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THE SAN DIEGO
COUNCIL ON LITERACY
IMPROVING QUALITY OF LIFE

WHEN WORDS GET IN THE WAY:
A COLLABORATIVE PLAN TO
ADDRESS HEALTH LITERACY IN SAN DIEGO COUNTY

Advisory Committee

Chris McFadden – Committee Chairperson
Manager of Program Services
San Diego Council on Literacy

Jose L. Cruz
Chief Executive Officer
San Diego Council on Literacy

Tracy Delaney, Ph.D., R.D.
Chief, Chronic Disease and Health Disparities Maternal, Child & Family Health Services
County of San Diego Health & Human Services Agency

Nora Faine, M.D., M.P.H.
Chief Medical Officer
Sharp Health Plan

Kristin Garrett, M.P.H.
Executive Director
Community Health Improvement Partners

Dorothy Lujan
Director of Patient Services Programs
Vista Community Clinic

Helga Moore
Secretary, Board of Directors
San Diego Council on Literacy

Elvia Romero
Health Educator
Healthy San Diego

Aglaé Saint-Lot
Events Manager
City Heights Performance Annex, Weingart Library

Shreya S. Sasaki, M.P.H.
Access to Care Project Manager
Community Health Improvement Partners

Diane Strum
Director of Government and Community Affairs
Kaiser Permanente

Funded by a grant from Kaiser Permanente

Prepared by:

Michael J. Moder
Kelli Sandman-Hurley

Report available at the Community Health Improvement Partners and San Diego Council on Literacy Websites:

<http://www.sdchip.org/> and <http://www.literacysandiego.org/>

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Executive Summary

The goal of the project is to develop a collaborative health literacy plan for San Diego County. This report was produced through the cooperative leadership of the Community Health Improvement Partners (CHIP) and the San Diego Council on Literacy (SDCOL) with the generous support of Kaiser Permanente. Findings and recommendations are based on an in-depth review of published literacy and health literacy research and meetings with key stakeholders including low literate adults, promotoras, medical front office staff and physicians.

This report presents a wealth of information related to literacy and health literacy and provides an extensive list of useful resources for additional information and links to organizations throughout the United States that are addressing the health literacy issue.

Several of the key findings include:

- Low health literacy is a critical quality issue that impacts the health of an estimated 90 million adults in the United States and results in \$73 billion of potentially avoidable health care expenditures annually.
- Those most at risk for health-related problems due to low health literacy include the functionally illiterate, persons for whom English is not their native language and seniors, typically persons age 65 and over.
- The interaction between the patient and the provider can be complex and challenging for persons with proficient literacy. When persons with low literacy enter the health care environment, the interaction between the patient and provider typically becomes one-way, with patients frequently describing the process as intimidating.
- Factors affecting low health literacy include:
 - The ability of patients to read and understand English, Spanish or their native language.
 - The ability of healthcare providers to communicate effectively with patients, at a level patients can understand, both orally and in writing.
 - The ability of patients to understand what is being presented by healthcare providers and their ability to communicate. This includes being able to express themselves effectively orally and having adequate listening skills to understand what health providers are asking or telling them.
 - Cultural norms that impact the patient/physician relationship.
 - Fear of the unknown.
 - Intimidation.

H health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (US Department of Health and Human Services, 2000).

Executive Summary

- Among providers, the awareness of low health literacy and its impact is increasing. However, there are no generally accepted methods or materials available to help providers effectively address the literacy levels of the patients they serve.

The initial recommendation of this study is the development of a joint CHIP and SDCOL taskforce comprised of literacy and health professionals to champion the awareness of health literacy in the San Diego community. Additional recommendations eight include:

Short-term recommendations:

- Investigate promising practices for addressing health literacy in other communities.
- Identify opportunities for inclusion of health literacy curricula in adult literacy courses currently being offered within San Diego County.
- Create and implement a program to train volunteers to advocate for low literate patients in the healthcare setting.

Longer-term recommendations:

- Facilitate the development of methods and tools to help front and back medical office staff deal more effectively with low literacy and low health literacy adults.
- Increase the healthcare communities' awareness of low literacy and low health literacy issues through the development of articles, presentations and courses.
- Provide resources to assist healthcare organizations to develop written materials with special emphasis on appropriate grade level and simplicity.
- Create a health literacy website to provide resources for adult literacy and healthcare professionals.
- Sponsor health literacy information sharing forums for healthcare professionals, adult literacy professionals and adult learners.

In 2003, Hablamos Juntos, a program of the Robert Wood Johnson Foundation, completed an evaluation of the use of symbol graphics in medical settings. Hablamos Juntos translates from Spanish to English as "We Speak Together" is a program intended to eliminate language barriers and improve the quality of health care provided to Latinos with limited English proficiency. The symbol graphics appearing in the call-outs of this report were developed as part of this program and are widely used to improve communication between health care providers and those with low literacy and limited English proficiency.

For more information about this program go to:
<http://www.hablamosjuntos.org/default.about.asp>

Background

Background

In February 2005, CHIP published *An Action Plan of the Safety Net in San Diego: Response to the Urgent Matters Safety Net Assessment* (Action Plan). The Urgent Matters Action Plan was the result of a cooperative effort by members of the CHIP Access to Care Committee to respond to a study of San Diego's safety net completed by an assessment team at the George Washington University Medical Center in March of 2004, which was funded by the Robert Wood Johnson Foundation.

One of the 23 recommendations contained in the Action Plan called for the development of a strategy to utilize new and existing literacy programs to improve the health literacy of safety net users and providers. This is thought to be an emerging area in both the literacy and medical fields. Based on this recommendation, CHIP and SDCOL established a collaboration to develop a joint health literacy project.

The goal of the project is to develop a collaborative health literacy plan for San Diego County. This report represents the first step in this plan. The objectives include:

- Assess the health literacy problem
- Complete a thorough literature review
- Conduct an inventory of current and potential local, regional and national assets
- Conduct qualitative research with key stakeholders including adult learners, promotoras (health advocates), medical office staff and physicians
- Develop and prioritize a set of program objectives along with an implementation plan

This project is a unique collaboration which capitalizes on both the adult literacy and healthcare resources in San Diego County. The majority of the research to date and the health literacy initiatives nationwide are not collaborative efforts. This project will bring the two professional communities together in order to provide the resources that the patients need the most.

The following report presents the results of this effort, a preliminary set of recommendations, and objectives along with an implementation timetable.

In addition to asset mapping and focus groups, CHIP and SDCOL formed an advisory committee. The advisory committee was created so that it would represent both the adult literacy community and the healthcare industry. This advisory committee included representatives from adult literacy programs, the public health sector, the health insurance industry, medical providers and the hospital industry.

The advisory committee met with the researchers throughout the project, SDCOL and CHIP to give feedback about the progress of the project and their input for next steps. The next steps presented in this paper are representative of that collaborative effort.

Health Literacy

What is health literacy?

Since first used in a 1974 paper titled *Health Education as Social Policy* (National Institutes of Health, Current Bibliographies in Medicine – Health Literacy 2000), the term health literacy has been defined in a variety of ways. Currently, the more widely used and commonly accepted definition of health literacy is:

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (US Department of Health and Human Services, 2000).

This definition, like many others, places the responsibility for health literacy directly on the individual. In its 2004 seminal report, *Health Literacy: A Prescription to End Confusion*, the Institute of Medicine (IOM) presented a different conceptual framework that shares the responsibility for health literacy with both the individual and healthcare systems. This approach acknowledges many of the challenges of improving health literacy. Included in these challenges is the training of healthcare providers to more effectively communicate with their patients both orally and in writing.

The IOM completed a meta-analysis of health related materials, such as brochures, which revealed that these materials were written at a tenth grade level, on average. The 2003 National Assessment of Adult Literacy (NAAL) revealed that nearly 46 million adults do not read sufficiently enough to comprehend these resources. The NAAL did not assess verbal or numeracy skills, so it has to be speculated that those skills, which are required to understand prescriptions and verbal directions, are also insufficient.

Health literacy, therefore, is impacted not only by an individual's capacity (made up of his or her skills to read, process, and understand health-related information being presented) but also the healthcare system's ability to present critical health-related information to the individual at a level that is easily understood. This entire process is impacted by the individual's literacy level, the provider's ability to communicate effectively at levels appropriate for the recipient of health-related information, and the cultural context in which the communication is taking place. Without including these three elements in the health-related communications equation, the result will likely be the individual's inability to make well informed, appropriate health-related decisions.

The nurses told me to take the elevator and go to where it says 'x-rays.' I took the elevator and I just went home because I couldn't read the signs. It's a scary thing when you don't know the words.

--Enrique Ramirez

What Are The Consequences of Low Health Literacy?

According to the Partnership for Clear Health Communication, a coalition of national organizations that are working together to promote awareness and solutions around the issue of low health literacy and its effect on health outcomes, individuals with low health literacy often fail to seek preventive care, are at a higher risk for hospitalization, average longer hospital stays, and are less likely to comply with prescribed treatment and self-care

Health Literacy

regimens. Various studies examining the impact of low health literacy found:

- A potentially avoidable \$73 billion is spent annually for health care as a result of low health literacy skills among more than 90 million adults in the United States.
- A significant number of patients were unable to read basic health materials; did not comprehend directions for taking medications on an empty stomach; were unable to understand information on an appointment slip; or did not understand a standard informed consent document.
- Medicaid patients reading below third grade level have average annual health care costs four times those of the overall Medicaid population.
- Emergency room patients with inadequate literacy were twice as likely to be hospitalized as those with adequate literacy.



Cardiology
Cardiologia

Overall, adults with low literacy tend to utilize significantly more hospital resources while visiting physicians less often.

Who Is At Risk?

There are three specific groups of patients who are at significant risk for health-related problems due to low health literacy. The first group is those who are functionally illiterate, meaning they read below the eighth grade reading level albeit native English speakers. These patients are the hardest to identify for healthcare providers. They are reluctant to admit to their reading problem in public situations and therefore are at a significant risk for health-related complications.

The second group is those patients for whom English is not their native language. They are not only compromised in their reading and writing skills but they also have impaired verbal communication skills. This group also faces significant cultural barriers related to understanding generally accepted health care practices and how to navigate the US health care system.

The third group at risk is seniors, typically persons age 65 and over. A relatively high proportion of persons in this age category (20% according 2003 NAAL) have less than a basic level of health literacy. This results in less health knowledge, inferior self-management skills for those with chronic diseases such as hypertension, diabetes mellitus, asthma and heart failure, lower use of preventive services, and worse health in general according to a variety of studies.

What are the Key Issues Impacting Health Literacy?

The following presents some of the key issues and barriers impacting the improvement of health literacy based on an extensive literature review and discussion with key stakeholders including patients, physicians and others involved in providing healthcare throughout San Diego County.

Health Literacy

Health Literacy in the United States

Included in the 2003 NAAL was an assessment of health literacy. The assessment measured individual health literacy in three domains of health and healthcare information and services. These domains and their associated tasks included:

Clinical – Activities associated with the healthcare provider-patient interaction, clinical encounters, diagnosis and treatment of illness and medication.

Prevention – Activities associated with maintaining and improving health, preventing disease, intervening early in emerging health problems and engaging in self-care and self-management of illness.

Navigation of the health system – Activities related to understanding how the healthcare system works and individual rights and responsibilities.

The addition of these health literacy domains and associated tasks to the 2003 NAAL has allowed the creation of a health literacy scale that adds to the understanding of the complex relationship between adult literacy and health literacy.

The following presents some key health literacy findings from the 2003 NAAL.

- The health literacy levels of the overall U.S. adult population fell into the following categories of literacy.

Literacy levels and definition

Below Basic indicates no more than the most simple and concrete literacy skills.

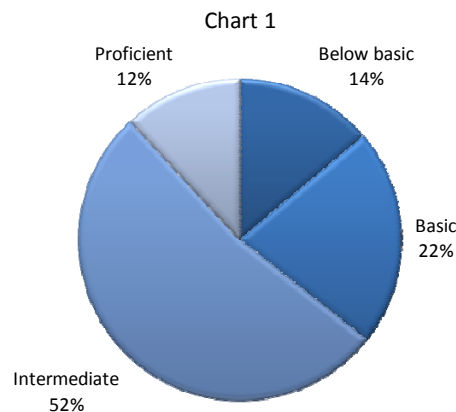
Basic indicates skills necessary to perform simple and everyday literacy activities.

Intermediate indicates skills necessary to perform moderately challenging literacy activities.

Proficient indicates skills necessary to perform more complex and challenging literacy activities.

Health Literacy Level

U.S. Adult Population*
(Age over 16 years)



*This chart does not include an additional 3% of the population who are non-literate.

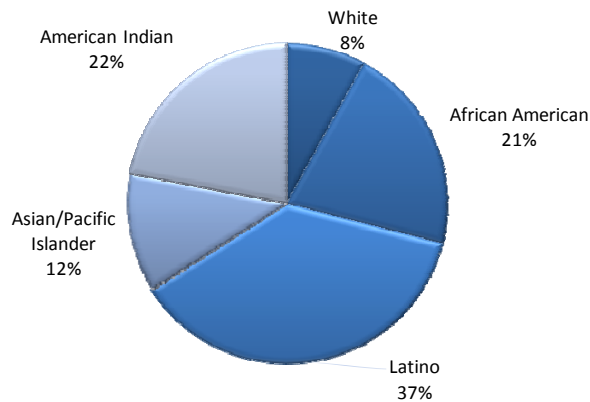
Source: 2003 National Assessment of Adult Literacy (NAAL)

Health Literacy

- A higher percentage of men than women are below basic health literacy, 16% and 12%, respectively.
- Examination of health literacy by race and ethnicity identified the proportion of those in the below basic category were:

Health Literacy Level Proportion Below Basic by Race/Ethnicity

U.S. Adult Population*
(Age over 18 years)
Chart 2



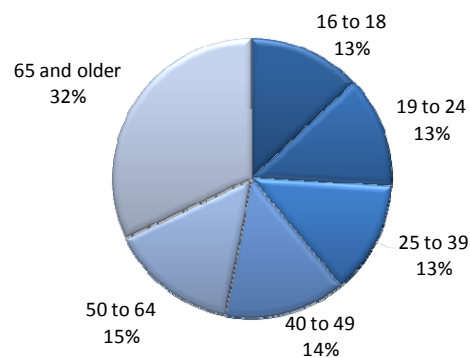
*This chart does not include an additional 3% of the population who are non-literate.

Source: 2003 National Assessment of Adult Literacy (NAAL)

- Examination of health literacy by age category identified the proportion of those in the below basic category were:

Health Literacy Level Proportion Below Basic by Age Category

U.S. Adult Population*
(Age over 16 years)
Chart 3



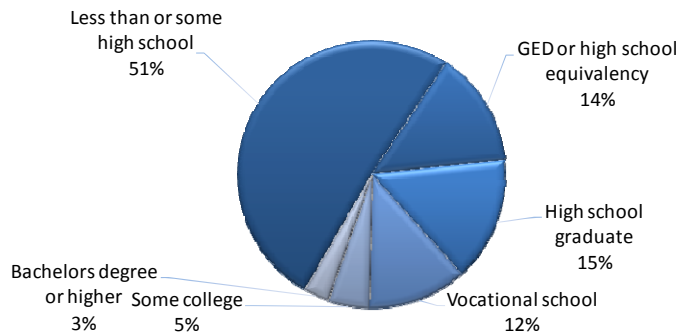
*This chart does not include an additional 3% of the population who are non-literate.

Source: 2003 National Assessment of Adult Literacy (NAAL)

Health Literacy

- Examination of health literacy by highest educational attainment identified the proportion of those in the below basic category were:

Health Literacy Level
Proportion Below Basic by Level of Education
U.S. Adult Population*
(Age over 18 years)
Chart 4

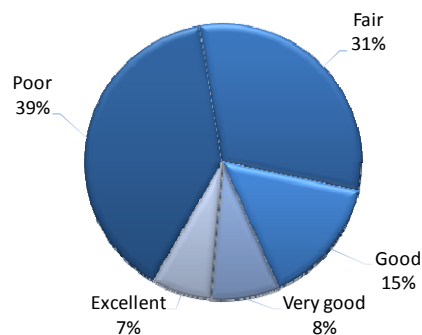


*This chart does not include an additional 3% of the population who are non-literate.

Source: 2003 National Assessment of Adult Literacy (NAAL)

- Examination of health literacy by a self-assessment of overall health identified the proportion of those in the below basic category:

Health Literacy Level
Proportion Below Basic by Self-assessment of Overall Health
U.S. Adult Population*
(Age over 18 years)
Chart 5



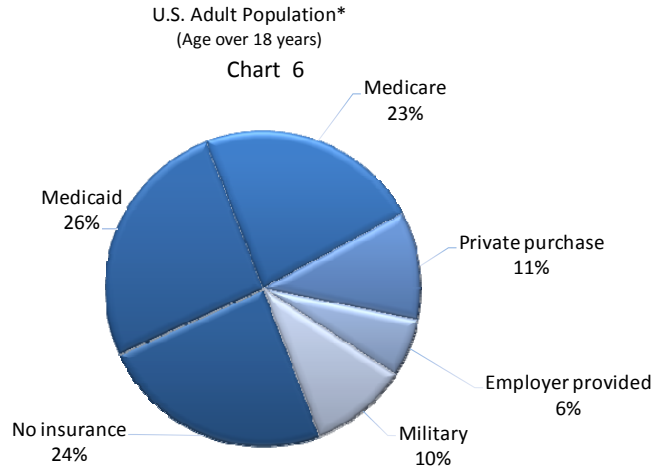
*This chart does not include an additional 3% of the population who are non-literate.

Source: 2003 National Assessment of Adult Literacy (NAAL)

Health Literacy

- Examination of health literacy by type of health insurance identified the proportion of those in the below basic category were:

Health Literacy Level
Proportion Below Basic by Type of Health Insurance

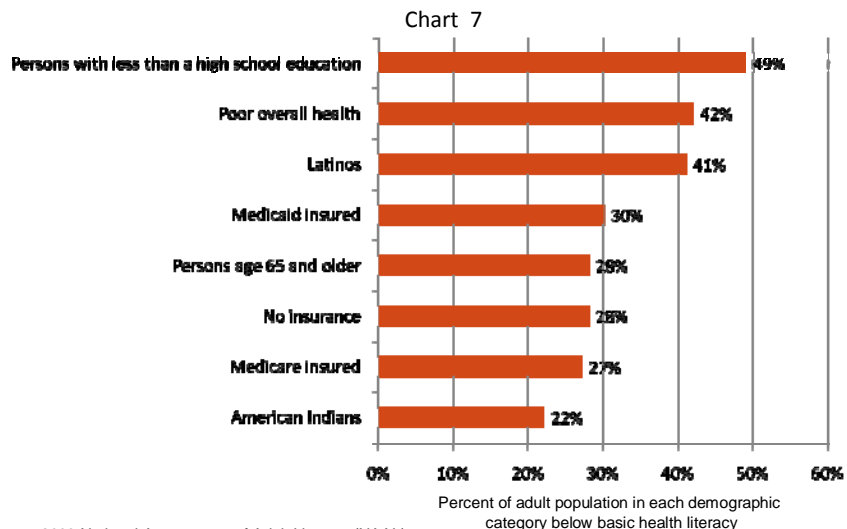


*This chart does not include an additional 3% of the population who are non-literate.

Source: 2003 National Assessment of Adult Literacy (NAAL)

In summary, based on the information presented in the 2003 NAAL health literacy assessment, eight characteristics that are potentially useful in identifying persons at risk for low health literacy are shown in the following chart.

Health Literacy Level
Those most impacted by low health literacy



Source: 2003 National Assessment of Adult Literacy (NAAL)

Health Literacy

The Healthcare System in the United States

Healthcare in the United States is delivered through a complex mix of providers and financing. Some of the elements that make navigating the US healthcare system difficult, especially for persons with lower literacy levels, include:

- Healthcare has its own language and terminology used by those involved in providing care including physicians, nurses, technologist, medical office staff and insurance providers
- Care is provided by a complex hierarchy of providers and facilities
- Accessing and paying for care is frequently controlled by a mix of public and private entities
- Reading, writing and numeracy demands required to interface with healthcare providers (physicians, hospitals, insurance companies, public health organizations and pharmacies) typically exceed the health literacy skills of most adults
- Health professionals and staff have limited education, training, continuing education and practice opportunities to develop skills for improving health literacy

Healthcare Assets

A large array of healthcare assets currently exists in the San Diego community that can be used to address low health literacy. Many organizations currently have programs addressing select elements of the health literacy problem such as the use of appropriate reading levels and pictograms for disease specific materials distributed to patients (e.g., The Whittier Institute for Diabetes Project Dulce) and several use communications strategies such as the Ask Me 3 program offered by the Partnership for Clear Health Communications. This program is currently used at a number of physician offices and community clinics in San Diego County.

Healthcare Providers

Healthcare providers are a primary asset in addressing the health literacy issue in San Diego County. The following describes the depth and breadth of this asset. Based on our research, there is a general agreement among providers that health literacy is a serious issue facing both providers and patients.

The Ask Me 3 program creates shared responsibility for clear health communications by:

- *Providing a consistent approach to patient-provider dialogue*
- *Allowing patients to get information they need to manage their health*
- *Being time-efficient to providers to reinforce healthcare instruction*

The 3 questions are:

What is my main problem?

What do I need to do?

Why is it important for me to do this?

For more information see: <http://www.npsf.org/askme3/>

Health Literacy

Each of the following groups of healthcare providers sees patients in a different context and each offers a unique opportunity to positively impact the health literacy of the patients they treat. (Refer to Appendix B for a detailed description of each provider).

- Physicians
- Community Clinics
- Hospitals
- Military Healthcare System
- Other Types of Treatment Services
- Native American Health Services Agencies
- Advocacy and Community Service Agencies
- Medical Insurance Providers
- County of San Diego Health and Human Services Agency
- Pharmacies
- Other assets

Adult Literacy

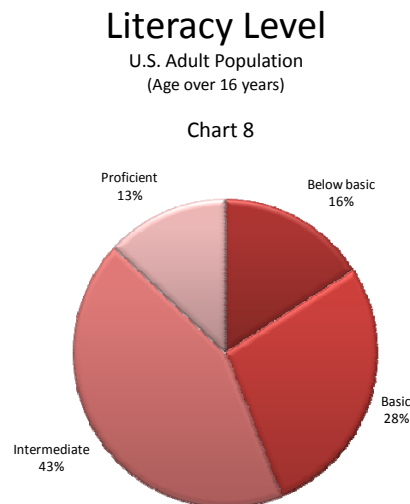
Adult Literacy in the United States

The National Assessment of Adult Literacy (NAAL) defines literacy as being able to use printed and written information to function in society, to achieve goals, and to develop knowledge and potential. The 2003 NAAL measures the English literacy of adults in three dimensions:

- **Prose** – the knowledge and skills needed to search, comprehend and use information from texts that were organized in sentences or paragraphs.
- **Document** – the knowledge and skills needed to search, comprehend and use information from noncontiguous texts in various formats.
- **Quantitative** – the knowledge and skills needed to identify and perform computations using numbers embedded in printed materials.

The following presents some key findings from the 2003 NAAL. (Note, the percentages shown for the below basic literacy category that follow are the average measure of prose, document and quantitative.)

- The literacy levels of the overall U.S. adult population fell into the following categories of literacy.



Source: 2003 National Assessment of Adult Literacy (NAAL)

The NAAL defines the levels the following way:

- Below Basic: no more than the most *simple* and *concrete* literacy skills
- Basic: can perform simple and everyday literacy activities
- Intermediate: can perform moderately challenging literacy activities
- Proficient: can perform complex and challenging literacy activities

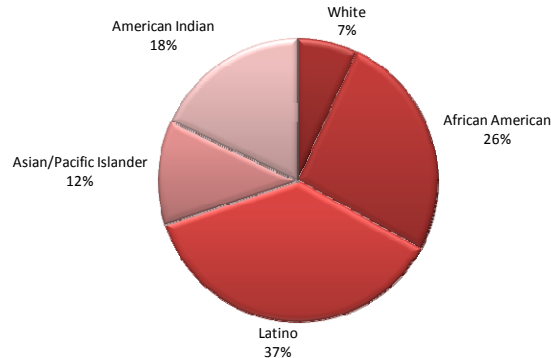
Adult Literacy

- When analyzed by race and ethnicity, the 2003 NAAL found the percentage of adults in the below basic category were:

Literacy Level Percent Below Basic by Race/Ethnicity

U.S. Adult Population
(Age over 16 years)

Chart 9



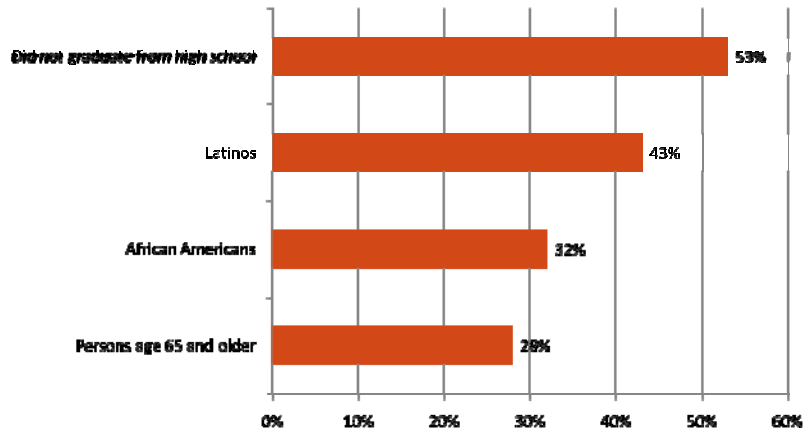
Source: 2003 National Assessment of Adult Literacy (NAAL)

- Nationally, Latinos represented 12 percent of the 2003 NAAL population but 39 percent of the adults with *Below Basic* prose literacy.
- In terms of age, adults 65 and older had the lowest average literacy with 28 percent below basic.
- Examination of educational attainment found literacy was lowest for adults who did not complete high school; 53 percent of these adults are below basic literacy.

Literacy Level

Those most impacted by health literacy

Chart 10



Percent of adult population in each demographic category below basic literacy

Source: 2003 National Assessment of Adult Literacy (NAAL)

Adult Literacy

The 2003 NAAL is a representative sample of the United States; however, the demographics in San Diego may be slightly different due to the high percentage of Latinos in San Diego in comparison to the majority of the United States. Therefore the incidence of low health literacy may be a higher among Latinos in San Diego County.

I tried to donate blood for my daughter who was ill with cancer. When they handed me medical history forms to complete, I ran out of the room because I couldn't fill out the forms. It was embarrassing.

-Anonymous San Diego County adult student

It is important to note that individuals who were not able to complete the beginning questions of the NAAL were not included in this sample. Therefore, approximately 3% of the population who is unable to read English at any level is not represented in the NAAL data, which increases the number of low literate adults in the community that is not represented in the NAAL report.

Adult Literacy Services in San Diego County

Approximately 60,000 low literate adults enroll in adult literacy programs throughout San Diego County each year. Adult literacy services in San Diego County are diverse, well-established, free and available to any low literate adult. These services include instruction for native English speakers, English as a Second Language (ESL) which includes native born and non-native born learners who speak English as a Second Language, Learning Disabled (LD), Families for Literacy (FFL), and senior citizens. Programs are open-entry, open-exit programs, giving learners the opportunity to attend when they are able. Literacy administrators, practitioners, volunteer tutors and learners who are invested in these programs have expressed a need, interest and willingness to incorporate health literacy into their programs.

The Families for Literacy (FFL) program serves low literate parents or primary caretakers of children under the age of five. The program is designed to break the cycle of illiteracy by teaching parents/caregivers how to be their child's first and most important teacher. The program includes giving brand new, high quality children's books to each family, modeling and practicing literacy activities parents/caregivers can do at home, and providing parenting classes. Families for Literacy (FFL) programs in San Diego County are offered in Library-based literacy programs, but also exist under different names in many of the community-based programs, such as the International Rescue Community (IRC).

Of the literacy programs interviewed, only one program actually teaches a health literacy class. The other programs stated that while they have disease specific materials, these are rarely used in tutoring sessions and are often out of date. Additionally, several of the programs stated that they do not have a health literacy curriculum.

Adult Literacy

The adult literacy community in San Diego was unable to identify any health literacy resources that would be appropriate for low literate adults who read below the sixth grade level. They also expressed an interest in participating in this partnership. The adult literacy community will be a viable and malleable place in which to incorporate health literacy curricula, training and professional development.

Adult Literacy Assets in San Diego County

Adult Literacy services are offered in four distinct formats, all of which are free.

- Adult Basic Education (ABE) classes
- English as a Second Language (ESL) classes,

Typically both ABE and ESL classes are offered through local community college districts and high school districts.

- Library-based adult literacy services offered through public libraries and community-based organizations (CBO's)
- Workforce Literacy offered through companies that wish to improve the literacy levels of their own employees.

Each of these providers of adult literacy services has its own set of enrollment procedures, types of classes offered, and infrastructure which are described in the asset mapping section of this report.

The adult literacy services community is user-friendly. Potential learners are only required to consent to an initial assessment and then enrolled in the program of their choice. They are encouraged to set their own goals, which are usually the impetus for their enrollment. Some programs have the curriculum and the flexibility to develop the curriculum around those stated goals, whereas other programs utilize one curriculum for each student, independent of their individual goals. Library-based literacy programs tend to have the most flexibility because their learners meet one-on-one with a tutor rather than in a classroom setting.

Adult literacy professionals have the unique opportunity to address low health literacy to a targeted audience -- those who have the lowest literacy levels. The adult literacy community incorporates topics that are the most requested or identified as the most in need. During the course of this research, adult literacy practitioners have identified a need to incorporate health literacy curriculum into their lesson plans. Finally, by improving the health literacy of adult literacy learners, one can speculate that the health of their children will improve by proxy. Adult learners who become more knowledgeable about the healthcare system, their own illnesses, the illnesses of their children/family members and navigation of the system, and learn to become their own health advocates will be better equipped to successfully manage the health of their children.



Surgery
Cirugía

Adult Literacy

The following is a description of participating adult literacy programs in San Diego County, all of which are part of the collaboration of literacy programs that partner with the SDCOL network:

Library Literacy Programs

Library-based adult literacy programs are volunteer based programs that offer one-on-one instruction by trained volunteer tutors for adults who read below the 8th grade level, many of whom have a learning disability. Library-based adult literacy programs in San Diego County range from serving 60 learners to over 500 learners per year. Other literacy services provided include the Families for Literacy (FFL) program, computer-



aided instruction, and small group instruction. The following participating library literacy programs in San Diego County have agreed to participate in a health literacy initiative (Refer to Appendix A for a detailed description):

- Carlsbad City Library - Adult Learning Program
- Oceanside Public Library - Oceanside READS
- San Diego Public Library- READ/San Diego

Adult Basic Education and English as a Second Language

One community college district and one high school district who participated in this project provide free literacy services for learners who need to study for their General Education Development (GED), high school diploma, computer skills, and ESL. Adults attend classes that are taught by paid instructors. The following is a list of participating ABE/ESL adult and continuing education schools (Refer to Appendix A for a detailed description):

- Sweetwater Unified High School District, Division of Adult & Continuing Education
- San Diego Community College District - Continuing Education
- San Diego Community College Auxiliary Organization- Even Start Program

Community-Based Adult Literacy Services

Community-based literacy programs are the most diverse in the services they provide. The two programs that are participating in this project are both ESL programs. Both programs are free and both programs serve mainly immigrants and refugees (Refer to Appendix A for a detailed description):

- International Rescue Committee – First Things First & Students Plus
- Laubach Literacy Council Of San Diego County, Inc.

Stakeholder Input

Key Stakeholder Input

A critical part of this research project was to hear firsthand from those most affected by low literacy and low health literacy. To achieve this, a series of focus groups and discussions was held with the following key stakeholders:

- Adult literacy learners
- Medical office front office staff
- Promotoras
- Physicians

The following presents more details about each group.

Adult Learners: Voice of the Consumer

Two groups of low literate adults in San Diego County were assembled and asked about their experiences with healthcare. The learners were ethnically diverse and ranged in age from 22 to 65 years. There were native English speakers, Somalian and Iraqi refugees and immigrants from Mexico. All the learners assembled read below the sixth grade level, with the majority reading below the fourth grade level.

Four common themes emerged from these groups:

- Front office medical staff is unable/unwilling to help low literate patients. This includes staff at the front/check-in desk and nurses. Learners reported that staff often tell them they are too busy to help, or that they “need to figure it out” on their own.
- Forms (e.g. consent forms, intake forms, insurance forms) are written at a level that exceeds their reading level.
- Learners are not likely to ask for help in a crowded waiting room.
- Verbal communication used during appointments is confusing and often not understood.

Comments from learners included:

- “It’s embarrassing to ask them to help you.”
- “I take the paperwork home.”
- “Reading prescriptions is impossible.”



Family Practice Clinic
*Clínica de Práctica
Familiar*

Stakeholder Input

Possible Solutions Suggested by Learners

- Nearly every learner suggested that an advocate in the doctor's office, emergency room and pharmacy be assigned to help those who cannot read well enough to understand the medical information given to them. Each learner requested that this person be discrete but readily available. *
- Learners suggested that the consent form was very difficult and/or impossible to understand. An alternative to the traditional consent form might be to have the consent form read to them. The suggestion of having the terms of the consent form on video or audio tape was proposed. This is also an opportunity for an advocate who is assigned to help with reading materials.
- The front line staff should be trained in identifying and/or understanding the low literate adult in order to avoid more serious complications. *
- Adult literacy programs should create and implement curriculum in classes/workshops that would teach learners how to navigate the system in any situation. *

* Suggestions represented in the recommendations

Voice of the Medical Office Staff

Front Office Staff

A roundtable discussion was held with six medical office staff members to discuss what is being done to deal with health literacy in their offices. Participants in the roundtable included office staff from the following:

- Vista Community Clinic, Vista, CA
- La Maestra Community Health Centers, San Diego, CA
- Clinicas de Salud del Pueblo, Brawley, CA

Not reading English very well made my life and school work very difficult. I knew that reading and writing better would help to improve my life. I completed my high school diploma and one year of medical assistant training.

-- Elvia, medical assistant, age 39, children ages 13, 16, and 19, 30 months in Oceanside area literacy program

The following highlights the impact of low health literacy in their medical offices.

Complex Environment

- Medical language and terminology used by physicians and staff in the medical office setting are often too complex for patients to understand.
- Participants expressed frustration in dealing with patients with low literacy and the lack of training on how to help patients with low literacy or low health literacy. The advice they typically receive when dealing with patients with literacy problems is to "be patient" and "use family members to help."

Stakeholder Input

- Some of the most serious problems encountered related to low literacy include:
 - Consent forms are too complex and require a high level of literacy to understand. Participants indicated they typically explain the consent forms to patients, but most patients still don't understand what is being presented to them or what they are being asked to sign.
 - Patients become confused and frustrated by the words used in the consent forms. This is especially true when consent forms address potential risks related to procedures.
 - Patients typically sign the consent forms out of frustration. When asked if they understood what the doctor had just told them, "no" is the most common response.
- Participants indicated that even the best efforts of the office staff don't effectively solve the health literacy problem. Comments included:
 - "The patients don't ask questions."
 - "Many patients don't know what they are filling out, even when the form is in Spanish and after we have explained it to them, they still don't understand."
 - "Some patients don't know what medications they take or what procedures they have had. This is especially problematic for patients who can't read."
- Patients presenting the most problems with health literacy include:
 - Persons over 65
 - Person with English as a second language
 - Those with little education or reading difficulties

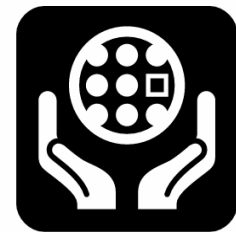
Possible Solutions Suggested by Front Office Staff

Participants presented some suggestions on what they felt would be effective in helping them deal with persons with limited literacy or low health literacy. These suggestions included:

- Provide case management services to low health literacy persons with complex medical needs. The case manager could help ensure the patients understand their medical needs and help the patients navigate their way through the medical system.
- Provide patient advocates when needed to help patients who:*
 - Are unable to read or write at the necessary level (this applies to both native English and Spanish speakers)
 - Need explanation of diagnosis, test results, procedures, consent forms and other complex issues related to healthcare

Stakeholder Input

- An example of a program called “Teen Smart”, which was an assessment program, was offered as an example of an advocacy program that has been offered in the clinics that seems to work effectively. This program provides personal help completing forms and making sure the patients understand the questions on the forms they are asked to complete during their medical visit.
- Provide videos in the clinics related to specific topics and procedures that would help patients understand.
- Provide more medical terminology training to translators. This training should include being able to explain complex medical procedures and risk to patients in very simple term. Often, translators don’t understand the medical terminology and information they are being asked to translate, making it difficult to effectively translate what the medical professionals are trying to explain to the patient. (Note, participants indicated professional translators are very expensive and the clinics, rather than incur the expense, will often use an untrained translator such as someone from the accounting department to provide translation services.)
- Provide cultural competency training to both office staff and providers (physicians, nurses and other medical professionals) focusing on the needs of their recipient populations in a way that acknowledges and is sensitive to their cultural differences. This includes finding ways to communicate in a manner that is culturally and linguistically appropriate. *



Oncology
Oncología

Cultural Issues

Participants indicated that some of the issues related to health literacy are made more complex by cultural issues that exist among their patients. Examples experienced include:

- Patients don’t understand the use of non-physician providers such as nurse practitioners and physician assistants in the U.S. When patients are seen by a non-physician provider, they often become upset and feel they have not received adequate healthcare or are receiving poor quality healthcare.
- Patients are accustomed to receiving medicine when visiting a physician. If, for example, the patient presents with a viral infection, they expect an antibiotic. When not given medicine, patients become upset and question the quality of care being provided.
- Among Somali patients, there are cultural issues related to male dominance of females. If a married female patient visits a clinic, the husband will typically be present and do all of the talking and not allow the female patient to be seen by a male physician.

*Suggestions represented in the recommendations.

Stakeholder Input

Needed Skills and Tools

Participants were asked to discuss what types of skills they need or tools they could use to more effectively address the literacy and health literacy issues they face in the clinics. Ideas mentioned include:

- Training on how to effectively deal with patients low literacy
- Easy access to information on how to present complex medical issues to patients
- Help with consent forms
- Access to simplified general and disease specific medical information written in both English and Spanish



Laboratory
Laboratorio

Voice of Promotoras

A roundtable discussion was held in Chula Vista, California with promotoras (community health workers) to discuss issues of health literacy among the populations they serve. Participants in this roundtable were promotoras and health educators providing the following types of services:

- Diabetes health education
- Cancer screening promotion related to breast, pap and colorectal cancer screening
- Weight management and nutrition
- English reading development with young children
- Mental health

The discussion included the following topics:

- Provide a brief overview of literacy and health literacy.
- Discuss the impacts of low health literacy.
- Learn what is being done in their communities to address low health literacy.
- Identify needs in terms of learning more effective methods for dealing with low health literacy.
- Identify potential resources needed to reduce the burden of low health literacy.
- Prioritize which health literacy issues should be addressed first.

Stakeholder Input

The following briefly highlights several of the key themes from our discussion.

Status of the physician

The most common theme heard during our discussion was the critically important role the physician plays in the health-related decision making process for Latinos. Some of the comments participants used to describe the relationship between physicians and the community served include:

“What the doctor says is always right.”

“Even if we don’t understand what the doctor says, we say ‘okay.’”

“I trust my doctor.”

“You can ask your doctor questions, but often you can’t understand the answer because of the words they use.”

“Most patients do not have a medical background and do not understand what their doctors are saying.”

“Patients often don’t know the names of the medications they are taking or why they are being taken. They only know that their doctor told them to take the medication.”

The promotoras acknowledge that this blind faith in physicians is part of traditional Latino culture. For some people, especially those with serious medical problems such as diabetes, they feel this non-questioning attitude among patients is a problem because patients do not understand their disease or the treatment. Participants felt strongly that physicians need to better understand the population they are serving to be effective healthcare providers within the Latino community.

Alternatives to U.S. Healthcare

Because of our proximity to Tijuana, Latinos have an alternative source of healthcare. The promotoras described how it is common for some Latinos to visit physicians in Tijuana when they are ill. The following are some of the comments given when asked why patients would travel to Tijuana for healthcare.

“People like to go to Tijuana because they will receive medicine and feel better. In the U.S., doctors only recommend water. Patients expect to receive medicine when they feel bad.”

“Mexico has good doctors but not the technology.”

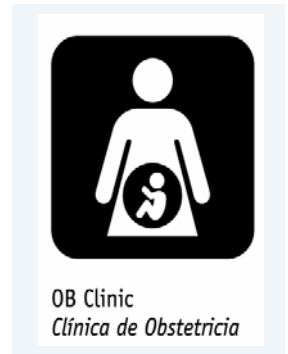
“It’s easier to access specialty care in Tijuana. I feel American doctors keep you coming back because they want more money.”

While the participants claim they do not encourage traveling to Tijuana for care, they feel it is often a result of American physicians not taking the time to sit down with their patients to discuss their health issues.

Stakeholder Input

Experience and Training

Participants were asked to discuss how they deal with the health literacy issues of the people they provide services to and describe any special training they may have received related to working with people with low literacy. The two most common methods described by participants when helping their clients understand health issues such as diabetes control, breast self-examination and nutrition were the teach-back method and simplification of the words and concepts being presented. When asked about formal training related to helping their clients better understand the health issues, most indicated they had not received any formal training. Two of the participants indicated they had attended a program sponsored by San Diego State University related to improving communication. Most of their training related to dealing with cultural issues. Several indicated that many of the methods they use to help their clients understand the various health issues were learned informally on the job.



When asked what they felt would be most useful in helping them deal effectively with persons with low literacy and low health literacy, participants offered the following suggestions:

- Educate physicians about the culture and customs of the people they care for.
- Provide patients with materials that present medical information and concepts in simple and common words that people without a medical background will easily understand. *
- Have physicians support them by knowing what is happening in the community.
- Provide them some tools they can give to their clients that will help organize their medical history such as notebooks or binders in which they can record and store important medical information. *
- Teach interpreters how to present medical terminology to patients in a more understandable manner.

*Suggestions represented in the recommendations

Stakeholder Input

Voice of Physicians

A roundtable discussion was held at Scripps Mercy Hospital San Diego to discuss health literacy and learn from the physician's perspective how it impacts medical practices and the quality of medical care. Participants in the roundtable included the following:

- Lance Fuchs, MD, a Kaiser Permanente primary care physician interested in health literacy and working on a pilot health literacy program for patients with allergies
- Mits Tomita, MD , primary care physician and Director of Continuing Medical Education for Kaiser Permanente
- Diane Strum, Director, Government and Community Relations at Kaiser Permanente and a member of the health literacy advisory council
- David Shaw, MD, cardiologist, Scripps Mercy Hospital, Director of Medical Education and Residency Program
- Davis Cracroft, MD, Scripps Mercy Hospital, Medical Director and emergency department physician
- Ralph Ocampo, MD, retired surgeon interested in health literacy and active with the San Diego County Medical Society Foundation
- Steven Carson, MD, pediatrician, chief medical officer at the San Diego County Medical Society Foundation and regional medical director for Molina Health Care
- Abe Krems, MD, retired physician interested in health literacy
- Kristin Garrett, Executive Director of Community Health Improvement Partners



Internal Medicine
Medicina Interna

Topics covered in the roundtable included:

- A brief overview of literacy and health literacy.
- How low health literacy impacts the patients seen in practices.
- What physicians are doing to address low health literacy in their practices.
- What physicians need in terms of learning more effective methods for dealing with low health literacy.
- Potential resources physicians can use in their practices to reduce the burden of low health literacy.
- Which health literacy issues should be addressed first.

Stakeholder Input

The following highlights the discussion following a brief overview of literacy and health literacy.

Challenges and opportunities

Physicians feel there are enormous challenges and opportunities to effectively address the low health literacy issues. Some of the challenges mentioned include:

- The size and complexity of healthcare systems make it difficult to keep current information related to various treatments and drugs.
- There are many “touch points” within the healthcare system, making it difficult to coordinate efforts to effectively address health literacy in a coordinated manner. (Note: a touch point is any interaction between a patient and a medical professional while receiving care and treatment within the healthcare system.)
- Hospitals and medical offices are not generally user friendly.
- There is significant potential for duplication of effort.
- Some organizations may be unwilling to share their efforts related to health literacy because they believe what they are doing will give them a competitive edge.
- Perceived liability issues related to information given to patients. This is especially the case with the drug information sheet given by pharmacists when receiving prescription medications; these are also known as “scare sheets” and medical consent forms patients are required to read and sign prior to receiving various medical procedures in hospitals and physician offices.

Some of the opportunities mentioned include:

- Working collaboratively across provider organizations (including hospitals, physician practices, health plans and drug companies) to increase the awareness of low health literacy issues and share promising methods to improve the communications between patients and providers. *
- Build on existing efforts by utilizing and implementing materials and methods that have been developed nationally rather than recreating materials on the local level. This will require an effort to identify a broad range of organizations and collaborations that are working on the health literacy problem. *
- Increase awareness among physicians, residents, nurses and office staff about issues related to low literacy and health literacy. *
- Promote October as Health Literacy Month to kick off a campaign to raise the awareness of health literacy issues among both the medical community and

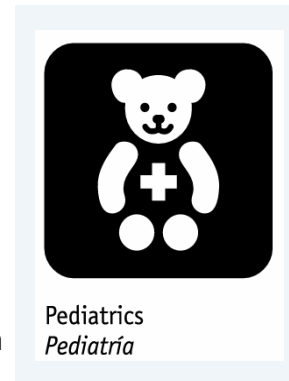


Mammography
Mamografia

Stakeholder Input

consumers. (Helen Osborne, a health literacy advocate, started October as health literacy month in 1999. According to her website http://www.healthliteracy.com/hl_month.asp October is the month “to let the world know why health literacy matters.”)

- Provide continuing education credits to physicians and nurses for attending presentations on issues directly related to health literacy such as more effective communications with patients. An entire curriculum could be developed using many of the materials readily available through organizations such as the AMA Foundation (Health Literacy Tool Kit) and Partnership for Clear Health Communications (Ask-Me-3 program.) *



These presentations could be offered as part of Grand Rounds at hospitals and incorporated into various CME and GME courses. It could also be added to mandatory annual training requirements. Additionally, presentations could also be offered to medical groups such as Mercy Physicians Medical Group and others.

- Have physicians champion this effort. This could include presentations by practicing and retired physicians with an interest in health literacy. *

Concerns

Physicians expressed the following concerns about how to address health literacy:

- Do not make health literacy another “initiative.” While they felt health literacy is an important quality of care issue, it should be addressed by building on existing national efforts.
- Who will manage the effort as it relates to disease and specialty specific areas?
- How will we know the information is current and who will maintain it?
- Duplication of effort in addressing health literacy must be reduced.

Next steps

Physicians agreed that a program should be developed within San Diego County to get people excited about health literacy. They recommend that the health literacy program be low cost and be phased in over time.

*Suggestions represented in the recommendations.

Recommendations

Health Literacy Program Next Steps

The proposed recommendations are the outcome of the asset mapping, interviews and focus groups with key stakeholders. The recommendations address the multifaceted nature of literacy and health literacy and the services provided by adult literacy and healthcare professionals in San Diego County. A primary finding of research conducted thus far indicates a need for the healthcare industry and the adult literacy field to partner to provide appropriate cross-training.

The implementation of next steps will draw upon national and regional resources, methods and best practices for development of program materials. Additionally, there will be continued exploration of opportunities to work with regional and national organizations in the development of programming and evaluation.

Recommendations

The following nine recommendations are presented in priority order as determined by the advisory committee.

Immediate Action

1. Establish, through the leadership of CHIP and SDCOL, a joint taskforce of literacy and healthcare professionals to champion the awareness of health literacy in the San Diego community. The taskforce will oversee the implementation of this plan and monitor its progress. \$

Following the establishment of the joint health literacy taskforce the following eight recommended action steps should be initiated based on priorities established by the taskforce. Some of these action steps may be carried out simultaneously.

2. Identify and/or create health literacy curricula for inclusion in adult literacy courses and healthcare settings. \$\$\$
 - a. Research what health literacy products/curricula/promising practices are already available and in use in comparable programs. Some programs to contact are the Rhode Island Health Literacy Collaborative, the New York City Office of Adult Education and the Iowa Health Literacy Collaboration.
 - b. Develop curricula that are written at the 0-3 grade level. There are currently no curricula that are written below the third grade level. Curricula written at this level will be accessible to every patient, independent of their literacy level. Adopt and modify curriculum that already exists for reading levels above the third grade. Curricula will include units on signage, forms, communication, vocabulary, etc.
 - c. Create a train-the-trainer curriculum/workshop. This training will provide the professional development needed for adult literacy practitioners, health educators

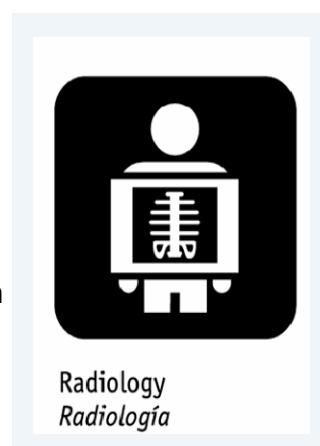
Costs associated with each of these recommendations are difficult to determine at this time. However, based on similar activities, the following cost categories have been estimated for each recommended action step.

*\$ = Minimal
\$\$ = Moderate
\$\$\$ = Expensive*

Recommendations

and other appropriate professionals to implement the health literacy workshops.

- d. Create health literacy curriculum to be implemented in a workshop format. This curriculum will include resources for the participants as well as a guidebook and resources for the teacher. Field test and evaluate the newly developed health literacy curricula in at least one volunteer-based program and ABE and ESL program at a local community college and/or high school district. This ensures that the field test is taking place in a variety of settings.
 - e. Field test and evaluate the newly developed health literacy curricula in at least one community health clinic.
3. Create a SDCOL and CHIP sponsored website that would include resources and referrals for adult literacy and healthcare professionals. \$
 - a. Research other promising practices websites to determine what is working and what would be appropriate for San Diego County. Some programs websites to investigate are Rhode Island Health Literacy Collaborative, the New York City Office of Adult Education and the Iowa Health Literacy Collaboration
 - b. Include links to sites that teach healthcare and adult literacy professionals how to write brochures using plain language.
 - c. Include links to resources for both healthcare professionals and adult literacy practitioners. (e.g., Ask Me 3, online health literacy presentations, health literacy conference announcements).
 - d. Include links to resources for adult literacy professionals to create lesson plans.
 - e. Provide resources to assist in the development of written health materials with special emphasis on appropriate grade level and simplicity. These resources may be accessed via a website or may be contracted for training. These services may be provided on fee-for-service bases to help cover its costs.
 4. Develop appropriate methods, tools, and policies to help medical organizations train their front and back office staff to better understand and deal more effectively with low literacy and low health literacy adults. This ideally would be a collaborative effort between literacy professionals and medical office and front-line hospital staff. The policies, methods and tools developed will be presented to physicians and their office staff during voluntary “lunch and learn” programs. \$\$
 - a. Develop model policies for organizations to use to promote health literacy as one of their cultural competencies.
 - b. Provide technical assistance and training to healthcare professionals on effective methods for working with persons with low literacy.



Recommendations

- c. Create trainings that include methods to help front office staff, physicians, nurses and pharmacists identify low literate patients.
 - d. These trainings will also include a component that will teach healthcare staff techniques to use with low literate patients
5. Increase awareness of low literacy and low health literacy issues within the healthcare community through the development of articles for organizations publications, Grand Rounds presentations, continuing medical education courses and other educational opportunities. \$
- a. Develop presentation materials (PowerPoint presentation, CME's, CEU's via the internet) for physician champions to present to physicians, nurses and other healthcare professional throughout the community
6. Develop and implement a *pilot* program utilizing trained volunteers on-site in the healthcare setting to work as advocates for low literate patients. \$\$
- a. Determine if any of the promising practices already mentioned have explored this option and determine via phone interviews and/or email what worked and what did not work.
 - b. Identify volunteer who will be trained via training offered by participating adult literacy programs in San Diego County.
 - c. Assign trained volunteers to various healthcare settings to be advocates for low-literate patients. Pilot test the program at a medical facility (e.g., waiting room, pharmacy, etc.)
 - d. Co-supervision of the volunteers by the adult literacy program and the assigned healthcare setting.
 - e. Train volunteers to help patients fill out paperwork, read prescriptions, and clarify any instructions given to them before or after appointments. This training will also include a component on liability issues relating to volunteers knowing the limits of their duties and not providing medical advice to patients. Volunteers might also conduct workshops.



Outpatient
Paciente Ambulatorio

Recommendations

7. Create a marketing campaign. \$\$\$
 - a. Create a campaign logo and slogan
 - b. Create an implementation plan
 - c. Define the audience
 - d. Promote programs such as Ask Me 3, the Teach back Method, Health Literacy Month, etc.
8. Implement health literacy sharing forums. These sharing forums will include. \$\$
 - a. Healthcare professionals (i.e. physicians, nurses, administrators, office staff, paraprofessionals)
 - b. Adult literacy learners
 - c. Adult literacy practitioners (program coordinators, classroom teachers, administrators, volunteer tutors)
9. Investigate the inclusion of multimedia formats to improve the health literacy of San Diego County adults. \$\$
 - a. Locate and research current health literacy videos, websites and CD-ROMS that might improve health literacy.
 - b. Examine the current use of kiosks and interactive games in healthcare settings.

Appendices

Appendix A: Adult Literacy and English as a Second Language Providers in San Diego

The following programs are a sampling of adult literacy programs that are offered in San Diego County. The programs listed below participated in this project and were key informants during this process. For a complete listing of adult literacy programs in San Diego County, please access the SDCOL website: <http://www.literacysandiego.org>.

Carlsbad City Library - Adult Learning Program

Description: The Carlsbad Adult Learning Program provides one-on-one literacy services in Carlsbad to English-speaking adults from north coastal San Diego County. The program also provides literacy tutoring to selected high school students.

Oceanside Public Library - Oceanside READS

Oceanside READS provides one-on-one tutoring for adults over the age of 18, as well as computer assisted literacy services to English-speaking adults who work or reside in the City of Oceanside. It also has a youth literacy program for children in grades one through 12 who are below grade level.

San Diego Public Library- READ/San Diego

This program provides one-on-one tutoring and computer assisted literacy services for English-speaking adults 18 years of age and older throughout the City of San Diego. They also provide family and workforce literacy services. Family literacy programs exist at Malcolm X Library, Weingart/City Heights Library, Serra Mesa Library and College Heights Library. General tutoring takes place in any of the city's 35 libraries and in the following community learning centers:

- Old Town- Ballard Parent Center
- Clairemont Mesa- Clairemont Lutheran Church,
- Hillcrest- CSSE (Center for Social Support and Education)
- Rancho Penasquitos- North County Learning Center at Canyon Rim Apartments
- Valencia Park- READ/San Diego
- Downtown- St. Vincent de Paul Village

Appendices

Adult Basic Education

One community college district and one high school district that participated in this project provide free literacy services for learners who need to study for the their General Education Development (GED), high school diploma, computer skills, and ESL. Adults attend classes that are taught by paid instructors. The following is a list of participating ABE/ESL adult and continuing education schools:

San Diego Community College Auxiliary Organization- Even Start Program

This program provides family literacy services to children ages birth to 7 and their parents within the San Diego Unified School District.

San Diego Community College District - Continuing Education

This program provides classroom instruction at beginning (grade levels 0-3) and intermediate (grade levels 4-6) basic skills levels in reading, writing, math, spelling, and vocabulary, pre-GED, high school diploma, GED and ESL at six locations throughout the City of San Diego. The locations include:

- Center City 1400 Park Blvd., San Diego, CA 92101
- Cesar Chavez Center 1960 National Ave., San Diego, CA 92113
- Educational Cultural Complex 4343 Ocean View Blvd., San Diego, CA 92113
- Mid-City Center 3792 Fairmount Ave., San Diego, CA 92105
- North City Center 8401 Aero Dr., San Diego, CA 92123
- West City Center 3249 Fordham St., San Diego, CA 92110

Sweetwater Unified High School District, Division of Adult & Continuing Education

This program provides classroom literacy, high school diploma, GED, and English language instruction to adults in Bonita, Chula Vista, National City, San Ysidro, and Imperial Beach.

Community-Based Adult Literacy Services

Community-based literacy programs are the most diverse in the services they provide. The two programs participating in this project are both ESL programs. Both programs are free and serve mainly immigrants and refugees:

International Rescue Committee (IRC) – First Things First & Students Plus

The International Rescue Committee provides literacy services for women and children who are political refugees. Programs include ESL instruction, life skills training, family literacy, homework help, and small group literacy activities. Their programs are located in City Heights and El Cajon.

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Laubach Literacy Council of San Diego County, Inc.

The Laubach Literacy Council provides one-on-one and small group English language literacy instruction to limited and non-English-speaking adults throughout San Diego County. Laubach Literacy has learning centers in the following cities:

- Campo
- Carlsbad
- Chula Vista
- Clairemont
- El Cajon/College Area
- Encinitas
- Escondido
- Fallbrook
- Lakeside/La Mesa
- Pauma Valley
- Rancho Bernardo
- Rancho Penasquitos
- San Diego/La Jolla
- San Marcos
- Solana Beach
- Vista

Appendices

Appendix B: Healthcare Providers and Assets in San Diego County

The following is a comprehensive list of healthcare providers in San Diego County. This list includes a detailed description of the services and populations they serve.

Physicians

Currently, there are over 5,700 physicians practicing medicine in San Diego County. Of these, over 1,400 are primary care physicians (family practice, internal medicine and pediatrics), who typically are the physicians with whom patients have an ongoing relationship (their medical home). Additionally, there are approximately 1,300 physicians providing specialty services, ranging from general surgery to psychiatry, who patients may see for episodic care.

Physicians have access to a variety of resources to help them deal with low health literacy. One that is easily accessible by all physicians is the Health Literacy Kit offered by American Medical Association Foundation. The Health Literacy Kit offers an educational program to physicians designed to help them understand the full scope of health literacy. The program's stated educational objectives include:

- To understand the full scope of health literacy
- To recognize health system barriers faced by patients with low health literacy
- To improve verbal and written communications to patients
- To create a "shame-free" environment for patients

The kit is available to all physicians at <http://www.ama-assn.org/ama/pub/category/9913.html>

Community Clinics

There are 18 community clinic organizations with over 90 clinic sites located throughout San Diego County. During 2004 these clinics had over 422,000 patient care visits. The patients using the community clinics tend to be lower income, have no medical insurance coverage or have insurance provided through the state Medi-Cal program. Depending on the clinic's location, the racial and ethnic mix of patients range from 86% Latino at the San Ysidro Health Center to 43% Asian/Pacific Islander at Operation Samnahan located in National City. A high percentage of patients using the community clinics also speak English as their second language.

Community clinics are an intricate part of the healthcare safety net in San Diego County, providing health care services to patients who typically rank low on both the literacy and health literacy assessment. The Council of Community Clinics, a non-profit organization supporting the community clinic organizations, is currently completing needs assessments related to interpreter services and language access in San Diego Community Clinics with

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the goal of improving access to care and the quality of care for non-English speaking patients. Sponsored by a grant from The California Endowment, many aspects of this assessment relate closely to the communication skills of providers and health literacy. Because of their increasing awareness about the importance of effective communications, the community clinics offer an excellent opportunity to work collaboratively with SDCOL in the development of programs and tools designed to improve communication skills with low literacy patients.

Hospitals

There are 20 acute care hospitals located throughout San Diego County. During 2005, San Diego County hospitals discharged 299,352 patients. In terms of discharges from acute care, a significant proportion of patients served are those who typically rank low in health literacy assessments. These patients include:

- Persons aged 65 years or older – 93,725 discharges (31.3% of 2005 patient discharged)
- Latino – 82,957 discharges (27.7% of 2005 patient discharged)
- Medi-Cal insurance – 58,922 discharges (19.7% of 2005 patient discharged)

Additionally, hospital emergency departments discharge between 500,000 and 600,000 patients annually. A significant number of these patients are those who typically rank low in health literacy assessments. These patients include:

- Persons aged 65 years or older – (14% of hospital emergency department discharges)
- African Americans – (9% of hospital emergency department discharges)
- Latino – (27% of hospital emergency department discharges)
- Medi-Cal insurance – (18% of hospital emergency department discharges)
- No insurance – (16% of hospital emergency department discharges)

There is a growing awareness among hospital leaders nationally that patient-centered communication with vulnerable populations is critical to improving the quality of care delivered by hospitals and an effective means of reducing the cost of care. In a recent report by the Health Research and Educational Trust, an affiliate of the American Hospital Association, "Report of The National Steering Committee on Hospitals and the Public's Health," September 2006, one of several recommendations made was that hospitals need to become more aware of low literacy and begin using clear language. Additionally, hospitals are encouraged to provide effective language assistance services to those unable to communicate effectively in English and be more aware of cultural diversity.

Discussions with key stakeholders at several large San Diego based hospitals reveals an awareness of the low literacy and health literacy issues and a willingness to actively address the issue. These stakeholders feel there is an outstanding opportunity to begin

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developing a community-wide approach among hospital-based providers (physicians, nurses and other direct care professions) to actively address the awareness of health literacy issues and develop strategies to overcome some of the barriers such as the use of complex oral and written communications with the lay public.

Military Healthcare System

The military healthcare system including the Naval Hospital and clinics and the VA Hospital and clinics serve over 100,000 active duty service personnel and an unknown, but substantial number of retired military in San Diego County.

Other Types of Treatment Services

There is a wide array of other outpatient treatment services and inpatient facilities located throughout the county including:

- Home health agencies (61 agencies)
- Mental health facilities (18 inpatient and 91 outpatient)
- Substance abuse treatment facilities (7 inpatient, 67 residential and 80 outpatient)
- Homeless services (140 organizations offering services to the homeless)
- Assisted living facilities (87 facilities)

While little information is available describing the populations served by these organizations, it is assumed that many of the people served typically rank low in health literacy assessments. These include:

- Age 65 and over
- Poor overall health
- Covered by Medi-Cal or having no medical insurance
- Low income

The opportunity with these organizations is to assist them in the development of tools to help identify persons using their services who have low levels of literacy or health literacy. Once identified, these individuals can be referred to community organizations for programs that can address their specific literacy issues.

American Indian Health Services Agencies

Eight different organizations offer the potential to address low health literacy issues among the American Indian population within San Diego County. These include:

- Indian Health Council, Inc.
- Indian Health Council, Santa Ysabel Clinic
- San Diego American Indian Health Center

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- San Diego American Indian Health Center, Behavioral Health Department
- San Pasqual Band Of Mission Indians
- Southern Indian Health Council Campo Clinic
- Southern Indian Health Council
- Viejas Indian School

Advocacy and Community Service Agencies

There is a wide range of health related services offered by a variety of social and community service agencies located throughout San Diego County. The following are some of the agencies that could impact the health literacy of persons to whom they provide services. Populations served by these organizations include the elderly, homeless, persons with drug dependency and mental illness and youth.

- Catholic Charities
- Episcopal Community Services
- Ecumenical Council of San Diego
- Jewish Family Services
- SAY San Diego
- Alzheimer 's Association
- Lutheran Social Services
- Interfaith Community Services
- San Diego Rescue Mission
- St. Vincent de Paul Village
- The Salvation Army
- Vietnam Veterans of San Diego
- Brother Benno's Foundation
- Volunteers of America
- YMCA and YWCA

Medical Insurance Providers

Medical insurance providers offer a unique opportunity to address the health literacy needs of the populations they serve. Based on a 2005 estimate, 2,571,000 persons representing 86.9% of San Diego County's population are covered by some form of medical insurance. Those insured with Medi-Cal insurance account for approximately 269,000 (9.1%) persons. Additionally there are 60,000 children enrolled in the Healthy Families program. For this population, six medical insurance companies provide much of the coverage. The Healthy Families providers include:

- Community Health Group

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- Molina Health Plan
- Health Net
- Blue Cross
- Blue Shield
- Care1st Health Plan
- Kaiser Permanente

Currently, insurance companies that offer coverage as part of the Healthy Families program are required by the State of California to address readability of their forms and brochures. The Healthy Families insurance companies are currently working together on this issue. Because this is required by the state, there is an opportunity to work with this group to help them improve their understanding of health literacy and the practices they are implementing with their providers to better meet the health literacy needs of patients. Much of the focus of this group is on non-English materials and cultural issues. Working collaboratively with these organizations will be critical to the success of any health literacy improvement effort in San Diego County.

An estimated 334,000 seniors living in San Diego County receive their medical insurance coverage through Medicare. Based on the 2003 NAAL data, approximately 29% of persons age 65 and over scored below basic on health literacy. Seniors on Medicare are presented with an array of options including health maintenance organizations (HMOs), preferred provider organizations (PPOs) and traditional private fee-for-service plans. Many seniors find making decisions related to selection of a plan confusing and frustrating because of the various restrictions, limitations and requirements associated with each type of plan. Some of the organizations offering these plans are acutely aware of the problems seniors face and are actively working on solutions. The following is a list of the major providers of these plans to seniors in the San Diego market:

- Kaiser Permanente
- Health Net
- SecureHorizons
- Advantra Freedom
- Aetna Medicare
- Blue Cross
- Humana
- SCAN Health Plan
- Today's Option
- WELLCARE

Medical insurance providers are a major asset for addressing health literacy in San Diego

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County because they have the ability to reach such a large segment of the population with their newsletters, publications and other activities.

County of San Diego Health and Human Services Agency

The County of San Diego offers a wealth of healthcare related programs that provide care and services to those with the lowest levels of health literacy. Working collaboratively with these programs will be critical to the success of any health literacy improvement effort in San Diego County. Several of the key programs that must be included are:

- Aging and Independence Services
- Behavioral Health
- Children's Services
- Public Health
 - AIDS
 - Immunization
 - Maternal, Child and Family Health
 - California Children's Services

Pharmacies

Pharmacists offer an outstanding opportunity to access patients. Because most pharmacists are in the private sector and employed by large corporations, the process of including them in this project will be long term.

Other assets

The category of other assets ranges from potential funding sources for the operation of the health literacy projects to affiliation and collaboration with health literacy programs operating regionally and nationally. Some of these include:

- National assets include the following organizations that are actively exploring health literacy issues and have produced a variety of advocacy materials.
 - The Joint Commission <http://www.jointcommission.org>
 - Partnership for Clear Health Communication <http://www.npsf.org/pchc/>
 - American Medical Association <http://www.ama-assn.org/ama/pub/category/8115.html>
 - Harvard School of Public Health <http://www.hsph.harvard.edu/healthliteracy>
 - National Patient Safety Foundation <http://www.npsf.org>
 - National Institutes of Health <http://www.nih.gov/icd/od/ocpl/resources/improvinghealthliteracy.htm>

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- Institute of Medicine of the National Academies <http://www.iom.edu/?id=19750>
- State and regional assets include a variety of organizations across the United States that are addressing health literacy issues. These include:
 - The El Paso Collaborative has developed a health literacy curriculum available at <http://healthliteracy.worlded.org/docs/el Paso/>
 - Iowa Healthcare Collaborative <http://www.ihsdesmoines.org>
 - Virginia Adult Education Health Literacy Toolkit <http://www.aelweb.vcu.edu/publications/healthlit/>
- Potential funders may include:
 - First 5 Commission of San Diego
 - The California Endowment
 - Alliance Healthcare Foundation
- Affiliation and collaboration
 - Ask Me 3 – Sponsored by the Partnership for Clear Health Communication (PCHC), a national, non-profit coalition of organizations working to build awareness and advance solutions to improve health literacy and positively impact health outcomes.
 - AMA Foundation’s Health Literacy Train-the-Trainer program.
 - California Health Literacy Initiative - Launched by California Literacy in 2003 with its goal to inform and partner with individuals and organizations to craft collective and lasting solutions that will positively impact the health and well-being of individuals with low literacy skills, their families, and their communities.

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Appendix C: National Promising Practices

The following list is the result of a nationwide search for promising practices in the area of health literacy. This list is not meant to be a comprehensive list of all the health literacy services/initiatives in the United States, but rather a list of promising practices that could inform this project.

The ALE Wiki http://wiki.literacytent.org/index.php/Health_Literacy

This website provides adult literacy professionals a forum to share ideas from the classroom and the from empirical research. Topics include English language learning, numeracy, and adult basic and secondary education. The ALE Wiki is a community of practice with links to research for practitioners, researchers, learners and others. Discussions are archived which have taken place on electronic lists elsewhere.

Iowa Healthcare Collaborative <http://www.ihsdesmoines.org>

The Iowa Healthcare Collaborative (IHC), in cooperation with health care providers across the state, has developed a Health Literacy Toolkit. The toolkit is a compilation of resources to support the understanding of Health Literacy and the importance of improved health communication.

Literacy Partners of Manitoba <http://www.plainlanguage.mb.literacy.ca/index.htm>

The Literacy Partners of Manitoba help people improve their literacy skills. They urge organizations to write simply and clearly so that more readers can understand the message. They offer a structural and copy editing service, which reorganize health material to be logical and convincing.

The Literacy Partners of Manitoba offer training sessions in plain language communication, ranging from a short introduction to a full day session. These courses teach participants how to prepare well laid out documents in a language that people really understand.

New York City Mayor's Office of Adult Education <http://www.nyc.gov/adult-ed>

The Mayor's Office of Adult Education was established in 2006 to create better outcomes for the City's adult education system. The office coordinates strategy, promotes best practices, and connects participating agencies to the administration's education, community development, and social policy priorities. The office works with a range of city, state, and federal agencies to advance adult education in New York City.

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The Rhode Island Health Literacy Project (RIHLP) <http://www.rihlp.org>

A statewide coalition of public health, adult education, and medical organizations formed in July 2005. The primary objectives of the coalition are:

- To collaboratively develop and execute health literacy initiatives aimed at increasing the health literacy level of all Rhode Islanders, and
- Increase the size of the population who understand health information and self-care instructions.

The mission of the RIHLP is, through a collaborative approach, to heighten awareness of health literacy issues so that all Rhode Islanders better communicate and understand health information, treatment options, and self-care instructions.

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Appendix D: A National List of Websites Informing the Development of Patient Materials

The following list will be useful to health literacy professionals/researchers who are looking for resources to help aid the development of health related materials.

Development of Patient Education Materials

Clear and Simple: Developing Effective Print Materials for Low Literate Readers

<http://cancer.gov/cancerinformation/clearandsimple>

The National Cancer Institute has developed this guide, outlining a process for developing publications for people with limited-literacy skills. The process was derived from communications, health education, and literacy research and practice. In addition, writers who have produced low-literacy materials contributed their expertise. Thus, the guide features both proven principles and a discussion of the real life issues that individuals developing low-literacy materials face, such as the constraints of time, budget, organizational pressures, and the Government publications process.

Consumer Health: An Online Manual

<http://nnlm.gov/outreach/consumer/index.html>

From the National Network of Libraries of Medicine, this manual provides information for librarians on their roles in health literacy.

Patient Education: An Author's Guide

<http://www.med.utah.edu/pated/authors/>

The University of Utah has compiled a useful guide on all aspects of writing for patients.

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Appendix E: Online Health Literacy Videos

The following online videos will be useful to those who looking for training tools.

Online Videos

AMA Foundation's Health Literacy Video

<http://www.ama-assn.org/ama/pub/category/8035.html>

The 20-minute video, also included in the AMA's Health Literacy Introductory Kit, can be viewed in its entirety at this link. It is designed to raise awareness and spark discussion about patients' low health literacy skills.

In Plain Language—Rima Rudd

<http://www.hsph.harvard.edu/healthliteracy/overview.html#TWO>

In Plain Language was produced by Dr. Rima Rudd and Dr. William De Jong, with a team of health literacy studies professionals and researchers from the Harvard School of Public Health's Health Literacy Studies Program. This 15-minute video/DVD was developed for medical and public health professionals who are interested in learning about adult literacy in the U.S. and implications for medicine and for public health.

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Appendix F: Health Literacy Websites

The following list will be useful to health and literacy professionals who are looking for more resources related to health literacy from a wide variety of resources .

Agency for Healthcare Research and Quality (AHRQ)

Literacy and Health Outcomes. 2004 comprehensive report on literacy and health.

Full report: <http://www.ahrq.gov/downloads/pub/evidence/pdf/literacy/literacy.pdf>

The American Medical Association Foundation

Health literacy toolkits available at <http://www.ama-assn.org/ama/pub/category/8115.html>

Videos titled: Low Health Literacy: You Can't Tell By Looking (18 minutes) and

Health Literacy: Help Your Patients Understand (23 minutes) may be downloaded for free at: <http://www.ama-assn.org/ama/pub/category/8035.html>

The Center for Health Care Strategies, Inc.

The Center for Health Care Strategies, Inc. prepared the fact sheets in 1997, which were revised in 2003. They include: What is Health; Who Has Health Literacy Problems; Impact of Low Health Literacy Skills on Annual Health Care Expenditures; Health Literacy and Understanding Medical Information; Strategies to Assist Low-Literate Health Care Consumers; Preparing Patient Education Materials; Tools to Evaluate Patient Education Materials; Health Communication and Cultural Diversity; Resources for Health Literacy Information and Publications; and a Bibliography.

<http://www.chcs.org/>

Coalition for Health Communications

The primary goal of the Coalition for Health Communications is to serve students, scholars, and practitioners with a focal point for information relevant to the research, study, teaching, and application of health communication.

<http://www.sla.purdue.edu/healthcomm/>

Food and Drug Administration

Easy to read publications in English and Spanish

<http://www.fda.gov/opacom/lowlit/7lowlit.html>

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The Harvard School of Public Health: Health Literacy Studies Web Site

Has a variety of health literacy materials including a section on how to create and assess print materials.

<http://www.hsph.harvard.edu/healthliteracy/>

Health Canada

Health Canada is the federal department responsible for helping the people of Canada maintain and improve their health. The site includes literacy-related information and papers. (In English and French.)

<http://www.hc-sc.gc.ca>

Health Literacy Consulting

This home page for Health Literacy Consulting links to health literacy tips, articles and resources, information about the services of the organization, and tools to raise people's awareness about the importance of health literacy.

<http://www.healthliteracy.com>

Health Literacy Month

The Health Literacy Month provides tools to raise people's awareness about the importance of health literacy. All the articles on this site are written by health literacy advocates. Some are clinicians; some are adult educators. Others are consultants, researchers, and administrators.

<http://www.healthliteracymonth.com/>

Health Literacy Project

The Health Literacy Project offers information on programs, services, and materials (including Literacy, Health, and the Law: An Exploration of the Law and the Plight of Marginal Readers within the Health Care System: Advocating for Patients and Providers.)

<http://www.hpcpa.org/hlp.html>

Health Literacy Public Health Forums: Partners for Action. Rima E. Rudd and Emily K. Zobel

This guide was designed to assist public health professionals and members of departments of health to conduct a forum on health literacy and thereby raise awareness about health literacy and links to health outcomes.

<http://www.ncsall.net/index.php?id=899>

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Health and Literacy Special Collection

This is an excellent health literacy resource with information for teachers and students, links to many sources of written health information, some health related curriculum topics and Family Health and Literacy: A Guide To Easy-to-Read Health Materials and Web Sites.

<http://healthliteracy.worlded.org/index.htm>

Initial National Adult Assessment of Literacy Results

A First Look at the Literacy of America's Adults in the 21st Century

<http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006470>

The Institute of Medicine

The IOM report Health Literacy: A Prescription to End Confusion may be read for free or purchased at: <http://www.nap.edu/catalog/10883.html>

Joint Commission

2006 Hospital requirements related to the provision of culturally and linguistically appropriate health care. http://www.jointcommission.org/NR/rdonlyres/A2B030A3-7BE3-4981-A064-309865BBA672/0/hl_standards.pdf

Medline Plus

How to Write Easy to Read Health Materials. Excellent resource with step by step instructions

<http://www.nlm.nih.gov/medlineplus/etr.html>

Interactive tutorials with audio about a large number of health topics, tests and diagnostic procedures:

<http://www.nlm.nih.gov/medlineplus/tutorial.html>

National Adult Literacy Database

A Canadian site with a variety of publications and resources from a Canadian perspective. Materials available in French.

<http://www.nald.ca>

National Cancer Institute

Clear & Simple: Developing Effective Print Materials for Low-Literate Readers, step by step guide

<http://www.nci.nih.gov/cancerinformation/clearandsimple>

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National Center for Educational Statistics

The Health Literacy of America's Adults:

Results from the 2003 National Assessment of Adult Literacy (NAAL)

<http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483>

National Institute on Alcohol Abuse and Alcoholism

A variety of easy to read materials about alcohol related topics

<http://www.niaaa.nih.gov/Publications/PamphletsBrochuresPosters/English/default.htm>

National Institute of Diabetes & Digestive & Kidney Diseases

"What I need to know about Eating and Diabetes" in English and Spanish

http://diabetes.niddk.nih.gov/dm/pubs/eating_ez/index.htm

National Institute for Literacy

Has a large searchable database of documents

<http://www.nifl.gov/>

National Women's Health Information Center

Some documents available in easy to read format, including bulimia and anorexia nervosa

<http://www.4woman.gov/faq/>

Plain Language.gov

Examples and tools for developing plain language materials

<http://www.plainlanguage.gov/>

Refugee Health Information Network

Health information in many languages for patients. Refugee health information for providers.

<http://rhin.org/>

SMOG (Simple Measure of Gobbledygook) Readability Calculator

Copy and paste text or entire document (up to 2000 words) and program calculates reading level.

http://linda-andrews.com/readability_tool.htm

<http://www.harrymclaughlin.com/SMOG.htm>

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University of Minnesota Bio-Medical Library

An extensive compilation of publications, web resources and articles about how to create patient education materials

http://courses.lib.umn.edu/page.phtml?page_id=839

Wisconsin Literacy, Inc.

Coordinates activities of Wisconsin Community-based Literacy organizations

<http://www.wisconsinliteracy.org>

Health Literacy PowerPoint with speaker notes by Paul Smith, MD and patient story video clip

http://www.wisconsinliteracy.org/news_article.php?id=3

Publications:

Teaching Patients with Low Literacy Skills. Doak, Doak and Root. This book is considered a classic text in health literacy, but is out of print. It is available free for download at: <http://www.hsph.harvard.edu/healthliteracy/doak.html>

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Appendix G: Summary of Recommendations

The following nine recommendations are presented in priority order as determined by the advisory committee. Some of these action steps may be carried out simultaneously.

Recommendation	Estimate Cost	Action Step
Establish, through the leadership of CHIP and SDCOL, a joint taskforce of literacy and healthcare professionals to champion the awareness of health literacy in the San Diego community.	\$ Minimal	One (Immediate)
Identify and/or create health literacy curricula for inclusion in adult literacy courses and healthcare settings.	\$\$\$ Expensive	Two
Create a SDCOL and CHIP sponsored website that would include resources and referrals for adult literacy and healthcare	\$ Minimal	Three
Develop appropriate methods, tools, and policies to help medical organizations train their front and back office staff to better understand and deal more effectively with low literacy and low health literacy adults.	\$\$ Moderate	Four
Increase awareness of low literacy and low health literacy issues within the healthcare community.	\$ Minimal	Five
Develop and implement a pilot program utilizing trained volunteers on-site in the healthcare setting to work as advocates for low literate patients.	\$\$ Moderate	Six
Create a marketing campaign.	\$\$\$	Seven
Implement health literacy sharing forums among healthcare professionals, adult learners and adult literacy professionals.	\$\$ Moderate	Eight
Investigate the inclusion of multimedia formats to improve the health literacy of San Diego County adults.	\$\$ Moderate	Nine

