

**"Following the Physician's Recommendations Faithfully and Accurately:"  
Functional Health Literacy, Compliance, and the Knowledge-Based Economy**

**Sondra Cuban**

*University of Lancaster, England*

**Abstract**

*The author will explore the functional health literacy (FHL) concept through a critical analysis of the definition --examining its limitations and applications within the context of the "knowledge-based economy." The functional approach, derived from a medical model, serves as an information commodity within a human capital approach to literacy and healthcare.*

**Purpose of This Exploration: Functional Health Literacy as the "Prescription to End Confusion?"**

*"The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." (definition of functional health literacy by Ratzan & Parker, 2000).*

Functional health literacy (FHL) is a powerful new term. It serves as a regulatory mechanism for health care reform, by turning health into an information commodity for the industry. It also serves as a tool for the transmission of bio-medical information from medical professionals to patients, "following the physician's recommendations faithfully and accurately in treatment and lifestyle." (Weiss in Giorgianni, 1998, p. 8). The functional health literacy agenda crafts an 'expert patient' (capable of searching for, reading, and understanding bio-medical information), relieving doctors of their administrative work so they can carry on with 'real medicine' and reducing their responsibility levels to patients (Graham, 2006). It is

patients who now have “rights and responsibilities,” under health care reform, that is, if they can read their consumer-driven health plans and medical accounts (Friedsam and Kindig, 2004, p. 1; Robertson & Minkler, 1994).

According to health literacy experts, “the goal is functional health literacy....working within a health system, having a dialogue with professionals and acting on this knowledge” (Rudd in Giorgianni, 1998, p. 8). Although there have been attempts to apply functional healthy literacy skills and tasks to other environments and practices (Rudd, Kirsch, & Yamamoto, 2004), it is this medical skills-based definition that predominates, setting a high bar for “the ability to perform basic reading and numerical tasks required to function in the health care environment” (Parker et al., 1999 in Greenberg, 2001, p. 69). The U.S. health care industry demands this standard, and it has exported it around the world.

In a downsized health care system that relies on self-care, prevention, and with large social distances between providers and patients, in what has been referred to as “not just a gap, but a chasm” (Institute of Medicine, 2003, p. 1), functional literacy skills become significant for gaining access to services. Once inside, providers and patients are configured within a “partnership model” of service (Kerka, 2003), that would assume a care ethic and time to develop human relationships, but which instead focuses on pushing paper. This model invokes a discourse of lifestyle choice and self-sufficiency for patients while protecting providers with clauses and recorded transactions from possible lawsuits (Perkins et al., 1998). Self-management and perfunctory communication about health is promoted because “active patient cooperation [is, sic] essential to the success of most outpatient medical treatments.” (Giorgianni, 1998, p. 13). The assumption is that “people must be able to advocate for themselves as they are increasingly seen as active consumers rather than passive recipients of treatment and care” (Osborne, 2004, p. 3). Functional health literacy is presented as a public good.

But is it? While the saturation of print and electronic information sources into medical interactions intensifies, and becomes naturalized and unquestioned, it burdens individuals to decipher solipsistic texts (Brandt, 2001; <http://www.physorg.com/news/76768376.html>) in order to handle their own individual health problems. The solution

has been to create downsized texts. Plain Language or Clear Language campaigns try to overcome text-based barriers by creating greater access routes for health care information (see: <http://www.texamen.com/index.php?id=11>). Yet, poorly designed, unevaluated Plain Language texts may contain overly-simplistic explanations (Madden, 2002; Osborne, 2004; Shohet, 2004) and be used as a substitute for patient-physician personal contact (Shohet, 2004); any medical professional relying solely on Pfizer's Principles for Clear Health Communication Principles could fall into this trap (Pfizer, 2004). Contexts and guidelines need to be established for making quality Plain Language documents, and ensuring they are indeed, useable and helpful to patients. The Communication Research Institute of Australia has challenged the claims of Plain Language proponents, as well as their evidence about the effectiveness of Plain Language documents (Shohet, 2004). Still, it is better written communication that is the so-called, “prescription to end confusion” (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 1).

The entrepreneurial model of health care shifts accountability away from the health care industry and its financial interests, towards people's individual skills (to read texts), ignoring the more salient conditions for poor health and literacy, like social class disparities and racial discrimination. National figures, for example, show that poverty, and the number of people without health care coverage has increased over the last five years---46 million, with Hispanics as the highest group (<http://www.npc.umich.edu/poverty/>).

Under globalized, neo-liberal policies, things have worsened for these disenfranchised groups and for those who are soon-to-be marginalized. Many employers, for example, no longer pay for health insurance, and the government has not intervened or compensated for this trend. The emergence of the large-scale service economy, with its part-time and contract work, in conjunction with rising health care costs, make workers ineligible for health care coverage and they often cannot pay it on their own, due to wage loss. The lack of unions, a natural advocate, has not helped. In an unstable labor market, more people too, are in transition and losing jobs, which again, means losing health care coverage and increased poverty. In addition, welfare reform restrictions and medicare and Medicaid limitations have made it even more difficult to receive health care services (<http://www.nchc.org/facts/coverage.shtml>), especially for immigrants and poor women (Polit, London, Martinez, 2001). But the real problem is

not their low levels of *income*, discrimination, or the exorbitant costs of privatized health care, so much as individuals' low levels of *reading*. Policymakers are more alarmed about statistics that show, for example, "approximately half of Medicare/Medicaid recipients read below the fifth-grade level" than these other major issues (<http://nnlm.gov/outreach/consumer/hlthlit.html>). In addition, Medicare and Medicaid are harder than ever to receive.

Without insurance, when people get sick, and can't pay, they go to emergency rooms, which are overloaded and only provide acute care. Emergency room visits are also expensive for the industry to run. Upon being admitted, patients who have low literacy skills and income levels, according to industry spokespeople, drain the health care system and cost taxpayers as well as other health care members more money, upwards of 69 million, according to the Institute of Medicine, because they use it more intensively: their rates of hospitalization are higher, and they stay longer (<http://www.nchc.org/facts/coverage.shtml>).

Moreover, they are viewed as using more services as a result of years of no access to health care, and chronic illnesses. One doctor quoted a 1998 study, saying, "beyond the lost sales, poor health outcomes hurt not only patients, but cost the nation's healthcare system about \$73 billion annually" ([http://www.consumer-health.com/press/2002\\_1018\\_article.htm](http://www.consumer-health.com/press/2002_1018_article.htm)). These people are perceived as pariahs who are taking up too much of medical professionals' time and resources.

Functional health literacy is seen as the solution for dealing with these systemic disparities. Yet, the individualistic health literacy focus, and concern for industry profits, undermines the greater need for better welfare and public services in society for vulnerable populations. The discourse on health literacy reflects larger views on the role of literacy in society.

### **Health Capital**

Literacy has been seen as the magic bullet for every societal ill for over a century. Historically, literacy has been viewed as increasing moral, social, and cultural capital, and more recently, wealth for the knowledge-based economy (Brandt, 2002; Brandt, 2005). Since the 1980s, policymakers have promoted literacy for economic purposes;

citizens, according to adult literacy policy makers need literacy skills to survive in the workplace, and to benefit the nation's ‘new economy.’

Workers today need a much broader and stronger set of skills than they did ten or twenty years ago. They must also learn new ones continually if they are to adapt and contribute to companies competing in the fierce global marketplace.”  
(Comings, Sum, Uvin, 2001, v.)

According to national tests, industrialized countries' populations are not only functionally illiterate—over 40 million Americans, for example, cannot read health-related materials, bus schedules, or simple work papers (Institute of Medicine, 2003; Kirsch et. al, 1993)---but they are in poor health, cannot work, and, are not contributing citizens. Businesses and government policymakers warn that this group is hurting the nation's economy and they are overusing public services. They call on adult basic education programs to raise the nation's literacy skills through a functional literacy skills agenda. Economists and education policymakers hammer out lists of basic skills that all successful adults need to become more self-sufficient and productive members of society (Murnane and Levy, 1996).

Functional health literacy fits well into this agenda. The equation goes like this: Frontloading skills into low-literate individuals can help them read prescriptions, receive training in positive lifestyle change, and go to health care facilities, but, only when it is necessary. They will become more self-reliant in managing their health care, go to work, and call in sick less often. They will be in better health. Low functional health literacy in individuals means they carry less health care knowledge and comprehension of diseases, and they are unable to follow out prescribed regimens for acute (e.g., accidents) and chronic illnesses (e.g., asthma); low-literates who have AIDS, for example, are perceived as problematic because they do not take their medicine, and are confused, despondent, and want to clean their bodies (Kalichman, Ramachandran, Catz, 1999). The experts infer that if they could read, they would know better.

This approach centralizes official knowledge for transmission in prescribed sequences to people who have low literacy, and are considered laggards, deficient in cognitive, written, and oral communication skills that endanger their healthcare (Smedley, Stith, & Nelson, 2002). They are a “hidden risk” (Schwartzberg in Levine, 2001, appendix

D) because they are not positioned to get their needs met--- “silence is equivalent to an illness,” (Rudd in Levine, 2001, p. 18). As passive recipients, they need to rectify their “quiet disability,” “lack of knowledge,” and “problem-solving abilities” (Giorgiani, 1998; p 7-8). For example, if they are recalling, rather than writing down medical advice, they will not likely follow therapeutic treatments. They are dependent on the medical system to transfer biomedical information within an efficiency model of care (Waerness, 1996). “No wonder patients do not take their pills,” one doctor stated, “they think the real problem is something different. Lack of understanding is a powerful predictor of compliance” (in Giorgiani, 1998, p. 15).

The literacy ‘myth’ (Levine, 1982) is reinforced with a formula for optimizing skills to increase health access and benefits and the alleviation of all health problems: “Health literacy... remains a neglected, final pathway to high-quality health care.” (Nielsen-Bohlman, Panzer, Kindig, 2004, xi). This agenda, matched to government and business interests, maximizes control over the language, as well as the direction of the health care industry. George Bush, the ‘wealth care’ president (Rahm Emmanuel in Rutenberg, 2006), has proposed health savings accounts, and, foresees increased technology and electronic records as a solution to the crisis (<http://www.washingtonpost.com/wp-dyn/articles/A41595-2005Jan27.html>). He said: “One of the amazing discrepancies in American society today is we’re literally changing how medicine is delivered in incredibly positive ways, and yet docs are still spending a lot of time writing things on paper and sometimes it’s hard to read their handwriting” (Riechmann, 2004). The fallacious functional health literacy, founded on, and rooted in a dysfunctional health care environment that enforces text-based transactions, becomes a self-fulfilling prophesy which more accurately should be renamed “healthcare literacy” (Giorgianni, 1998, p. 8).

While the medical community has been targeted for change by those in public health to produce ‘cultural competence’ (Ad Hoc Committee on Health Literacy, 1999) through better navigational features, the focus has been almost entirely on the patient to conform to standard medicalized norms, reinforcing “The Tyranny of Health Promotion” (Robertson & Minkler, 1994, p.296; Kennen, Martin, & Davis, 2004). This problem has rarely been critiqued from an industry perspective and there are no conceptual frameworks to give it meaning (Shohet, 2004). Therefore, a critical

analysis (focusing on the use of the language in health literacy policy speeches, studies, curriculum, and reports) is needed.

### **Background and History of Functional Health Literacy**

Although there are a number of definitions (Osborne, 2004), the standard explanation of functional health literacy, found in the National Library of Medicine, 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.” (Ratzan & Parker, 2000). The dominant approach to health literacy, by the medical professions, is functional. This approach focuses first and foremost on language and numbers from a health industry point of view (Nutbeam, 1999; Shoet, 2004; 2005). The content emphasizes the transmission of medical facts, of health risks, knowledge of health services, and, adherence to prescribed actions.

The functional approach is close to what is called, “interactive health literacy” in that they both support health care industry objectives. But interactive health literacy is a little different, according to, health literacy proponent, Don Nutbeam. It means the ability to read, *and* act on health information (Shoet, 2004). Interactive health literacy has strong backing from public health proponents because it is the implementation of functional health literacy in the health care setting. The content of interactive health literacy focuses on everything within FHL, but there is an emphasis on matching cultural customs and belief systems of health care settings with marginalized communities. Cultural competence is promoted with the viewpoint that people are more able and ready to use health care systems when they are familiar. They may, for example, actively seek out preventative treatment if they feel comfortable being in a health care environment (Shoet, 2004).

Both functional and interactive health literacy focus on developing people’s information-seeking skills and their ability to act on medical advice, as well as, influence social norms. These agendas support patient ‘self-efficacy,’ because with more choices and information, they are meant to feel more ‘empowered.’ Patients may feel like they are making ‘choices’ through these new ‘cultural competence’ standards: “The only person whose behavior we can control is our own,” Choice Theory claims (<http://www.wglasser.com/whatisct.htm>). The choices, however, in the

health care industry, are limited, and really a “one-way street” (O’Connor, 1995, p.14).

When did all of this start and why is it so important? Although international health work, since the 1960s has addressed health literacy (Chesnay, 2005), it was first coined in 1974, as part of a set of minimum standards for health education (Selden et al., 2000). During this period, health literacy and health education were focused on as part of community development, and they were not exclusively about individual behaviors, attitudes, and access, or, the information-based economy, like now. Health literacy has since expanded, becoming a burgeoning agenda, spearheading health and literacy policymaking in what has been opportunistically referred to as a, “maturing partnership” between the fields (Hohn, 2002; Rudd, 2002a). FHL has won the greatest acceptance in the U.S. because it fits with commercialized care, a focus on individuals, and, the importance of following out the regimens of doctors (Nutbeam, 1999; 2000). Although other countries, like Australia, have broader definitions of health literacy (Nutbeam, 1999), it is the U.S. FHL definition that is most popular internationally. The World Health Organization (WHO), for example, repackaged its health promotion strategies recently to fit more with FHL (Pridmore, 2006). A WHO global conference in 2000, that was sponsored by Pfizer, focused on health literacy as a predictor for population health (Kickbush, 2001). Pfizer has an invested interest in FHL because it is profitable for the company if doctors can prescribe and be certain that patients are taking their medicine. Removing barriers is important. Their Senior Vice President for Disease Management stated: “the goals of this partnership are improved adherence to therapy and more efficient use of health care resources and delivery of care. These will ultimately lead to improved clinical outcomes and increased patient satisfaction with the health care system” (Giorgianni, 1998, p. 5).

Functional health literacy implies that people who have low literacy levels and are in poor health are not only deficient individuals, but, they are poor customers. Pfizer refers to them as, “low-literate health care consumers” (Pfizer, 2003/2004, p. 3). The cure, according to proponents, is to improve low-literates’ health through better risk communication and medical information (Hyde, in Osborne, 2002), for, “it is not easy to separate literacy from information-gathering or decision-making competency.” (Fortenberry in, Giorgianni, 1998, p. 10).



The transmission of certain skills, behaviors, and the use of established information-based systems for healthcare by individuals characterizes the functional “read to do” approach (Rudd, 2002b; see also: [http://www.hsph.harvard.edu/healthliteracy/literature/lit\\_2002.html](http://www.hsph.harvard.edu/healthliteracy/literature/lit_2002.html)). The discourse of cooperation, consent, and compliance for conventional biomedical advice (Madden, 2002) are key underlying assumptions of functional health literacy, “as one component of functional literacy” and its systems-based transmission, “to enable people to seek and obtain effective health care” (Rudd in Levine, 2001, p. 16). Low functional health literacy, therefore, is equated with limited compliance with the health care system, with treatment plans, and minimal lifestyle change:

Patients with inadequate health literacy have a complex array of communication difficulties, which may interact to influence health outcomes. These patients report worse health status and have less understanding about their medical conditions and treatment (JAMA in Shoet, 2004, p. 68)

The problems of low literacy and health are not viewed as part of systemic discrimination, but in terms of people’s individual skill levels. The functional health literacy construct was developed in response to the International Adult Literacy Survey (IALS) of 1995, and the U.S. National Adult Literacy Survey (NALS) of 1992. In North America, the IALS revealed that nearly half of the adult Canadian population had reading difficulties and the NALS showed that millions of people in the U.S. had very low literacy levels (Singleton, 2002, Rudd, 2003; Speros, 2005). Of these NALS respondents, many also had low-income levels, and they reported health problems too. Policy makers used these test results to show that people’s low literacy levels impede access to health information, ignoring issues of social class. Over a decade later, thousands of citations could be found on functional health literacy to match with the NALS and IALS definition (Levine, 2001) with the emphasis on literacy skills. Later, health literacy measures were embedded into national adult literacy assessments, called the National Assessment of Adult Literacy (NAAL), initiated in 2003 ([nces.ed.gov/NAAL/index.asp?file=Highlights/HealthLiteracyFactSheet.asp&PageId=21 - 22k](http://nces.ed.gov/NAAL/index.asp?file=Highlights/HealthLiteracyFactSheet.asp&PageId=21-22k)).

FHL’s expansion in the adult basic education (ABE) field also reflects neo-conservative educational reforms with endorsements for skills-based reading instruction, focused on “what works” (Erickson, 2005). This approach now adorns the

ABE field, lending it an esteemed anchor in the medical sciences and an easily measurable, known quantity (functional literacy) with which to study, teach, and assess. Prescriptions for skills-based programming prevail with teachers being encouraged to instruct students on health industry vocabulary (see: <http://healthliteracy.worlded.org/teacher-1.htm#activities>; <http://literacynet.org/vtd/>).

Raising public awareness is a key factor in this “social marketing” effort (Rudd, R., Moeykens, B., & Colton, 1999, p. 183). Health Literacy month was inaugurated in October of 2000, in what was referred to as a “grassroots campaign” (Osborne, 2005) to reduce health disparities across America. But it was typical of many health innovations, in that it was spread through a diffusion model campaign (Rudd, 2002a). This campaign would heed the call among public and private agencies to reduce the “alarming disparity between skills needed to comprehend and act upon basic health information” (Pfizer, 2001, p.1) among a “socially complex” low-literate (Smedley, Stith, & Nelson, 2002) population who are viewed as devouring health care costs for other members, and pose “a recipe for disaster” for both taxpayers and the industry (Baker, 1997, in Giorgianni, 1998, p. 8). It is considered to be a “silent epidemic” and antithetical to compliance (Marcus, 2006, p. 1).

Critical health literacy, as opposed to functional health literacy and interactive health literacy (Nutbeam, 1999; 2000; Kerka, 2003), has its roots in the community development health movement of the 1960s and 1970s. Critical health literacy is important because it counters the current myth of literacy as a commodity and the accrual of information capital and health consumption (Gee, 1996; Freebody & Freiberg, 1997; Wallerstein & Bernstein, 1994; Kickbush, 2001). It focuses on community empowerment, with critical analysis and social and institutional change. It is sensitized to what it is that people do with literacy and its liberating effects (Nutbeam, 2000; Freebody & Luke, 1990). It also includes media analysis, and knowledge of local, and government processes (Shohet, 2005). In this framework, health and health care are viewed less as an individual scarce resource to stockpile, and more as a social justice outcome. Health education “empowerment” programs (Boudin, 1983; Norton, 1997; Sissel & Hohn, 1996), allow learners, literacy programmers, and community health workers to analyze health problems and develop Freirean-based social action approaches to problems. These projects range from

participatory AIDS education to protesting the lack of social services in communities. One example in Scotland illustrates this type of agenda. Lyn Tett (2003) describes how twenty mothers in a health community course took collective action to develop their communities in ways that contributed positively to health outcomes. By working together, the women began to analyze their problems as public issues, especially social class discrimination, rather than private ones, and they became social actors in their communities for the first time. One group campaigned for, and got, better housing conditions. These types of programs offer a very different version of empowerment than is currently used by public health and adult literacy policymakers now. One conference, for example, promises to solve the health crisis through a conventional agenda. The conference is called: “Health Literacy: The Foundation for Patient Safety, Empowerment, and Quality Health Care” (<http://www.jcrinc.com/education.asp?durki=11276&site=5&return=11122>).

While functional health literacy promotes reading prescription labels, critical health literacy supports a type of education that challenges the aims and costs of pharmaceutical companies, like Pfizer (who fund many functional health literacy initiatives). Yet a perusal of health literacy literature reveals instrumental, rather than political approaches, which has little sponsorship (Nutbeam, 2000). And many critical health literacy programs disappear because they do not have the financial resources, support, or, lack the community organizing knowledge and skills to carry on into the future (Merideth, 1994). They also do not have the resources to prove their worth, in an era when education is infused with business models (Israel, 1994; Baptiste, 1998; 2001). Yet, their language lingers on in a co-opted discourse of health care as technocratic consumption (Wallerstein & Bernstein, 1994).

### **A Critical Survey of Functional Health Literacy**

From 2001-2006, the author searched major bodies of literature in four disciplines that address functional health literacy: Medicine, Law, Public Health, and Adult Literacy, to trace the definition, and find out why it has won such broad acceptance, especially in the U.S. Literature reviews in these disciplines were focused on (AHRQ, 2004, Brandes, 1996; Kerka, 2003; Kickbush, 2001; Sissel & Hohn, 1996; Rudd, Moeykens, Colton, 1999; Selden et al, 2000; Shohet, 2004). In addition, articles, editorials, medical and public health studies were also included in this critical survey. Then, a

discourse analysis was used to link functional health literacy to compliance (meaning, changing behaviors, attitudes, and identities to conform to medical procedures, practices, and belief systems) and the knowledge-based economy (typically defined as the “information society” driving economic development, and based on sci-tech models). The analysis revealed four major conceptual weaknesses of FHL, as it relates to the knowledge-based economy: 1) Absolutist policy language about the relationships between health and literacy that contradicts the preliminary research; 2) the conflation of assessment with knowledge; 3) the instrumental approaches to health education; and 4) the focus on technical communication and navigation problems of individuals, over structural problems in the health care system.

### **Health Literacy Relationships or Research Literacy?**

The first point, concerning health-literacy relationships, illustrates the importance of “research literacy” (Merrifield, 1997), because while the policy language sounds definitive, the research is in more infancy stages, and correlative, than cause-effect. Conclusions are considered tentative and further research is needed to clarify the extent of the relationship. (Ad Hoc Committee on Health Literacy, 1999). They are limited because “studies identify individuals and groups in which only the print component of health literacy skills is measured” (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 67) and with this, a full range of print is not differentiated (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 49-50). Claims, for example, that, “improving people’s literacy skills can lead to improving their health” (Proliteracy, 2003, p. 15), need to be qualified and contextualized.

Moreover, separating direct from indirect ‘effects’ is important (Centre for Literacy of Quebec, 2001) but, is rarely done. Direct effects are the inability to read prescribed materials and instructions, as well as noncompliance, miscommunication, and medical errors. Indirect effects are poor housing, environmental hazards, safety, lack of exercise, and underemployment, which have the most severe outcomes for health status (Perin in, Centre for Literacy of Quebec, 2001; Tett, 2003). Indirect effects are harder to measure, often hidden, on a macro level, and structurally-based (Sullivan, 2000).

### **Assessment Leading to Knowledge?**

The second point, concerning assessment, arises because patients might not tell doctors about their low literacy skills due to feeling ashamed, or they may not know that their literacy skills are indeed very low (Parikh, et. al., 1996 in Greenberg, 2001). Many of the 40+ million people who were categorized in the lowest levels of literacy, reported that they had no literacy problems at all (Kirsch et al., 1993). But what is low literacy according to these tests? A typical functional health literacy assessment question (NAAL) focuses on instrumental tasks around medical definitions, like (White, 2004, p. 8): “Vitamin E (tocopherol)—helps protect red blood cells. May aid the circulatory system and counteract the aging process. Best sources: wheat germ, whole grains, eggs, peanuts, organ meats, margarine, vegetable oils, green leafy vegetables”.

Test scores reveal very little about the strategies that people use in their communities to deal with medical texts, for example, letting someone else fill out forms, or, to read them, or, about vernacular health modalities. Still when doctors suspect that patients have literacy problems, they are given a literacy test right away so that they can know their levels. The Rapid Estimate of Adult Literacy in Medicine (REALM) is administered within five minutes, and consists of lists of medical terms that patients read (Shohet, 2004). Yet these tests are problematic and as Greenberg (2001) has pointed out, there are some ethical and validity issues with regard to testing low-literate patients in medical facilities, especially when the vocabulary triggers anxiety, and they don't mirror real-world tasks.

Materials assessment is also done since most medical texts are often at a 10<sup>th</sup> grade or higher level (Safeer & Keenan, 2005). The aim is to reduce the level to make it readable to people who have lower literacy levels. Researchers first evaluate materials to determine levels of reading difficulty in patient consents, prescriptions, brochures, diagnostic instruments, and instructions. Readability criteria include: user-friendly layouts, little jargon, large print-size and fonts, good color contrasts, cultural appropriateness, and incorporates sentence and word difficulty levels. Specific materials-based evaluation formulas, like the Fry graph, PMSOE/IKIRSCH, SAM, REALM, and SMOG are used (Shohet, 2004). Government initiatives in Australia, Canada, Europe, Sweden, UK, and U.S. have attempted to make these texts more

useable for patients by simplifying the writing level (<http://www.plainlanguage.org/Government/>). The Canadian Public Health Association (CPHA) has created good Plain Language guidelines. However, they have been used unevenly across the country (Shohet, 2004). These reforms are important first steps in making health care *information* more available, and more needs to be done to make health care, itself, accessible. The idea of health care as a right in the U.S., and universal health coverage, gets constantly attacked by well-financed medical-based industries, making it hard to sell to voters (Corn, 2003).

### **Health Literacy Education?**

Teachers are expected to instruct students on how to find, acquire, and, use medical information. The self-improvement model that predominates in classrooms reproduces health consumerism with health facts and procedures, overlooking pervasive problems. Functional health literacy curriculum guides advise teachers to coach students on vocabulary, and other issues related to health care usage. But the curriculum doesn't often focus on social factors, like crowded health clinics, long waiting periods, unhealthy living or working conditions, and the high costs of medical treatment, which, neither, "prepares students for what they might encounter nor legitimates these experiences when students encounter them" (Buttaro & King, 2001, pp. 55-56). Teachers may also correct students' cultural idioms and misnomers, like, "If You Have a Cardiac Arrest, Does it Mean You Go to Jail?" (Wrigley, 2003). Some researchers recommend using "specific examples [including] reading signs and postings, or news articles; understanding risk messages in TV ads; using a clock and calendar for medicine; using measurement tools such as a thermometer, a scale, or a peak flow meter; understanding and using charts." (Rudd and Santos, 2006). Rarely, however, do teachers allow for action-research on community-based problems, or, alternative or complementary approaches to health treatments (Sissel & Hohn, 1996). Critical health approaches are not considered to be part of the health literacy education economy. This is ironic in light of one study of a health project, in which higher self-esteem and motivation among students was increased through the use of participatory methods, which had equal value, and more, to the health literacy content. Furthermore, the teachers reported that 'soft skills' like dialogue, as well as team building, and unity were key student outcomes (Rudd, Zacharia, & Daube, 1998).

## **Communication Competencies or Systemic Screw-Ups?**

The focus is on communication competencies, “when words get in the way,” (Rudd, 2002b) rather than inherent problems in the health care system, what doctors, Richmond & Fein (2005, p. 1), call, “the health care mess.” Technical issues are highlighted; for example, the 2005 Annual Institute for Health Care Advancement was entitled, “Culture, Language, and Clinical Issues: Operational Solutions to Low Health Literacy” ([http://www.findarticles.com/p/articles/mi\\_m0EIN/is\\_2005\\_Feb\\_4/ai\\_n9493105](http://www.findarticles.com/p/articles/mi_m0EIN/is_2005_Feb_4/ai_n9493105)). These quick fix approaches disregard the research showing that discriminatory practices in institutions often play a major role in communication. Bonny Norton (2000) found in her study of women second language learners, that power relations (over communication competencies) inhibited them from speaking to professionals. Yet the problem, according to experts, is that patients with low English literacy and language competencies are unable to disclose their problems articulately, and to receive correct medical messages, unlike well-educated patients who, according to studies, verbally communicate well with doctors and provide them with higher-order descriptors in their conversations about their symptoms (Smedley, Stith, & Nelson, 2002; American College of Physicians, 2002). It would seem, then, that functional health literacy is a compensatory strategy for managing undesirable customers (Smedley, Stith, & Nelson, 2002 ) in a system focused on cost reduction (Brandes, 1996; Perkins et al., 1996). The time to talk and listen to patients is limited, and cooperative patients are needed (Smedley, Stith, & Nelson, 2002). Although the health care system has been characterized as being in a disastrous state with more medical errors and patient complaints than ever before (Institute of Medicine, 2003; Richmond & Fein, 2005), policy makers turn to vacuous competency measures. More compensation than, “cultural competence” is needed to rectify these inequities that reflect power relations in society.

## **Implications**

The development and transmission of functional health literacy has produced irrelevant health education protocols and practices that reduce people’s health problems to oral and written goods to be traded on the market (Robertson & Minkler, 1994). In a health transmission model (see, Rudd, 2002a), both medical providers and teachers, become change-agents to the “target population,” teaching the words that are

the cure, with the expectation that they will adopt instrumental knowledge in intended ways (Giorgianni, 1998, p. 21). The laser attention to functional health literacy, as a positive innovation to be adopted by patients, sidesteps a serious critique of the medical establishment, in terms of its domination by particular interest groups, their world views of illness trajectories, and their promotion of certain problems over others (O'Connor, 1995), for example, diseases with large lobbies, rather than politically charged issues (like abortion), that no one wants to champion, but which is critical for the poor.

More importantly, it does not tap into the complex sociological variables that public health research has shown to be the crux of the problem—especially poverty and social class (Aday 2001 in Chesnay, 2005). There are also workplace barriers, reduced public services, and high health care costs. Critical literacy programs need to be better supported because they address these barriers, and the underlying factors of poor health and access. These programs view people with low-literacy as agents of change too. By addressing the “indirect” issues that are most salient for people’s literacy and health problems, advocates for health literacy may undercut their financing (from corporations like Pfizer) but boost their integrity and grassroots power and voice by focusing on systemic causes of poor health and access, like, lack of livable wages and poor labor conditions (see, Auerbach & Wallerstein, 2005).

It would be important to critique the political language of the helping professions (Edelman, 1975) and the medical monopoly over words like “compliance,” “choice,” “health promotion” and “functional health literacy.” The functional health literacy discourse does not do this. Instead, it establishes and manages safe and “false economies” about health care and literacy (Levine, 1982, p. 249), that not only mask, but reify societal inequities. Medical anthropologist Kleinman says:

Get rid of the term compliance. It’s a lousy term. It implies moral hegemony ...instead of a model of coercion, look at a model of mediation. The culture of biomedicine is...powerful. If you can’t see that your own culture has its own set of interests, emotions, biases, how can you expect to deal successfully with someone else’s culture?” (in Fadiman, p. 261).

The functional health literacy discourse does not eliminate compliance, but instead promotes it as part of Choice Theory, while overlooking how people’s selections are



already limited, and disparaging them if they don't make the right decisions. They have low functional health literacy.

Functional health literacy is for those who cannot afford to pay for services. People with the highest incomes don't have to read the signs or look for good doctors. They simply tap into their social networks, query their friends, pay for boutique doctors, and receive help to navigate around the system. The accountant explains the bills when they are difficult to read or understand. They get the best care of all. Perhaps Denny Taylor's prophetic words best sum up the technocratic functional health literacy paradigm, in her book, *Toxic Literacies*:

Who lives and who dies is controlled by the subtexts of society. Official documentation hides the human rights violations that take place....There is an official form to deal with every life situation. On paper, whatever action is taken can be justified. It's all on the record. Through toxic forms of print we abdicate responsibility.” (1996, p. 14).

## **Bibliography**

AHRQ (2004). *New Evidence Report Illustrates Links Between Health Literacy and Health Care Use and Outcomes*. Press Release, April 8, 2004. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/news/press/pr2004/litpr.htm>.

Ad Hoc Committee on Health Literacy (1999). *Health literacy: Report of the Council on Scientific Affairs*, American Medical Association. *Journal of American Medical Association*. February 10, 281 (6): 552-557.

Auerbach, E. & Wallerstein, N. (2005). *Problem-Posing at Work: English for Action*. Grassroots Press.

Brandes, W. (Ed.). (1996). *Literacy, health, and the law*. Philadelphia: Health Promotion Council of Southeastern Pennsylvania, Inc.

Brandt, D. (2001). *Literacy in American lives*. Cambridge: Cambridge University Press.

Brandt, D. (2002). Reading, writing, and wealth (Speaker series no. 21). Minneapolis: University of Minnesota Center for the Interdisciplinary Study of Writing.

Brandt, D. (2005). Writing for a living: Literacy and the knowledge economy. *Written Communication* 22 (2), 166-197.

Baptiste, I. (1998). Towards A Pedagogy for Disempowering Our Enemies. Presentation at AERC, San Antonio, Texas, June 1998.  
<http://www.edst.educ.ubc.ca/aerc/1998/98baptiste.htm>.

Baptiste, I. (2001). Educating lone wolves: Pedagogical implications of human capital theory. *Adult Education Quarterly*, 51 (3), 184-201.

Boudin, Kathy (1983). Participatory literacy education behind bars: AIDS opens the door. *Harvard Educational Review*, 63 (2) 207-32.

Buttaro, L. & King, K. (2001). Understanding adult ESL learners. *Adult Basic Education*. 2, (1), 40-60.

Chesnay, M. (2005). *Caring for the vulnerable: Perspectives in nursing theory, practice, and research*. Sudbury, MA: Jones & Bartlett, Publishers.

Centre for Literacy of Quebec (2001). *Health literacy project*. Montreal: QC.

Comings, J. Sum, A. Uvin, U. (2001). *New skills for a new economy: Adult education's key role in sustaining economic growth and opportunity*. Boston: Mass Inc.

Corn, D. (2003). Health care for all—now. *The Nation* 276 (1), 4-5.

Edelman, M. (1974). The political language of the helping professions. *Politics and Society* 4: 295-310.

Erickson, F. (2005). Arts, humanities, and sciences in educational research and social engineering in federal education policy. *Teachers College Press*, 107 (1), p. 4-9.

Fadiman, A. (1997). *The spirit catches you and you fall down*. NY: Farrar, Straus & Giroux.

Friedsam, D, Kindig, D. *Consumer Health Literacy: Preparing for Changing Roles, Rights, and Responsibilities in Health and Health Care*. Wisconsin Public Health and Health Policy Institute Issue Brief. Volume 5(3), May 2004.

<http://www.pophealth.wisc.edu/uwphi/publications/briefs/may04brief.pdf>

Gee, J. (1996). *Social linguistics and literacies: Ideology in discourses*. Taylor & Francis.

Giorgianni, S. (Ed). (1998). *The Pfizer Journal: Responding to the challenge of health literacy*, 2 (1). New York: Impact Communications.

Graham, R. (2006). Lacking compassion: Sociological analyses of the medical profession. *Social Theory & Health*, 4, 2006, 43-63.

Greenberg, D. (2001). A critical look at health literacy. *Adult Basic Education*, 11 (2), 67-79.

Freebody, P. & Freiberg, J. (1997). Adult literacy & health: Reading and writing as keeping well-practices. *Adult Literacy Research Network*, 5, *Practice Series*. Queensland: Griffith University.

Hohn, M.D. (2002). Literacy, health, and health literacy. *Focus on Basics* 5, C, 20-25.

Institute of Medicine (2003). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press. Executive summary report <http://books.nap.edu/catalog/10027/html>. Retrieved February 28, 2005.

Kalichman, S. C., Ramachandran, B., & Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV seropositive men and women of health low literacy. *Journal of General Internal Medicine*, 14, 267-273.

Kennen, E.M., Martin, L., & Davis, T.C. (2004). Stories of women, words, and wellbeing. *Women Studies Quarterly*, 32, (1& 2), 90-99.

Kerka, S. (2003). *Health literacy beyond basic skills*. ERIC Digest 245. ERIC Clearinghouse on Adult, Career, and Vocational Education. <http://www.ericdigests.org/2004-1/health.htm>

Kickbush, I. (2001). Health literacy: Addressing the health and education divide. *Health Promotion International* 16 (3), 289-297 <http://heapro.oxfordjournals.org/cgi/content/full/16/3/289>.

Kirsch, I., Jungeblatt, A., Jenkins, L., & Kolstad, A. (1993). *Adult literacy in America*. Washington D.C.: US Department of Education.

Levine, K. (1982). Functional literacy: Fond illusions and false economies. *Harvard Educational Review*, 52 (3), 249-66.

Levine, D. (2001). *Health literacy: Implications for seniors symposium proceedings*. August 1-2, 2001. Washington, DC. US Department of Education. Division of Adult Education and Literacy.

Madden, M (2002). *Improving health literacy: a physician's perspective*. Lecture to Health literacy symposium Greater Pittsburgh Literacy Council, October 2002. Unpublished paper.

Marcus, E.N. (2006). The silent epidemic—the health effects of illiteracy. *The New England Journal of Medicine*, 335 (10), 1076. See: <http://content.nejm.org/cgi/content/full/355/4/339>.

Merideth, E. Critical pedagogy and its application to health education: A critical appraisal of the Casa En Casa Model. *Health Education Quarterly* 21 (3), 355-367.

Merrifield, J. (1997). Knowing, learning, doing: Participatory action research. *Focus on Basics*, 1 Issue A, 23-26.

Murnane, R. & Levy, F. (1996). *Teaching the new basic skills: Principles for educating children to thrive in a new economy*. New York: The Free Press.

Nielsen-Bohlman, L., Panzer, A.M., Kindig, D.A.. (2004). *Health literacy: A prescription to end confusion*. Washington, D.C.: Institute of Medicine.

Norton, B. (2000). *Identity and language learning*. England: Pearson Education Ltd.

Norton, M. (1997). Learning about literacy, health, and participatory education. *Feminist Literacy Workers Journal*, 1 (1), 6-11.

Nutbeam, D. (1999). Literacies across the lifespan: Health Literacy. *Journal of Literacy & Numeracy Studies* 9 (2), 47-55.

Pfizer (2001). “Experts: Low health literacy takes toll on patients.” July 12, 2001. Pfizer Press release. Retrieved March 5, 2005. <http://www.prnewswire.com/comp/688250.html>.

Pfizer’s Clear Health Communication Initiative 2003-2004. <http://www.pfizerhealthliteracy.com/>.

O'Connor, B. (1995). *Healing traditions*. Philadelphia: University of Pennsylvania Press.

Osborne, H. (2002). *In Other Words... What They Need to Know... Communicating About Risk. On Call*. <http://www.healthliteracy.com/oncallfeb2002.html>.

Osborne, H. (2004). *Health literacy from a-z*. Sudbury, MA: Jones & Bartlett Publishers.

Osborne, H. (2005). *Health literacy month*. <http://www.healthliteracy.com/hlmonth/faq.html>.

Perkins, J., Simon, H., Cheng, F., Olson, K., and Yolanda, V. (1998). *Ensuring linguistic access in health care settings: legal rights and responsibilities*. National Health Law Program. Los Angeles, CA. Henry Kaiser.

Polit, D., London, A., Martinez, J.A. (2001). *The Health of poor urban women: Findings from the project on devolution and change*. New York: MDRC.

Pridmore, P. (2006). Health literacy: A new communication challenge for health. *Education For All: Language Matters*. See: [ioewebsserver.ioe.ac.uk/ioe/schools/leid/docs/eidreview/EIDRev5P09to15.pdf](http://ioewebsserver.ioe.ac.uk/ioe/schools/leid/docs/eidreview/EIDRev5P09to15.pdf).

Proliteracy Worldwide (2003). *U.S. Adult literacy programs: Making a difference*. Proliteracy America. March 2003.

Ratzan S.C., Parker R. (2000). Introduction. In: C.R. Selden, M. Zorn, S.C. Ratzan, R.M. Parker (Eds.), *National Academies of Medicine Current Bibliographies in Medicine: Health Literacy*. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services, 2000.

Rudd, R. (2002a). A maturing partnership. *Focus on Basics*. 5, C, 1-10.

Reichmann, D. (2004). Bush discusses medical records works to solidify support in Southern state. [http://www.staugustine.com/stories/052804/nat\\_2354946.shtml](http://www.staugustine.com/stories/052804/nat_2354946.shtml).

Richmond, J.B. & Fein, R. (2005). *The health care mess: How we got into it and what it will take to get out*. Cambridge, MA: Harvard University Press.

Robertson, A. & Minkler, M. New health movement: a critical examination. *Health Education Quarterly* 21 (3), 295-312.

Rudd, R. (2002). Functional health literacy: A role for libraries. [http://metro.org/SIGs/pdfs/chi\\_rudd\\_4\\_30\\_02](http://metro.org/SIGs/pdfs/chi_rudd_4_30_02).

Rudd, R.(2002a). A maturing partnership. 1-7. *Focus on Basics* 5, Issue, C.

Rudd, R. (2002b). *Health literacy overview*. Harvard University, School of Public Health, Department of Health and Social Behavior, Health Literacy Studies, National Center for the Study of Adult Learning and Literacy. <http://www.hsph.harvard.edu/healthliteracy/overview.html>.

Rudd, R., Kirsch, I., & Yamamoto, K. (2004). *Literacy and health in America*. Princeton, NJ: Educational Testing Service.

Rudd, Moeykens, Colton [1999]. Health and Literacy: a review of the medical and Public health literature, chapter in Comings, Smith, Garner (eds), *Annual Review of Adult Learning and Literacy*. SF: Josey-Bass.

Rudd, R. & Santos, M. (2004). “Health literacy skills: A new focus,” Session 201, Meeting of the Minds Symposium. [www.researchtopractice.org/files/H\\_pdfs\\_abstracts/201\\_RuddSantos.pdf](http://www.researchtopractice.org/files/H_pdfs_abstracts/201_RuddSantos.pdf).

Rudd, R., Zacharia, C., & Daube, K. (1998). *Integrating health and literacy: Adult educators experiences*. Cambridge, MA: Harvard University, National Center for the Study of Adult Learning and Literacy.

Ruttenberg, J. (2006). In Connecticut, Bush talks of soaring health care costs. *New York Times*, April, 16, 2006, A19.

Safer, R. & Keenan, J. Health literacy: the gap between physicians and patients. *American Family Physician* (August 1, 2005). [http://findarticles.com/p/articles/mi\\_m3225/is\\_3\\_72/ai\\_n14919957](http://findarticles.com/p/articles/mi_m3225/is_3_72/ai_n14919957).

Selden, Catherine; Zorn, Marcia; Ratzan, Scott C.; Parker, Ruth M., compilers. *Health literacy* (2000). Bethesda (MD): National Library of Medicine; 2000. <http://www.nlm.nih.gov/pubs/resources.html>.

Shohet, L. (2004). Health and literacy: Perspectives. *Literacy & Numeracy Studies* 13 (1), p 65-84.

Shohet, L. (2005). Health literacy: More than words on paper. Presentation to the Centre for Literacy of Quebec, May 9, 2005. <http://www.ns.literacy.ca/whatwedo/collab/nsthink.pp>.

Singleton, K. (2002). *Health literacy and adult English language learners*. ERIC/NCLE Digest.

Sissel, P., & Hohn, M. (1996). Literacy and health communities. In P. Sissel (Ed.). *A community-based approach to literacy programs: taking learner's lives into account*. *New Directions for Adult and Continuing Education*, 70. San Francisco: Jossey-Bass.

Smedley, B.D., Stith, A.Y., & Nelson (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: National Academies Press.

Speros, C. (2005). Health literacy: Concept analysis. *Journal of Advanced Nursing* 50 (6), 633-640.

Sticht, T. (1997). NLA Discussion: Metaphors & Analogies In Adult Literacy Education: Commentary [10 paragraphs]. Available email: nla-approval@world.std.com.

Taylor, D. (1996). *Toxic literacies*. Portsmouth, MA: Heinemann.

Tett, L. (2003). [Health] Paper from the Adult Education Research Conference, San Francisco State University, San Francisco.

Waerness, K. (1996). The rationality of caring. In, S. Gordon, P. Benner, & N. Noddings (Eds.), *Caregiving: Readings in knowledge, practice, ethics, and politics* (pp. 231-254). Philadelphia: University of Pennsylvania Press.

Wallerstein, N. and Bernstein, E. (1994). Introduction to community empowerment, participatory education, and health. *Health Education Quarterly*, 2 (2), 141-148.

White, S. (2004). An overview of the 2003 National Assessment of Adult Literacy (NAAL). A webcast presentation September 8, 2004. [www.nifl.gov/nifl/webcasts/transcripts/NIFL\\_September2004NAAL.doc](http://www.nifl.gov/nifl/webcasts/transcripts/NIFL_September2004NAAL.doc).

Wrigley, H. (2001). Do you want to go to jail for cardiac arrest? Health and immigrants new to English. In Levine (Ed). *Health literacy: implications for seniors symposium proceedings, August 1-2 2001*, Washington, DC.: OVAE.

### **Author's Details**

Sondra Cuban has worked in, and been in advocate, for social justice in the field of adult literacy for the past ten years. She is a lecturer at Lancaster University, in Educational Research, and is researching the lives and literacy practices of women migrants in the service sector in Northwest England.

### **Correspondence**

s.cuban@lancaster.ac.uk