**The California Health Literacy Initiative**
*A Project of California Literacy, Inc.*

# Low Literacy, High Risk:

*The Hidden Challenge Facing Health Care in California*

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## Executive Summary

The California Health Literacy Pilot Study reveals that for low literate adults in California, obtaining health care can be a process that is confusing, humiliating, dangerous and sometimes deadly. For low literate adults, every stage in the process of obtaining health care is a potential obstacle. Cumulatively, problems associated with filling out forms, comprehending written information, understanding verbally-communicated medical instructions, articulating health concerns to medical staff, and effectively pursuing treatment outside of the medical establishment make it difficult, and sometimes impossible, for low literate adults to obtain the care that they need. Because of these challenges, low literate adults often avoid or delay seeking needed health care. When they do seek care, they often have a difficult time actively participating in this care.

Many doctors and administrators surveyed recognized the devastating impact that low literacy has on their ability to successfully provide health care services. Almost all of the physicians surveyed reported that patients with low literacy receive a lower quality of care than do their patients with high literacy skills. Many physicians were aware of at least one case of a serious medical error that resulted from a patient's limited literacy skills. In fact, the survey of medical professionals and administrators revealed three reports of death as a result of communication barriers between the medical provider and the patient. Few of the physicians surveyed, however, considered

*(continued on page 3)*

# *Acknowledgements*

**Principal Investigator and Report Author:**
Dionne Bennett, PhD

**Editor and Project Manager:**
Beccah Rothschild, Health Literacy Manager, California Literacy, Inc.

**Research Team:**
Faith Ruperto, Health Literacy Coordinator, California Literacy, Inc.
Molly Klarman, Health Literacy Coordinator, California Literacy, Inc.

**Contributor:** Dean Schillinger, M.D., Soros Advocacy Fellow, The Open Society Institute

**Graphic Designer:** Daniel Pedroza, Systems Administrator, California Literacy, Inc.

**Media Liaison:** Ken David, Communications Manager, California Literacy, Inc.

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**Executive Director:** Lisa Bennett-Garrison
**Statewide Programs Director:** Matthew Scelza

California Literacy, Inc.
133 N. Altadena Drive, Suite 410
Pasadena, CA 91107
(800) 894-READ
www.caliteracy.org

themselves equipped to address the literacy problems that are undermining their ability to serve their patients. Only a small percentage of physicians had received any health literacy training.

The issue of health literacy puts low literate patients at high risk on a daily basis. Low literate patients know this, as do physicians. However, more than half of the hospital administrators who participated in our pilot study, those who are responsible for implementing policy at the institutional level, feel that health literacy is given a low priority in California's current health system.

Based on suggestions from participants in the pilot study, there are multiple recommendations that we propose to lessen the problem of low health literacy in California. Some of these recommendations include allocating more resources to adult literacy organizations to provide health literacy instruction, developing effective interventions to avoid medical errors due to low literacy, forming partnerships between literacy- and language-access advocates, and creating quality standards and measures around health literacy which are accepted by the medical community at large.

## OVERVIEW OF LOW LITERACY IN HEALTH CARE

The state of California is suffering from a silent and invisible threat to the health of millions of its citizens. That threat is low health literacy. Health literacy is defined as "the capacity of an individual to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which are health-enhancing," (National Health Education Standards, 1995). While low health literacy can affect people who function at all literacy levels, low literate adults are at the highest risk of suffering from its sometimes devastating consequences. Our collective failure to address the health and literacy needs of millions of low literate adults is a significant source of what can only be described as a health care crisis.

The health care system that we all depend upon to preserve, and at times, save our lives, has been inadvertently designed for an educated populace. This has created what is frequently referred to as a "mismatch" between the high literacy levels required to successfully obtain quality health care and the significantly lower literacy levels of many patients. The negative consequences of this mismatch range from problematic to catastrophic.

However, the use of the term "mismatch" may grossly understate the issue. The health care system is an extremely complex cultural process that requires highly specialized knowledge to participate in successfully. Low literate adults who attempt to obtain health care are not just being asked to read, write, speak, and understand at high literacy levels; they are being asked to do all of these things while managing a large amount of specialized health-related information *and* they are being asked to do all of these things while attempting to navigate a complex health care system. Every professional that low literate adults encounter in this process has been trained, in some cases for years, to successfully access this information and to participate in this process. Low literate adults are *not* trained to understand health-related information or the health care process, so they are, for all intents and purposes, overlooked.

The process of obtaining even the most basic health care services includes participation in a number of activities. Each activity involves the use of a range of reading, writing, speech, and comprehension skills, which currently require extremely high literacy levels. The stages in the process of obtaining health care include, but are not limited to, the following: 1) Patients should be able to read, comprehend, and write forms that document medical history and current health concerns; 2) Patients should be able to verbally communicate health care concerns to medical staff; 3) Patients should be able to comprehend doctors and other medical staff as they verbally discuss treatment options and plans; 4) Patients should be able to read and comprehend treatment literature including prescriptions, pamphlets, Web-based resources, and other treatment instructions; 5) Patients should be able to act on the information read, written, spoken, and heard at every previous stage in the process.

If a patient has a serious or chronic illness, the stages in this process must be repeated for different health care specialists as additional stages are added for each element of their treatment. For low literate adults, the literacy demands of each and every stage in the process of acquiring health care presents unique and significant obstacles that are, at times, difficult to surmount. Collectively, these literacy obstacles make it difficult or impossible for low literate adults to take full advantage of health care services and to fully participate in their own care.

Contrary to prevailing notions of health care as an assembly line of "broken" patients that are "repaired" by doctors, successful health care demands that patients and medical professionals engage in a mutual dialogue that enables patients to play an active role in their own care. Low literate adults are denied this foundation of effective communication and as a result may be denied quality health care.

Within the United States, the term functional literacy describes "the ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society" (National Literacy Act of 1991). Literacy affects every single area of an individual's private and public life including education, employment, social relationships, and of course, health. In fact, literacy skills are a stronger predictor of health status than a range of other categories including, race/ethnicity, income, age, employment status, and educational level (Partnership for Clear Health Communication, 2003).

Yet, literacy is a skill that is often taken for granted unless one has been deprived of it. Low literacy may be misunderstood, in part, because many underestimate its pervasiveness. A conservative estimate places 24 percent of Americans at the lowest level of literacy (National Adult Literacy Survey, 1992). While low literacy is strongly associated with a number of other factors including poverty, education, age, and ethnicity, the majority of low literate adults are white Americans (National Adult Literacy Survey, 1992).

**Low literacy skills cost the United States an estimated $73 billion annually.**

In recent years, a national movement to address the problem of "health literacy" has developed. National research has revealed that low literacy skills cost the United States an estimated $73 billion annually in the form of longer hospital stays and increased emergency room visits, doctor visits, and medications (National Academy on an Aging Society, 1998). The health of more than 90 million Americans (one-in-three) may be at risk due to difficulties associated with low health literacy (Kirsch et al, 1993). Low literate patients have less knowledge about and greater difficulty managing chronic illnesses than high literate patients, (Schillinger et al, 2002; Baker et al, 1998), and a full 46 percent of public hospital patients cannot understand the label on their prescription medicine bottle (JAMA, 1999). In addition, only 50 percent of all patients take medications as instructed (Center for Health Care Strategies, 1997). This research suggests that low literacy has a profound effect on national health care.

Because the field of health literacy is relatively young, we are only beginning to witness efforts to assess its effects on state as well as national levels (Hohn, 2002). While a national agenda devoted to improving health literacy should be pursued, it should also be supplemented by state-based health literacy research and programming. Due to specific historical immigration patterns, each state features a unique demographic composition. Because literacy involves issues of cultural competency and language access in conjunction with particular language skills, the health literacy needs of each state should be addressed with some demographic specificity. Attention to health literacy on a state level may enable health literacy to be assessed more accurately based on specific demographic concerns and, as a result, health literacy solutions may be applied more effectively to meet local and statewide needs.

**24 percent of California's adults are considered functionally illiterate.**

California Literacy, Inc., a private non-profit adult literacy organization, has been serving low literate adults in the state of California since 1956. Twenty-four percent of California's adults are considered functionally illiterate (National Adult Literacy Survey, 1992). In addition to those who have been identified as functionally illiterate, millions more are challenged by varying degrees of low literacy, meaning that they possess literacy skills that are sufficient for them to function, but not for them to thrive.

California is one of the most ethnically diverse states in the union, and the wealth of that diversity is reflected linguistically. Five million adults in California (approximately 22 percent) speak a language other than English in their home (U.S. Census). While many of these adults are bilingual, others are still in the process of obtaining language proficiency in English.

While we fully acknowledge that language and literacy are difficult to separate, it is the goal of the California Health Literacy Initiative to expand the current discussion around language access and to explicitly include the challenges of literacy in this discussion. Throughout this report, the issues of language and literacy are often intertwined; we propose building a partnership between advocates for those populations which have difficulty navigating the health care system due to both language and literacy access issues. Within the confines of health literacy, there exist issues which result in a challenge of both language and literacy access. However, there are also challenges in health care navigation and management that exist solely because of lack of literacy skills.

As demonstrated, there exists an astoundingly high number of adults in California who are functioning at low levels of literacy. However, multiple studies show that the current adult education system provides classes and instruction for only about 11 percent of these adults. Within California, approximately 500,000 adults receive English as a Second Language instruction each year, and only 55,000 receive Adult Basic Education instruction each year (California Department of Education, July 2003). The adult education system is clearly underfunded, and collaborations with the healthcare system can only help in addressing and attacking this issue.

Low literacy is a complex phenomenon characterized by a range of causes and consequences. By focusing on health literacy within the state of California, California Literacy, Inc. hopes to develop resources that will meet the unique needs of California's low literate adult communities and, consequently, serve to improve the overall quality of health care throughout the entire state.

## California Health Literacy Initiative Pilot Study

In an effort to focus attention on the unique health care challenges faced by low literate adults in the state of California, California Literacy, Inc. developed the California Health Literacy Initiative, a multi-year project whose goals include improving the quality of health care for low literate adults, raising public consciousness about health literacy, and compelling politicians and legislators to place health literacy at the top of California's state agenda.

In order to ensure an accurate assessment of California's unique health literacy concerns, one component of the California Health Literacy Initiative has been the development of this pilot study. This pilot study was designed to:

1. Investigate how literacy impacts the health care experiences of California's low literate adult patients
2. Assess how health literacy is being addressed by physicians and administrators as these patients seek health care services
3. Create a foundation for future research

The study mixed quantitative and qualitative methodologies to survey 102 low literate adults, 64 physicians, and 16 hospital and clinic administrators throughout the state.

## LOW LITERATE ADULT INTERVIEWS
### Methodology

Low literate adults who participated in this study were recruited from adult literacy programs throughout California. The vast majority of these adults read below the sixth-grade reading level and have self-identified as struggling with literacy skills. California Literacy, Inc. has relationships with over 200 adult literacy organizations throughout the state of California, some of which assisted in obtaining respondents for the study.

Fifty-one adult learners participated in face-to-face interviews or one-on-one semi-structured telephone interviews; 50 of these interviews were conducted in English, and one was conducted in Spanish. The types of questions asked were both open- and closed-ended, and delved into issues such as their biggest challenges in managing their health care, the type of help they would like, the types of creative solutions they have used, and whether or not their medical provider knows about their struggle with reading, writing, and/or communication.

Thirty of these participants were women and 21 were men. Twenty-nine of the 51 were bilingual speakers of English and another language; these other languages included Spanish, Cantonese, Mandarin, Hindi, Japanese, and Ahta & Apatua.

An additional 52 adult literacy students participated in six focus groups. Thirty-seven of these participants were women and 15 were men. Fourteen of the focus group participants spoke English as a first language; other languages spoken by the participants include Vietnamese, Tagalog, Spanish, Portuguese, and Russian.

All six focus groups conducted for the pilot study included individuals who spoke English as a Second Language (ESL), and three of them were conducted in Spanish exclusively with women who spoke Spanish as their first language. All focus groups consisted of individuals enrolled in adult literacy programs except for one; this focus group was conducted exclusively with ten men who were confined to a correctional facility. Although only two of the ten men had enrolled in literacy programs, nine of the ten men in the correctional facility focus groups identified themselves as struggling with low literacy skills. Several of these men were signed up for literacy education by the facility's literacy supervisor during the course of the focus group. The questions for the adult literacy student focus groups were similar to those used in the one-on-one surveys.

Racial and ethnic groups represented in the one-on-one interviews and focus groups included individuals who were African American, Latino, White, and Asian American or Pacific Islander. All participants in both the focus groups and one-on-one interviews had experience with the U.S. health care system within the past 18 months.

## RESULTS FROM LOW LITERATE ADULTS

## Paperwork as a Barrier: Delaying or Avoiding Needed Health Care

*"Not being able to read has a lot to do with health."*
—A Latina woman in her 50s who participated in the Pilot Study

This statement, made during one of the interviews with low literate adults, is one of the most significant lessons of this research. One of the first things that any patient encounters in an effort to obtain health care is paperwork. Patients must fill out personal and insurance information as well as detailed descriptions regarding their medical and treatment history. For most patients, this paperwork is a necessary irritation. For low literate patients, paperwork can function as a seemingly insurmountable barrier.

The patients we interviewed identified difficulties with reading and filling out forms as one of the greatest literacy challenges they face in their effort to obtain health care. Some patients have difficulties with both reading and writing, and others with one or the other, though writing generally appears to be more challenging. Eighty percent had trouble completing medical paperwork, and 45 percent considered completing medical paperwork one of their greatest health literacy challenges. One individual simply stated, "By far, the paperwork is the hardest." Seventy-seven percent of respondents claimed to have

**"I'm afraid of that paperwork."**

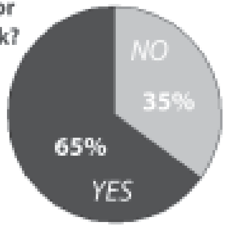
difficulty reading medical information such as brochures, pamphlets, and instructions from medical staff, and 35 percent considered reading medical information to be one of their greatest health literacy challenges.

The difficulties vary for each patient depending on their skills, their relationship with medical staff, and their support networks. Many patients ask for help from receptionists, nurses, other patients, or family members who accompany them. Others stumble through the process, simply answering the questions that they can. Still others dissemble. As one patient explained, she repeatedly tells the receptionist that she has "forgotten her glasses."

Anxiety produced by difficulties with paperwork may prevent low literate adults from seeking care at all. Sixty-five percent of participants reported avoiding going to the doctor because of difficulties associated with completing paperwork. As one patient explained, "I procrastinated and it prolonged my illness. I had to have someone go with me to the doctor and had to set my appointments around my family's schedule. I want to know by myself, but I have to depend on my family." Conversely, other patients made multiple trips to the doctor, first to pick up paperwork and then to return it after going home to obtain assistance with completion of forms or to use the dictionary to complete forms. One patient described the following process: "When I couldn't fill out a form, I would just leave [the office] or try to memorize what was on the form for later, so I could prepare the answers." Whether patients avoid going to the doctor or must make repeated visits in order to complete their paperwork, difficulties associated with filling out forms cause delays in care and anxiety about seeking it. One focus group participant simply explained, "I'm afraid of that paperwork."

**65% of participants reported avoiding going to the doctor because of difficulties associated with completing paperwork.**

Have you ever avoided going to the doctor because you had difficulties with the paperwork?



**...when low literate adults cannot find someone to escort them, they often fail to seek care for a medical issue.**

After patients fill out forms and meet with physicians, they often face more paperwork in the form of pamphlets, prescriptions, and medical instructions, which many low literate adults have difficulty reading and understanding. The following comments from adult literacy students about reading indicate the impact that difficulties with reading and filling out paperwork may have on health:

> *"I want to say I'm allergic to something, but I don't know how to write it."*

> *"I have trouble reading everything with regards to health. It's hard to even read my mail."*

Low literate patients may rely on family members and other support networks to assist them with reading and filling out paperwork. This requires them both to have access to these networks and to admit to those individuals that they have difficulty reading. This is something that some low literate adults are, reasonably, reluctant to do. As indicated by the two comments below, several individuals presented concerns related to the dependency that results when they must ask family and friends for help:

> *"Filling out paperwork is hard. Sometimes my friend can't make it, so I put off my going until a friend can come with me."*

> *"I want to get help, but it's a pain because I need to rely on others."*

Like the participants in the individual interviews, focus group participants were extremely frustrated by paperwork. At the focus group that featured men in a correctional facility, three of whom spoke English as a second language, eight of the ten participants reported skipping questions while filling out paperwork. None of those who did this attempted to fill in the missing information at a later period during their appointments. Six of the ten men reported making up answers to questions on medical forms when they did not know they answer. In every focus group, reading and filling out paperwork were listed as significant obstacles to obtaining care. One gentleman from the correctional facility confessed, "I'm scared of that paperwork."

The literacy levels of forms are a factor, as is the language in which they are written. In one focus group, some Spanish-speaking adults who had high Spanish literacy and had access to bilingual forms found them much less difficult to manage. One participant explained, "If forms are in Spanish, it's easier to fill out, but in English—it's impossible." These individuals also reported fewer problems with prescriptions as the instructions on their medications were written in Spanish.

## Paperwork as a Barrier: Interpretations and Recommendations

Based on the results of the pilot study, it is clear that paperwork is a significant barrier which low literate adults face when seeking health care and managing their health. Based on these findings, we propose three recommendations:

1. Create, use, and distribute more plain language materials.
2. Reduce paperwork. One such way to do so is by developing innovative technology to obtain and deliver health information in a user-friendly fashion.

3. Work with adult literacy and education providers to create methods which lessen the burden of such paperwork on low literate patients.

The first suggestion, create, use, and distribute more plain language materials, is one area in which some efforts are already being made. Plain language materials, or materials written at a widely accessible reading level, generally below the eighth-grade reading level, are employed by some facilities. Unfortunately, many plain language materials are still written at a level that exceeds the skills of many low literate adults. On average, health messages are composed at reading levels at least five grades higher than most patients' reading abilities (Davis, T.C., Crouch, M.A.,, Willis, G., Miller, S., & Abdehou D.M., 1990).

In addition, the focus group results, when assessed in conjunction with data from the individual interviews, indicate that efforts to provide accessible paperwork should do more than include bilingual forms in English and Spanish. These efforts should include the provision of bilingual forms in the different languages as well as forms written in plain language. There is diversity in the literacy skills for speakers of every language. Individuals who struggle with low literacy in both their first and second language, as was the case for several of the men in the correctional facility, are doubly disadvantaged. Thus, efforts to generate plain language materials should ensure that plain language is utilized for *every* language in which such materials are produced.

When low literate patients receive written instructions *in place of* verbal explanations, they are being set up to fail in the treatment of their illnesses. Being provided with excessive paperwork or instructed to do internet searches not only prevents patients from learning critical information about their health in a timely fashion, it also may serve to intimidate them or humiliate them if, for example, they don't have access to a computer or the skills required to use one.

Low literate patients may be reluctant to place the burden of asking their families and friends for help with medical paperwork, and they may be frustrated by the dependent position in which it places them; if health care providers could offer assistance to those who so desired it in filling out their paperwork, perhaps this burden would be lessened. As one adult literacy student said, "I'd like it if there was somebody designated to help me with forms, so I don't have to disrupt my wife's life and time to come help me."

The above sentiments illustrate two issues. First, there is a need for many low literate adults to depend on having a friend or family member escort them to medical appointments. Second, when low literate adults cannot find someone to escort them, they often fail to seek care for a medical issue.

Moreover, these materials do not address the problems of patients who struggle with writing as well as reading comprehension. While many paperwork omissions may be addressed verbally at a later time, the risk of critical information being omitted, such as allergies to particular medications, is increased when paperwork cannot be successfully completed.

The second recommendation, to develop innovative technology to obtain and deliver health information, should be explored. One example of this technology is kiosks with touch-screen prompts. In this example, patients may be prompted either verbally or via pictures and simple words to enter necessary information. Upon receiving this information, the kiosk could disperse any appropriate health materials. The development of such technology presents a powerful way for the public and private sectors to partner and collaborate.

The third recommendation, that of working with adult literacy and education organizations to lessen the burden of paperwork on low literate patients, can be done through additional classroom work. For example, adult literacy and education teachers can offer classes on how to fill out forms. They can also offer suggestions to their students, such as bringing a copy of all personal and medical information with them to appointments; this method will make it simpler to copy from one form to another.

## I Don't Have the Words: Inability to Express Health Concerns

> *"I didn't know how to tell my doctor I felt weird. I didn't know how to put words to it."*
> —A Caucasian woman in her 50s who participated in the Pilot Study

After negotiating paperwork, the next stage in the process of obtaining care is the verbal articulation of the health care problems that bring low literate adults to the doctor or hospital in the first place. Forty-nine percent of adult literacy students interviewed reported having difficulty explaining their conditions to doctors. Twenty-seven percent of patients reported failing to go to the doctor due to difficulties associated with expressing themselves; these patients were all patients who, while English may not have been their native language, spoke and comprehended it well enough to be interviewed for this survey in English.

**27 percent of patients reported failing to go to the doctor due to difficulties associated with expressing themselves.**

Nonetheless, articulating *health care needs* can be more challenging, and in many ways, is a skill that patients with a range of literacy abilities do not possess. Some participants found it extremely difficult to verbalize their conditions:

> *"I have a hard time explaining exactly how, where, and when it hurts."*

> *"I struggle explaining my problems to doctors. I am unsure about what is important."*

> *"I must ask the doctor the right questions, but sometimes I don't know what questions to ask."*

Many of these quotes indicate the degree to which some patients consider their health care experience as a kind of a test. To them, this is a test in which their communication skills as well as their bodies are being examined, and a test for which they are unprepared and feel that they are failing.

Others who do manage to express their concerns do not always feel that medical staff is attending to them, an experience that makes the experience of going to the doctor dehumanizing as it did for this patient: "I feel like a guinea pig with new medications they've given me. I don't feel like they are listening to me. They are in control." While patients with varying degrees of literacy may share such sentiments, for low literate patients, these experiences may intensify feelings of powerlessness over one's health.

Focus groups with Spanish-speaking Latina women who are currently learning to speak English revealed that for new English speakers, communication might be a significant health care concern. For Californians who are learning to speak English, regardless of their literacy skills in their primary language, expressing themselves to monolingual English-speaking doctors or doctors who are not fluent in the patient's language can be one of the most difficult aspects of obtaining health care. One participant in a focus group said, "Without an interpreter, I'd be six feet under." While she made this statement as a joke, a lack of a qualified interpreter can have devastating consequences. As some female focus group participants who and are learning English as a second language said:

> *"They ask me certain things, and I just don't know how to answer. If my husband couldn't help me, I'd be very much alone."*

> *"I can't explain in English what the problem is, and the doctor says he speaks Spanish, but he really doesn't."*

> *"I have problems because I understand what they're saying, but they don't understand what I'm saying."*

ESL students also referred to the problem of discrimination in the treatment they received by individuals reluctant to work with patients who do not speak fluent English. In one focus group of women who spoke Spanish as their first language, seven out of eight reported receiving inferior treatment in comparison to patients who spoke fluent English. In another group of Spanish-speaking women, eight out of nine reported receiving inferior treatment. Comments explaining this treatment included:

> *"Americans get treated better."*

> *"Sometimes we get cut off and the doctor doesn't pay enough attention to my full question."*

> *"If I ask questions, I get ignored, and then I also have to wait a longer time."*

One participant reported having receptionists simply hang the phone up on her whenever she called the doctor's office and spoke in Spanish, despite the fact that the receptionist was fluent in Spanish. As a result, she was forced to physically visit the office simply to make an appointment. Others reported being forced to wait longer than English-speaking patients, encountering translators who spoke Spanish but refused to help them. One individual reported overhearing racist remarks from medical staff. Another individual who was in the process of acquiring English language skills explained, "They give me more attention now that I speak English."

## I Don't Have the Words: Interpretations and Recommendations

In the state of California, due to our unique patterns of immigration and political history, many individuals who speak English as a Second Language are also people of color. These individuals may experience linguistic discrimination that is directly related to racial discrimination and anti-immigrant prejudices, and they run the risk of experiencing this discrimination within the health care system and from individuals who have been hired, in part, to address their linguistic needs. Unlike low literate English-speakers, individuals who are in the process of learning English find it more difficult to conceal their literacy needs, and may, therefore, be more likely to be explicitly punished for them. There are four recommendations that we propose:

1. Interpreters should be trained to work with patients who, in addition to possessing limited English proficiency, possess limited literacy skills. Interpreters who have identified patients with low literacy skills may, in addition to providing verbal translation, provide translation of written medical information.
2. It is important that advocates for those denied access to care due to language or literacy barriers, join efforts. As mentioned earlier in this paper, the issues of language and literacy are very closely connected, and building partnerships between these two advocacy groups may be crucial in developing solutions. Patients who have limited English proficiency and have low literacy appear to be in a double bind and are extremely dependent on interpretation services.
3. Provide additional training for medical professionals in how to solicit valuable information from their patients who have difficulty expressing themselves. This training should be provided not just for current medical professionals, but also for those in postgraduate training. Low literate adults should be involved in the development of this training material.
4. Adult literacy programs can offer classes to help students better their articulation and verbal communication skills. Learning these skills is useful for all aspects of life, not just for health advocacy.

## Speaking in Code: Poor Communication Prevents Shared Decision Making

> *"I just have to trust the doctor. I put a huge amount of trust in the medical staff. I just sign forms without really understanding them."*
> —Caucasian woman in her 30s who participated in the Pilot Study

Participants of all linguistic backgrounds found that physician's use of medical terminology had a negative impact on their ability to obtain health care. Medical terminology, also known as "medical jargon," is part of an extremely exclusive professional dialect spoken and written by health care providers. The overwhelming majority of patients, regardless of their literacy skills or educational background, are not members of the medical language speech community, and most find the use of medical terminology by health care professionals alienating, at best. For low literate adults, however, the excessive use of medical terminology can be experienced as a threat to their ability to obtain adequate health care.

When a patient seeks treatment, understanding medical instructions is essential for providing self-care after they leave the office or hospital. However, 73 percent of interview participants stated that they have had difficulties understanding what medical professionals have told them about their health due to the usage of medical terminology. By putting such trust in the medical staff in signing forms without truly understanding the meaning and possible consequences, patients are prevented from fully participating in the decision making process regarding their health care.

**73 percent of interview participants stated that they have had difficulties understanding what medical professionals have told them about their health due to the usage of medical terminology.**

While these numbers are slightly lower than those related to paperwork, the frustration associated with the excessive use of medical terminology was perhaps more intense than that which surrounded any other health literacy issue:

> *"I need someone to offer information. I need a full explanation. A lot of people in this country do not read and understand. Comprehension is important."*

> *"My doctor doesn't talk to me in plain language. He told me I had a disease and told me to look it up on the Internet."*

> *"He [the doctor] is real educated, and it's kind of hard to understand what he says. The long words he uses are hard to understand."*

The intimidation associated with hearing their diagnosis and treatment in medical language may, in some cases, contribute to the difficulty that low literate adults have with communicating their health concerns to doctors. One participant explained that, "doctors need to give patients more information so patients know how and what to ask…I don't know the right things to ask. I want to be informed enough at the time I'm with the doctor." In some cases, patients felt that physicians failed to explain critical health issues as indicated by a patient who said, "I was not given any information prior to surgery even though I was coherent." Another patient stated, "The doctor just gave me pills and a video."

Low literate patients often hear about the diagnoses and treatment of their illnesses in language that is impossible for them to understand. It is impossible not merely because of the literacy level of these patients, but because the language that they are hearing is foreign. As one participant stated, "My doctor talks in code."

This "talking in code" is detrimental in multiple ways. One particularly problematic and concerning aspect of not understanding exactly what a medical provider is explaining is that of informed consent. When a patient gives informed consent for any type of medical procedure without fully understanding the possible consequences, he or she is no longer participating in the decision-making process.

**"I was going to get my tubes tied. What's that mean? What are tubes?"**

Another participant in our study explained the devastating combination of simultaneously having difficulties with paperwork and receiving confusing or inadequate verbal explanations. As he said, "I learned that I'm a diabetic. I didn't understand what the doctor was saying to me and I couldn't read the pamphlets he gave me. I didn't know what was happening to me or what I was supposed to be doing." Such omissions can be extremely dangerous in the case of a serious illness. A gentleman scheduled to receive a vasectomy described his confusion about the specifics of his surgery, by stating, "I was going to get my tubes tied. What's that mean? What are tubes?"

## Speaking in Code: Interpretations and Recommendations

The seven recommendations that we propose to lessen the above problems are:

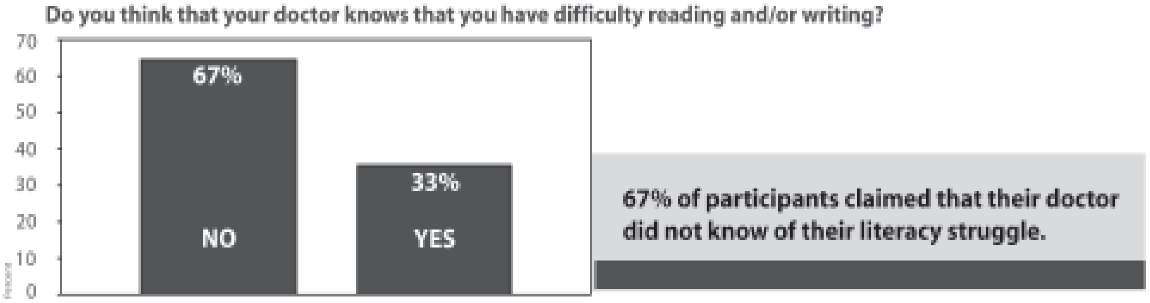
1. Medical professionals should avoid medical and lay jargon. When doctors use medical terminology with other health care professionals who understand that

terminology, they are increasing their efficiency. When they use that terminology with patients, especially patients who are burdened with low literacy, they are decreasing their efficiency and effectiveness. When physicians fail to translate medical language into accessible and understandable terms, they alienate low literate patients from full participation in their health care.

2. Medical professionals should never assume patient comprehension. In an above quotation, a physician explained to the patient that he was going to have his tubes tied. While this physician did use words thought to be plain language terms and used the phrase "tubes tied" rather than "vasectomy," the patient still did not understand what the procedure entailed. Care should be used when assuming the patient will comprehend simpler terminology.
3. Rather than assume information has been comprehended, physicians and other medical professionals can use what is called the "teach-back" method. This method involves the physician explaining a concept to their patient. After the explanation, the physician then asks the patient to "teach-back" what he or she has just learned. "Teach-back" is crucial in ensuring that communication is not just one directional, but that information provided is actually comprehended.
4. Postgraduate training is needed to provide medical students with information on how to best communicate with their patients, without speaking "in code." Low literate adults should be highly involved with the development of this training and curriculum.
5. More research is needed, involving low literate adults, on how to best explain complex medical issues to low literate patients. Examples of other modes of explanation include audio or videotape materials.
6. Efforts need to be made to create an informed consent process that is adequate for, and comprehendible by, low literate adults.
7. The current health system needs to develop and support systems that ensure appropriate patient education.

## Shame: Easing the Burden by Creating a Culturally Competent Environment

> *"I didn't ask questions even when I didn't understand how the doctor told me to take my medications. I thought he would think I was stupid, so I just wouldn't say anything."*
>
> —A Latina woman in her 50s who participated in the Pilot Study



67% of participants claimed that their doctor did not know of their literacy struggle.

These words, spoken by a woman who participated in a focus group, indicate the degree to which the consequences of low literacy are emotional as well as physical. Moreover, key components of the identities of low literate adults, such as nationality, may intensify the shame low literate adults sometimes feel about their language skills. In a sense, low literacy becomes a key component of the identity of low literate adults, one that affects other aspects of their lives.

While all of the adult literacy students who participated in the study were currently or previously enrolled in literacy programs, the majority had not told their doctors that they had low literacy skills. Of those who completed individual interviews, 67 percent claimed that their doctor did not know that they struggled with reading and writing. Of these individuals, few feared that actual negative consequences affecting their care would occur if they did inform their doctors. Instead, they feared the shame and humiliation produced by the stigma associated with low literacy.

"People confuse illiteracy with stupidity," one participant explained. Unfortunately, this perception may also be internalized by low literate adults, preventing them from openly discussing their needs. The false association between low literacy and low intelligence affected the ability of some participants to obtain the care that they needed, as demonstrated below:

*"I felt like I was stupid, so I didn't ask questions."*

*"I wasn't prepared to tell people that I had a problem with writing."*

Participants in focus groups, like those who participated in individual interviews, also referred to shame as a factor that influences their health. The tension between the desire to preserve their "social face" and to acquire essential health care information is revealed in the following interaction that occurred in a focus group made up of Latina women who spoke Spanish as their first language:

Participant A: "It's embarrassing to ask for help. That's why we come to school here, to learn."

Participant B: "It's better to ask for help than to get the wrong information."

One focus group in particular repeatedly referred to shame as a significant deterrent to the pursuit of health care. This group was made up of the men from the correctional facility. Eight of the ten men reported "pride" as something that got in the way of them going to the doctor. References to issues of pride and shame included not asking for help at the doctor's office because, "I feel stupid" and "I feel embarrassed." One participant refused to inform family and medical staff of his literacy concerns because, he said "I feel less than. I have pride, you know?" One response to how pride interferes with paperwork was, "I don't read it, and I just sign it, because I'll have to read it at least three times to understand it, and there's just not time for that. It's too embarrassing." Nonetheless, four of the ten felt that their health care would improve if they informed doctors. Significantly, three felt that their care would get worse. The men stated that they felt this way as they feared their doctors would not only mock them for their lack of literacy skills, but would additionally provide them with a lower quality of care once they found out.

It is worth considering gender as a component to the issue of shame, not only because of the pressures of gender socialization, but also because of the practical considerations regarding childcare. Most of the women in the focus groups were mothers, many of small children, and their commitment to obtaining care for their children may have enabled some women to surmount feelings of shame regarding literacy skills. Also, mothers have access to pediatricians and several reported asking their children's pediatricians about general health care.

Many low literate adults are acutely aware of the stigma not only associated with low literacy, but also of how low literacy is related to other social issues. Differences in social and economic status between patients and doctors may influence the willingness of patients to discuss literacy with their physicians. The concern that doctors "would not understand" appears to play a role in the reluctance of a number of participants to communicate their literacy troubles to doctors. One participant stated, "Class, gender, and economics directly reflect literacy levels. Doctors are very well educated and have money. They are not understanding of this." As mentioned above, some participants expressed concern about race, class, and linguistic discrimination and may have worried that their low literacy skills would intensify such practices.

Even some of those who had informed their doctors about their literacy skills questioned whether or not the severity of their problems were fully recognized by their physicians, "My doctor doesn't really understand how bad my [literacy] problems are." One participant questioned not only whether her doctor would understand, but whether or not her doctor would accept information regarding her literacy. As she stated, "My doctor wouldn't understand…my doctor wouldn't believe it." Perhaps patients would be surprised to discover that many doctors do "believe it," but simply do not know what to do about it.

## Shame: Interpretations and Recommendations

Failure to communicate with medical staff about literacy skills may undermine the ability of low literate patients to fully participate in their health care, to demand improvements, or to receive and internalize critical information. Additionally, the fact that some low literate adults will sacrifice their health to avoid shame should be interpreted as indication of the profound emotional intensity with which their shame is experienced. Recommendations we propose are:

1. Expand professional training for medical providers around the issue of cultural competency to include the issues of shame and embarrassment raised by low literacy. This training should include materials on how to build trust in the provider/patient relationship. In developing this training, low literate patients should be queried to determine what words, what type of body language, what type of environment, and what else should be changed for them to feel less ashamed and more welcome to the idea of discussing their literacy issues with their provider. The process of creating a shame-free environment is also an area in which literacy professionals can help.
2. Hospital administrators set policy at an institutional level, and there should be a mandate at medical institutions for physicians to attend trainings on literacy, which include a segment on creating shame-free environments. Other personnel, such

as nurses, pharmacists, receptionists, and medical assistants should also attend these trainings.

3. Funding should be secured for peer health educators and patient advocates. Peer health educators and patient advocates can accompany patients to office visits and answer questions and explain terminology, paperwork, and procedures.
4. Community learning centers, which provide easy-to-read health and medical information, should be put in place at hospitals and clinics throughout California. These centers allow patients, while they are still at the hospital or clinic, to research and learn more about the information they have just received from their medical provider. The centers have a welcoming environment and are fully staffed by health and literacy experts; materials are available at a variety of reading levels and in a variety of languages.
5. Through self-advocacy training at adult literacy organizations, adult literacy students may become more empowered by learning what questions to ask their medical providers and how to get the information they feel is important, as well as methods to overcome their shame.

## PHYSICIAN SURVEYS

### Methodology

Physicians were sought for participation in this study via solicitation through publications of the California Medical Association, phone calls, and emails to their component medical societies, and surveying medical professionals who sought health literacy training. Sixty-four physicians completed self-administered surveys with both open- and closed-ended questions about how literacy affects their ability to provide health services. These physicians practice throughout California and have a wide range of specialties, ranging from general practice to gynecology to rheumatology.

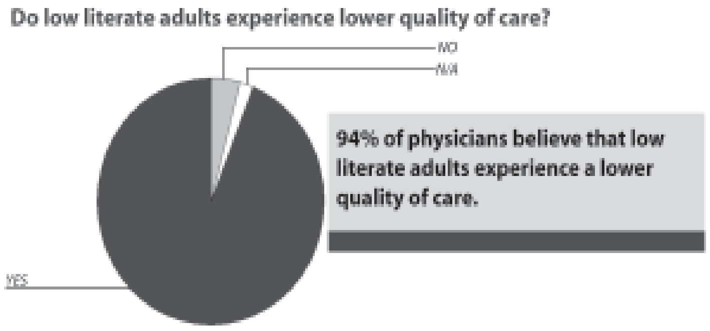
The physician surveys included questions regarding whether or not they knew what health literacy was and whether or not they viewed it as a barrier to providing adequate health care, what their biggest challenges were in providing care to patients with low functional literacy skills, and what type of training or assistance would be most useful to them in their practice.

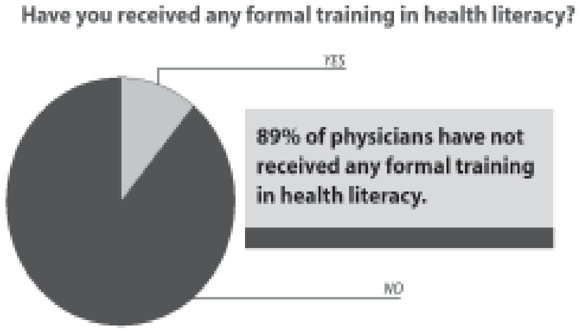
Responses to closed questions were tabulated using Statistical Package for the Social Sciences (SPSS) software, and responses to open-ended questions have been used to complement these data. This approach enabled us to describe the experiences of participants from both quantitative and qualitative perspectives. The goal of the questions was to obtain answers that would enable us to assess health literacy in California and to assess the quality of survey instruments, which will be redesigned for future systematic research.

## RESULTS FROM PHYSICIANS

### Good Physicians, Limited Resources: Lower Quality of Care and Medical Errors

"Help!" is what one physician wrote on her health literacy survey. As indicated by this statement, doctors care about servicing their patients. Unfortunately, resources are limited,





and health care providers often have limited information regarding how to effectively communicate with their patients.

Due to their interaction with a large number of patients, medical professionals were quite clear on the impact that low literacy skills has on patient care. Ninety-four percent of medical professionals believed that low literate adults in general experience a lower quality of care than other patients. One of the few physicians who considered the quality of care was equal, reported, "The care given is the same. What is different is the patient's ability to understand and participate in their care," thus indicating a recognition that despite the best intentions, low literate adults are not receiving equal care.

However, when asked how health literacy was prioritized within the overall provision of health care within California, only eight percent believed that health literacy received moderate priority and only one participant believed that it received high priority. Eighty-three percent believed that health literacy received low priority in the provision of health care in California. This reveals a disturbing discrepancy between how literacy is affecting quality of care for low literate adults and the attention that it receives in the larger health care system.

Medical professionals are aware of this discrepancy and many appear to be disturbed and frustrated by it. One of our more candid physician respondents wrote, "You know, I *barely* have time to identify their medical problems. I am *not* a social worker." While most providers recognized that it was not their "job" to solve the larger social issues that produce low literacy, others recognized that low literacy was preventing them from fulfilling their basic professional goals:

> *"Communication barriers limit quality of medical history obtained. Additionally, less time is available to probe deeper into preventative health practices."*

> *"Limited exchange of information leads to decreased compliance, increased risks for patient, increased liability for physician. Also, these patients frequently have limited resources and some therapeutic options are not available."*

> *"Even getting consent depends on the patient's trust since they rarely understand what the decision is. In fact, consents sometimes cause anxiety since patients feel responsible for the pain that comes along with the procedures."*

Medical professionals framed these concerns directly in terms of how they affected their work on behalf of their patients. These responses indicate how problems that low literate patients are having with communication may have a cumulative impact on overall quality of patient care.

Medical professionals observed the impact of literacy on their ability to communicate with patients. These issues include those such as cultural and practical concerns, as well as time. Ninety-five percent reported experiencing barriers to communication with their own patients. However, only 11 percent had received any health literacy training and only 49 percent used plain language materials in their practice. Although an encouraging 95 percent provided services for patients who did not speak English, such as bilingual staff and literature, these services did not appear to be sufficient in enabling medical professionals to communicate effectively with patients. As one provider explained, "No matter how hard one tries, even with a qualified interpreter, instructions are never as well understood as when English is the primary language."

Medical providers recognized that communication problems between themselves and patients were due both to the low literacy of patients and to provider assumptions about patient comprehension and concerns. The following quotes express a variety of these concerns:

> *"I am unable to adequately explain my directions, and they are unable to process large volumes of [written] materials."*

> *"We have a lot of information to give patients and we may not be aware of patients' literacy levels, so much of our talking and our written instructions may be lost on patients."*

> *"People often talk to their patients over their heads. Many times their patients are intimidated with the system and are reluctant to ask questions when they don't understand instructions."*

While many medical professionals realize their role in failed communication with low literate adults, few felt equipped to respond effectively. Of the 88 percent of medical professionals who considered themselves able to identify patients who were having trouble understanding them, most did so by assessing non-verbal cues such as eye contact. One provider admitted to merely "intuiting" that patients were having trouble understanding.

When asked if they were aware of medical errors that were the product of low literacy, 75 percent of medical professionals answered in the affirmative. The survey of medical professionals and administrators revealed three reports of death as the result of such errors.

Doctors and adult literacy students both complained about the problems of inadequate translation. In some cases, inadequate translation can be worse than none at all as it perpetuates the illusion that communication has occurred when it has, in fact, failed. Physicians acknowledge that the language and literacy issues are intertwined, and one physician reported a case in which medical personnel misunderstood that a patient's reference to "feet" was related not to her own feet but to those of the breach birth infant she was carrying. The physician reported that as a result of this misunderstanding, the patient's treatment was delayed and the baby died.

## Physician Survey: Interpretations and Recommendations

Some providers recognized that the problems they were having with low literate patients were indicative of larger concerns regarding health education. One provider reported, "Medical offices are not designed to deliver health information clearly when people have literacy issues, and in fact, we don't do a good job even for literate patients."

One huge challenge is the lack of time that medical professionals possess. When faced with the choice between more effective communication in the limited time they have with patients and simply treating patient bodies without fully attending to patient comprehension, many feel forced to do the latter. They do so with the hope that somehow treatment will be successful, despite such compromises. As one physician reported, "I muddle through and hope for the best."

This "muddling through," however, is devastating to individual patients, to low literate adults as a community, and to the entire health care system. Medical professionals whom we surveyed know it, but they do not know what to do about it. They feel frustrated, overextended, and abandoned by the larger health care system. Following are recommendations that we propose:

1. More knowledge and more research about *what and how* to train medical professionals are greatly needed. While there are some techniques that are being used by some medical providers, such as the "teach-back" method and reduction of medical jargon, more techniques should be created and used.
2. Because low literacy contributes to medical errors, the needs of patients with low literacy skills should be taken into consideration when researching and proposing methods that will ultimately reduce these errors.
3. Many physicians have received the message that health literacy, as an issue, exists. This message should now be spread to all allied health professionals, including pharmacists, nurses, nurse practitioners, and medical assistants.
4. Low literacy appears to contribute to important disparities in quality of care. In consideration of disparities in health care, the needs of low literate patients should be considered.
5. Quality measures and standards for health literacy should be created. These measures and standards will help institutionalize health literacy in the health care system.

## HOSPITAL ADMINSTRATOR SURVEYS

## Methodology

Sixteen hospital administrators completed self-administered surveys about how literacy affects their facilities' ability to provide health services. To solicit survey responses, hospital administrators representing public, rural, non-profit, and urban hospitals were contacted directly via phone, email, and fax; contact information was found in the 2003 Membership

Directory, published by the California Healthcare Association, Hospital Council of Northern and Central California, Hospital Association of Southern California, and Healthcare Association of San Diego and Imperial Counties.

As with the physician surveys, administrator surveys consisted of both open- and closed-ended questions. Responses to closed questions were tabulated using SPSS software, and responses to open-ended questions have been used to complement these data.

## RESULTS FROM HOSPITAL ADMINISTRATORS

### Concerned but Unaware: The Need for Institutional Commitment

While the hospital and clinic administrators who completed our survey were concerned about the issue of health literacy, few indicated that they fully grasped how deeply medical professionals and low literate adults are affected by the issue. Our response rate from administrators was limited in comparison to our responses from medical professionals and adult learners. However, we considered the data worth reporting because a single administrator may be responsible for dozens to thousands of patients. Thus, each response from an administrator carries implications that far exceed the individual respondent.

Administrators in our survey were much less likely than medical professionals and adult learners to consider low literacy as a serious threat to quality of care. Only 56 percent of administrators considered the overall quality of care for low literate patients to be inferior to patients with higher literacy levels. Seventy-five percent of administrators felt that low literacy was given low priority in the overall provision of health care in California. These are significant proportions of the group surveyed. However, they are lower than those of medical professionals who shared these opinions.

Few administrators indicated that low literacy directly impacted the effectiveness of their institutions. Only nine percent of administrators indicated that low literacy had a significant impact on the quality of care that they were able to provide for their patients, while 38 percent responded that it somewhat affected patient care and 25 percent indicated that it affected quality of care, "very little." All administrator facilities provided services for non-English speaking patients and 69 percent reported using plain language materials, which indicates both an awareness of health literacy issues and an effort to address such issues in the provision of care. However, despite these provisions, few administrators extended their concerns about health literacy to the level of staff education. Only 25 percent of administrators offered health literacy training to their staff.

Despite their optimism in comparison to medical professionals, 63 percent of administrators reported having heard about medical errors that were related to the literacy skills of patients. The stress that confusion over paperwork can have on an entire family, was reported by a hospital health education director who wrote, "The husband did not know that he signed a consent form to put his wife into a nursing home…The family and patient were extremely upset when the patient was transferred to the nursing home. It took several days and a translator to correct the situation."

The consequences of the failure to ensure that a patient has understood treatment instructions is described in one of the most chilling of the responses we received to our surveys. A hospital CEO reported a case in which follow up instructions from the emergency room were not comprehended due to the patient's lack of reading skills. The patient's condition deteriorated, and she did not understand that the deterioration was addressed in the discharge instructions. Had the patient recognized the situation, she would have sought care earlier. As a result the patient died. Because no efforts were made to ensure that the patient was able to actually understand the information provided, the entire system failed this patient in the most devastating manner possible.

## HOSPITAL ADMINISTRATORS: Interpretations and Recommendations

There are at least two ways to interpret the discrepancies between administrator perception and evidence from studies around literacy and health care. One may be that the administrators who responded to our survey represented facilities that were simply exceptional in their provision of health literacy accommodations for patients. This is a logical assumption as administrators who knew that they were failing in such care would be less likely to respond to the request for information. However, another interpretation of these responses may be that administrators do not fully recognize the impact of low literacy on the health care of their patients and on the resources of their medical professionals.

The fact that few administrators offered health literacy training to their staff indicates that they may be overestimating the success of their own facilities. If this is the case, the larger implication is that simply providing translator services and plain language materials to patients is inadequate. More significant interventions on behalf of low literate patients may be required, and we propose the following recommendations:

1. Consciousness raising has historically been focused on physicians, as they are the ones who see the consequences of low health literacy on a regular basis with their patients. To fully address the issue of health literacy, however, we should shift the focus to a systems approach. Because hospital and clinic administrators make policy decisions about their institutions, they should be included in the conversations about how to remedy this problem.
2. While awareness of health literacy is crucial, it is not enough. What is needed at this point is policy change, and this change should be made at a systemic level.
3. As a commitment at the institutional level to decrease the problems associated with low health literacy, hospital and clinic administrators can form collaborations to open Community Learning Centers. One example of such a center exists at the Santa Clara Valley Medical Center, the public hospital in San Jose. This center is the result of an innovative partnership between Vision Literacy, PlaneTree Health Library, and the Santa Clara Valley Medical Center. The center was established to provide people who have limited reading skills with access to free health information and adult literacy services, and to provide the general public with a resource on a wide array of health issues. The center features a health library with video, audio, and print materials, including materials for adult new readers, as well as assisted Internet searches. Materials are available in English, Spanish, and Vietnamese. One-on-one literacy counseling and tutoring are also available.

## CONCLUSION

## Prescription: Legislation, Education, Communication, and Research

The results of this pilot study indicate that for low literate adults, the state of California is, indeed, in the midst of a very serious health communication crisis. This crisis is taking a toll on medical professionals as well as patients. The condition of low literate adults on a statewide level may be even more severe than indicated in this paper, as those individuals we surveyed had already been identified as struggling with low literacy skills and were seeking education. The patients who are most deeply affected are those who have not yet sought help. Medical professionals and health care administrators may also be in a more challenging position than our results indicate. The individuals who completed our survey appeared to have thought seriously about the issues of health literacy; many physicians and administrators may be dealing with health literacy challenges without fully realizing the form of these challenges or the consequences to the care that they provide.

## KEY RECOMMENDATIONS

1. Low literate adults who are enrolled in adult literacy programs should receive training in health communication, self-advocacy, and articulation.
2. The health system, in its current state, is not set up to deal with the issue of health literacy. We should all realize that it is a systemic issue, and adult literacy practitioners, medical providers, hospital administrators, policy makers, and all those included in the system should collaborate to create solutions to this issue.
3. It is critical that adult literacy advocates partner with language access advocates, both of whom are working to reach similar goals.
4. Resources should be put toward adult schools and adult literacy programs to reduce the overall burden on current facilities. Additionally, resources should be put toward providing a means to develop and conduct health literacy trainings for students at these adult schools and adult literacy programs.
5. A health literacy clearinghouse should be created and filled with easy-to-read health information. This clearinghouse should be Web-based, and accessible to all, including adult literacy practitioners, medical providers, and low literate adults.

## AREAS FOR FURTHER RESEARCH

1. More health literacy research is needed among allied health providers, such as pharmacists, nurses, nurse practitioners, and medical assistants, to learn more about their challenges and needs.
2. Research among low literate adults is also needed, to:

    a. Measure the impact of low literacy on access to care,
    b. Develop effective interventions to enhance shared decision-making and to avoid errors, and,
    c. Measure and improve quality of care.
3. More research into the most effective means of communicating health information should be developed and implemented in health professional schools, using direct input from low literate adults.
4. Medical providers, clinics, and hospitals should work to create shame-free and trustworthy environments.
5. There appears to be a lack of standards and regulations surrounding the issue of health literacy; this needs to be further explored, and these standards and regulations should be created. Legislation should be generated and resources should be allocated.

As is demonstrated throughout this report, having low literacy skills adds an additional burden to the already difficult task of managing one's health. Low literacy affects people of every background and has the potential to undermine the diagnosis, treatment, and prevention of every known illness. Low literate adults suffer the most from this situation, physically and emotionally. They are not, however, the only ones who pay; their families and loved ones, the overextended medical community, and every individual affected by skyrocketing health care costs are all affected by our collective failure to address the impact of low literacy on California's health. Low literacy in California is at a crisis level, and we have the technology, in the form of education, to end that crisis.

While our ultimate goal should be universal literacy through education and legislation, the health of California's low literate adults cannot wait until this goal is achieved. In order to be effective, California's health care system, the documents used within it, and the people who play a role in it, should engage in a plain language revolution so that all written and verbally communicated health information is accessible to all those who seek care.

Greater intellectual energy should be committed to finding creative and effective solutions to the health literacy crisis, and such efforts should include the important input of low literate adults and rigorously tested for effectiveness. The existing knowledge must include the economic, legislative, educational, and individual support required for its implementation. This pilot study and our first report are offered as invitations to such profoundly essential labor.

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## Other Resources

A Selection of Health Literacy Articles and Research, Partnership for Clear Health Communication. www.pfchc.org.

Center for Healthcare Strategies, Inc.: http://www.chcs.org/resource/hl.html

Joint Committee on National Health Education Standards (1995). National Health Education Standards. Available from the American School Health Association (P.O. Box 708, 7263 State Route 43, Kent, OH 44240; the Association for the Advancement of Health Education, 1900 Association Drive, Reston, VA 22091, or, the American Cancer Society, 1-800-ACS-2345).

Pfizer: http://www.pfizerhealthliteracy.com

United States Census 2002: http://www.census.gov/

1992 National Adult Literacy Survey: http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid+2001534

# The California Health Literacy Initiative

A Collaboration Dedicated to Solutions

*A Project of California Literacy, Inc.*