edu/departml/bnet/bcbib.html>

University of Connecticut Health Center— contains resources (books, websites) pertaining to understanding the health care system

www.plainlanguage.gov/

The Plain English Network—tries to ensure that federal communications are simple enough to reach the general public

www.fda.gov/opacom/lowlit/7lowlit.html

Easy to read government health publications in English and Spanish

www.pls.cpha.ca/english/start.htm

The Canadian Public Health Association plain language service



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