Promoting Health Literacy
Concept, Measurement & Intervention

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Preface

In the spring of 1830 in Quebec, my Great Aunt Esther turned 21 and packed a meager bag. There was no celebration. Esther was leaving home because abject poverty left her too weak to bear children or work the farm. She was unmarriageable, illiterate, and her family could not afford her keep. Life expectancy was 22.

Esther went to live and work as a servant in the convent of the Sisters of Providence who taught her to read and teach and tend the sick. She was 25 when they sent her home because she could not maintain her health. Undeterred, she started a school in her village. She trained other teachers and started more schools. She scandalized the French Canadian Catholic Church by teaching girls to read and by teaching boys and girls together in “mixed schools”. When she was 40, the Church officially recognized Esther and her teachers as the Order of the Sisters of Saint Anne. She became known as Mother Mary Anne. Aunt Esther lived to be 81; she dedicated her life to promoting literacy and health, especially for women and girls. Now, 120 years after her death, the Sisters of St. Anne still operate schools and hospitals across Canada and the northeastern United States (Mailloux, 1997). Despite her unconventional ways, in 2001 the Catholic Church beatified Aunt Esther as Saint Mother Marie Anne Blondin.

Aunt Esther was born two hundred years ahead of her time. Today her vision of literacy as the foundation for health, an escape route from poverty and the key to the advancement of women and society is an idea whose time has come. She inspires my work at the intersection of health and literacy.

*five times removed
Abstract

This interdisciplinary study extends and strengthens the U.S. clinical care approach to health literacy by 1) proposing a theoretical framework that focuses on functional health literacy (FHL); 2) field testing an instrument for measuring FHL; and 3) investigating the impacts of home visitation on parental FHL. The theoretical framework incorporates Nutbeam’s concept of health literacy as progressive levels of functional, interactive and reflective skills to measure FHL as corresponding progressive levels of health functioning. The intervention aimed to develop FHL as a personal asset through community-based health promotion efforts. The overarching goal, to enable parents to use health information and services in ways that maintain and promote health and so to exert greater control over family health and health actions, differs fundamentally from the clinical goal of overcoming deficient reading skill in patients in order to improve their health and ensure efficiency in the system.

In this action research project of the Home Visitors Research Network, six home visitation programs and one telephonic service implemented the Beginnings Guides Life Skills Development Curriculum to promote FHL and reflective functioning in disadvantaged parents during the prenatal to preschool period. Visitors collected data on the health functioning of 2532 parent/child pairs during up to 36 months of service, using the Life Skills Progression Instrument (LSP) and the Functional Health Literacy Measure (FHLM say film) derived from the LSP for this project. Parents demonstrated statistically significant improvement in FHL in periods as short as six months regardless of reading level. Results show that 1) home visitation promotes parental FHL; 2) it is possible to meaningfully measure FHL using the FHLM; 3) the public health model of health literacy promotion is practical for implementation, improves understanding of health literacy, and opens new directions for intervention. Reflection emerged as a literacy skill potentially as fundamental as reading ability to attaining and promoting functional health literacy. A national public health response to health literacy may be feasible through existing national
networks of home visitation programs with short and long term benefits accruing to entire families over their lifetimes, to the healthcare system, and to the schools.
# Table of Contents

Acknowledgements .................................................................................................................. 3

Preface .................................................................................................................................. 4

Abstract .................................................................................................................................. 5

List of Figures ............................................................................................................................ 9

Chapter 1 Health Literacy: Clinical Risk & Personal Asset ...................................................... 13

  The Problem & Promise of Functional Health Literacy ......................................................... 14

  How We Lost Sight of the Function in Functional Health Literacy ...................................... 17

  Health Literacy as a Clinical Risk ......................................................................................... 19

  Health Literacy as a Personal Asset ..................................................................................... 21

  Research Question & Approach .......................................................................................... 26

  Organization of the Dissertation ......................................................................................... 30

Chapter 2 Health Literacy Measurement: Toward a Theoretical Framework ......................... 32

  Health, Literacy & Health Literacy in the Literature 1970-2000 ......................................... 32

  Health Literacy in the Literature 2000 - 2009 ...................................................................... 38

  Health Literacy from the Clinical Standpoint ....................................................................... 44

  Health Literacy from the Public Health Standpoint ............................................................. 53

  A Theoretical Framework for Measuring Health Literacy as an Asset ............................... 55

Chapter 3 Health Literacy Intervention: Promoting Function ............................................... 64

  Focus Intervention on Disadvantaged Young Families ....................................................... 65

  Home Visitation: A Feasible Channel for Health Literacy Promotion ............................... 69
List of Figures

Figure 1: Health literacy conceived as basic skills compared to health literacy conceived as functioning. Health literacy as functioning is a broader concept that includes health literacy as skill.................................................................17

Figure 2: Basic literacy skills do not readily translate to functioning in the healthcare system..........................................................................................................................52

Figure 3: Nutbeam (2000) applied Freebody & Luke’s (1990) conceptualization of “types” or “layers” of literacy to health literacy.................................................................57

Figure 4: Progressive levels of health literacy correspond to progressive levels of health functioning. In this theoretical framework, health literacy can be measured as progressive levels of health functioning..........................................................61

Figure 5: This logic model of health literacy promotion in the prenatal to preschool period illustrates how pregnancy and early parenting present a unique opportunity to establish appropriate health services utilization and personal health practices among primary health decision makers in growing families with potential lifelong benefits for entire families, the healthcare system and the schools........................................68

Figure 6: In the “Teach by Asking” model, reflective questions facilitate development of skills for effective use of health information and services, increase self-efficacy, support child development and school-readiness........................................................................82

Figure 7: This reflective drawing by Laurel Burch from the Beginnings Parent’s Guide promotes family literacy and raises issues related to reading. Reflective drawings and “coloring conversations” convey key messages without words, increase understanding, influence attitudes, and support behavior change...............................................................83
Figure 8: The LSP Parental Functional Healthcare Literacy Scale (FHcL), one of two scales comprising the FHL, rates parents’ use of healthcare services and health information. The shaded area represents the target range characterizing adequate to optimal functioning in the healthcare system.

Figure 9: The LSP Parental Functional Selfcare Literacy Scale (FScL), one of two scales comprising the FHL, rates parents’ ability to exert control over their personal health and health actions, their children’s health. The shaded area represents the target range characterizing adequate to optimal functioning in the healthcare system.

Figure 10: The primary purpose of the brief literacy screen (ELF) is to refer parents to literacy enhancing services. The data estimates reading level by producing proxy REALM scores.

Figure 11: Number of parent-child pairs followed at each site.

Figure 12: Race/ethnicity distribution by site.

Figure 13: Functional Health Literacy Scores at Initiation of Home Visitation Service show at baseline, only 43% of parents had adequate healthcare literacy; 59% had adequate selfcare literacy.

Figure 14: Change in Functional Healthcare Literacy and Selfcare Literacy for Parents with four observations. Functional health literacy increases over time with home visitation (p<.001).

Figure 15: After 12, 18, or 24 months of home visitation, experimental parents have significantly higher scores for Functional Selfcare Literacy (p<.001) and Functional Healthcare Literacy (p<.001) than matched comparison parents who have not yet had home visits.
Figure 16: Change in Functional Healthcare Literacy over time by reading level. Parents with lower estimated reading level made significantly greater gains in functional healthcare literacy than those with higher estimated reading level (p<.001)……………………………………102

Figure 17: Change in Functional Selfcare Literacy over time by estimated reading level. Parents made significant progress in self-managing personal and child health, regardless of reading level (p<.001)…………………………………………………………………………………………………………………………………………………………………………………104

Figure 18: Change in Functional Healthcare Literacy over time by race/ethnicity. Overall, parents in home visitation programs achieved a significant increase in healthcare literacy over time (p<.001)…………………………………………………………………………………………………………………………………………………………………………………105

Figure 19: Change in Functional Selfcare Literacy over time by race/ethnicity. Overall, all groups improved, but patterns of change in Functional Selfcare Literacy varied by race/ethnicity (p<.05)…………………………………………………………………………………………………………………………………………………………………………………106

Figure 20: Change in Functional Healthcare Literacy over time by age group. Younger parents start at a disadvantage and can make immediate gains in functional healthcare literacy to achieve par with their older counterparts in the first six months of home visiting………107

Figure 21: The correlation between initial FHcL score and change in FHcL after 12 months of home visitation: r =-.49; p<.001(n=577) indicates home visitation seems to have greater impact on the Functional Healthcare Literacy scores of lower functioning parents………108

Figure 22: The correlation between initial FScL score and change in FScL after 12 months of home visitation: r=-.40; p<.001 (n=614) shows home visitation also seems to have greater impact on the Functional Selfcare Literacy scores of lower functioning parents…………………………………………………………………………………………………………………………………………………………………………………109
Figure 23: Change in Functional Healthcare Literacy varied significantly by site (p<.001)........................................................................................................113

Figure 24: Between-site differences in FHcL scores of Experimental parents after 12-24 months of service and Comparison parents who had not yet obtained home visitation. Matched comparisons confirmed FHcL scores differ by site (<.001). Further analysis showed that parents in three sites (GA, CA, and MT) made statistically significant gains……..114

Figure 25: Matched comparison of parents’ Functional Selfcare Literacy scores shows scores differ significantly by site (p<.001); but the difference between groups is similar p<.001)........................................................................................................116
Chapter 1
Health Literacy: Clinical Risk & Personal Asset

In 2009, researchers and policymakers from the many disciplines concerned with the intersection of literacy and health are renegotiating the meaning and measure of health literacy. Efforts to achieve consensus on a broader interdisciplinary understanding and approach to health literacy face significant challenges. For example, both health and literacy are defined differently within and across disciplines addressing health literacy. Perhaps most striking are the differences between the clinical and public health approaches to health literacy research and practice (Nutbeam, 2008; Pleasant & Kuruvilla, 2008).

Through this project, I aim to contribute to an interdisciplinary understanding of functional health literacy beyond the current focus on reading in a clinical setting. By expanding our thinking about the function in functional health literacy, researchers and practitioners can reach a fuller, richer understanding of literacy and its relation to health, and discover new directions and strategies for health literacy measurement and intervention.

Functional literacy matters. Although there is a range of definitions of functional literacy, it is recognized as the currency that enables adults to participate more fully in society, both economically and socially, and to understand and exert a higher degree of control over their lives (McCaffrey, Merrifield & Millican, 2007).

More specifically, functional health literacy matters. While definitions abound, it is recognized as the currency that enables adults to access and participate in healthcare (Institute of Medicine, 2004a) and to exert a higher degree of control over their health and health actions (Nutbeam, 1998).

In this chapter, I discuss the concepts of functional literacy in adults, and more specifically, functional health literacy. I trace the development of the dominant clinical approach to
health literacy research, and then introduce the emerging alternative public health perspective. I expand the public health approach to incorporate an extended concept of functional health literacy that encompasses both the clinical and public health perspectives.

The Problem & Promise of Functional Literacy

The multiple disciplines involved in health literacy research have not achieved a standard lexicon. In research articles, government reports, and industry white papers, terms related to literacy and health literacy are used imprecisely and interchangeably. To clarify the subsequent discussion, consider the meanings of functional literacy and functional health literacy. Functional literacy is first adult literacy.

Adult literacy came to the national agenda, and health literacy came to the research agenda, in the mid 1990s following President George H. Bush’s campaign for adult literacy. Bush signed the National Literacy Act of 1991 (Public Law 102-73). The legislation marked a significant evolution in the meaning of literacy for adults in America. It established the concept of adult literacy as functional literacy. “Literacy means… 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, to achieve one's goals, and develop one's knowledge and potential.” (National Literacy Act of 1991 U.S. Public Law 102-73) Emphasis added.

The National Literacy Act aimed to broaden the concept of adult literacy beyond the “Three Rs” (reading, 'riting, and 'rithmetic) because the fundamental but narrow view of literacy as basic skills for acquiring knowledge leaves out other literacy skills, and other “types” of literacy that adults use for many practical purposes (functions). Still, there is a range of definitions of functional literacy; most focus on basic literacy skills. In its narrowest conceptualization, functional literacy also has been termed “autonomous” literacy (Culligan, 2005). In the autonomous view, functional literacy is seen as a generic set of technical skills independent of social context, so that

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1 Adult literacy is defined in the National Literacy Act of 1991 as literacy in adults over age 16.
reading skills, for example, transfer across situations without problems. The functional aspect is limited to autonomously performing certain fundamental literacy tasks (word recognition) or everyday tasks (fill out a form). This view relies on the assumption that a person with basic literacy skills can acquire knowledge about any subject; it further assumes that knowledge enables a person to function without assistance within any given, albeit limited, arena. In this narrow view of literacy as skills, literacy is a fixed trait that you have or you don't. Satisfactory scores on skills tests, such as reading and comprehension tests, or knowledge tests, demonstrate literacy as skills.

With Longsdale and McCurry (2004) and McCaffrey et al. (2007), I take a broader, more practical, sociocultural view in which literacy is shaped within social practices and relies on critical reflection to make meaning from information. Here the functional aspect extends to purposeful action in various social contexts so that functional literacy involves putting into practice in “real life” not only reading, ‘riting and ‘rithmetic, but a wide range of cognitive and non-cognitive communications, problem solving, interpersonal and lifelong-learning skills, notably critical reflection. In this broader view of literacy as functioning, literacy evolves over time with need, opportunity, experience and resources. Literacy as functioning is demonstrated by actions, behaviors, and practices.

In this way of thinking of literacy as functioning, a person may have, at one time, many context-specific functional literacies at different levels of proficiency. This idea of multiple functional literacies expands the concept of adult literacy beyond simple mental processing in order to understand; to include conceptual and practical knowledge and various ways and reasons for applying a range of cognitive and practical skills in order to act (function). For example, functional computer literacy enables a person use a computer, but not necessarily to read the manual or understand programming language. Similarly, functional health literacy enables people to use the healthcare system and take care themselves, but not necessarily to read insurance documents or understand medical terminology.
The National Literacy Act and its definition of adult literacy recognize that literacy as skills is inextricably linked to literacy as function. Basic literacy skills are fundamental, perhaps necessary, but clearly insufficient for effective functioning in many areas of modern society, particularly in the health arena with its unique, rapidly changing, highly technical and complex knowledge base, logic, language and culture. A person who passes a reading or comprehension test, thereby demonstrating literacy as skills, may nonetheless be unable to function adequately in a particular real life context. For example, a person with advanced reading and numeracy skills may struggle with healthcare tasks such as operating a medical device like a glucose monitor, or evaluating the relative risks of chemotherapy versus surgery versus watchful waiting. That highly literate person is said to have low functional health literacy. On the other hand, a person living with a chronic disease who has developed practical knowledge and experience with treatment regimens may have strong functional health literacy despite low reading skills. Therefore, literacy skills tests capture the most fundamental aspect of literacy (basic mental processing skills), but miss the deeper meaning and purposes of literacy for adults. I will return to measurement in Chapter 2.

Here it is useful to note that adjusting our focus from the narrow view of health literacy as skills to the broader view of health literacy as functioning also serves to broaden the dominant model of health literacy as literacy in clinical settings to health literacy as it is operationalized for this study in the alternative public health model. Figure 1 illustrates that health literacy as skill and health literacy as function are linked, and differentiates health literacy conceived as skill from health literacy conceived as function.
Figure 1. Health literacy conceived as basic skills compared to health literacy conceived as functioning. Health literacy as functioning is a broader concept that includes health literacy as skill.

*How We Lost Sight of the Function in Functional Health Literacy*

*Low Functional Literacy as a Risk to Economic Health*

Research interest in health literacy grew from The National Literacy Act of 1991, a highlight of then-President G. H. Bush’s campaign for adult literacy. The legislation reflects intentions at the highest level to improve adults’ literacy skills in order to improve their functioning as workers and citizens. Some observers suggest the lingering literacy “crisis” of the 1990s and 2000s, like other literacy crises in recent history, is a politically motivated attempt to explain deteriorating economic conditions (Hourigan, 1994). Taking a deficit approach, Bush and Congress presented adults’ low functional literacy as a cause of low productivity, a risk to individual and national economic opportunity. To gauge how poorly Americans function on the job and in society, Bush commissioned the 1992 National Adult Literacy Survey (NALS). Results showed widespread low literacy skills among U.S. adults (Kirsch, Jungeblut & Kolstad, 1993) raising concern throughout the economy. While interpretation of results by the media and experts in many fields generated significant controversy (National Academy of Science, National
Research Council, 2005), improving adults’ functional literacy promised to be the key to equitable individual economic opportunity, American global competitiveness, and civic participation.

Low Functional Health Literacy as a Risk to Personal and Public Health

Following Bush’s lead, and taking a similar deficit approach, commercial and professional healthcare interests commissioned clinical and academic research to identify the prevalence of low health literacy, and to quantify its risks to individual and public health and to the healthcare system (American Medical Association, 1998; Pfizer, 2009). Critics claim the initiation of research on functional health literacy may have been a politically motivated attempt to explain high costs, low quality and inequities in the healthcare system (Cuban, 2006).

Beginning in the mid 1990s, health literacy research in the U.S. introduced a clinical\(^2\) perspective distinctly different from previous studies related to the intersection of literacy and health. In the clinical (deficit) orientation, low health literacy is seen as a risk to patients and the healthcare system, which healthcare professionals need to identify and manage (Nutbeam, 2008; Pleasant & Kuruvilla, 2008). Soon after publication of National Adult Literacy Survey (NALS) results in 1993, authoritative reports stated “over half the U.S. adult population, 90 million Americans, lack the literacy skills necessary to function in the healthcare system” (Williams et al., 1995; Parker, Baker, Williams & Nurss, 1995). Over the next decade, this finding was repeated in the journals of nearly every medical specialty (Baker, Parker, Williams, Clark & Nurss, 1997; Moon, Cheng, Patel, Baumhaft & Scheidt, 1998; Baker, Parker, Williams, & Clark, 1998; Baker, Williams, Parker, Gazmararian & Nurss, 1999; Schillinger, Grumbach & Piette, 2002). Improving functional health literacy promised to be the key to efficient, effective, equitable healthcare (U.S. Dept of Health and Human Services, 2000; IOM, 2004a).

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\(^2\) Clinical refers to the bedside or clinic, pertaining to actual observation and treatment of patients, as distinguished from theoretical or experimental or occurring outside clinical settings. In the literature, the term medical is used interchangeably with clinical
From the outset of health literacy research, the perceived need to identify and manage low health literacy in patients led researchers to pursue clinically feasible measures\(^3\). In the quest for quick standardized screening tests, researchers and policymakers dropped the function from functional health literacy and shifted the focus back to basic technical skills and simple reading skills tests using medical vocabulary.

**Health Literacy as a Clinical Risk**

In the clinical approach, health literacy is viewed narrowly as basic literacy skills transferred to a medical setting. The Institute of Medicine defined health literacy as: “the … capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Dept of Health and Human Services, 2000; Institute of Medicine, 2004a). Emphasis added

Under this definition, health literacy is operationalized as reading to understand medical and healthcare information. The Institute of Medicine (IOM) (2004a) definition alludes to functioning (making health decisions) as the purpose of health literacy, but focuses exclusively on mental processes and transmission of information from experts to patients. The report goes on to say that “Health literacy comes from a convergence of education, cultural and social factors, and health services. While reading, writing, and math skills make up part of the basis of health literacy, many other skills and abilities are also important, such as speaking, listening, having adequate background information, and being able to advocate for oneself in the health system” (IOM, 2004a). This suggests that both system and social factors, in addition to reading and other cognitive skills, determine health literacy (Paasche-Orlow, 2007). But the functional focus, and the concern for social and system factors in health, is lost by zooming in to measure one readily quantifiable technical skill, reading ability. Thus, the prevailing fundamental but narrow clinical view of health literacy, together with narrower measures, limits understanding of health literacy to reading ability in a clinical setting.

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\(^3\) A clinically feasible measure is useful in treatment settings, meaning quick, simple, standardized, “elegant”. 
Further, the research focus on patients’ inability to read and understand medical information has restricted intervention to making information easier to understand by reducing cognitive demand. This important work reduces a significant barrier to health by making knowledge of disease, prevention and treatments more accessible for both skilled and unskilled readers (Berkman et al., 2004). However, the accumulation of research makes clear that while reading to understand information is an important part of functional health literacy, it is insufficient to achieve the goals shared by all concerned: effective use of the healthcare system, good selfcare and ultimately, improved health.

Practically speaking, the problem with the exclusive focus of health literacy intervention on reading and information is this: Information is like money. You need it; and the more the better. But it is not simply the money that you need; it is what the money enables you to do. Similarly, you need information for health, and generally, more information is better. But it is not simply information that you need; it is what the information enables you to do. That is the function in functional health literacy.

This study aims to complement the prevailing understanding of functional health literacy with the concepts of reflection and health functioning because the deeper meaning of literacy for health is not adequately realized, conceptually or as a matter of practice and intervention, when viewed simply as a cognitive deficit. By taking a wider view of health literacy that includes both the range of literacy skills and health functioning, researchers, practitioners and policymakers can achieve a fuller richer understanding of adult literacy and its links to health. By measuring not only skill, but also functioning, we can better understand how to make information more useful to people who need it. And we can discover new directions and strategies to take intervention to the next level, beyond facilitating understanding to facilitating functioning.
Health Literacy as a Personal Asset

The Public Health Approach

In the intervention presented here and its evaluation, I worked from a broader understanding of functional health literacy as *functioning* in the healthcare system and other health contexts, rather than as one technical *skill* (reading) applied in a clinical setting. I approached functional health literacy as a personal and community *asset* to be developed, rather than approaching a deficit of basic literacy skills as a health *risk* to be mitigated. I aimed primarily to facilitate functioning, rather than solely to facilitate understanding information.

My approach stems from my standpoint (Harding, 2006) as a certified public health education specialist. I worked from the public health concept of literacy and health literacy which is rooted in public health education and health promotion. *Public health education* is an interdisciplinary field that combines adult education and health promotion, epidemiology, biostatistics, and environmental health. *Health promotion* is the process of enabling people to increase control over, and improve their health. The concept holds that to reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment, including use of the healthcare environment (World Health Organization, 1986).

The science to support this conceptualization of health literacy as an asset than can be built through health promotion efforts is less well developed than the clinical model and more prominent outside the U.S., particularly in Canada, Australia and U.K. It is focused on the development of skills and capacities that enable people to exert greater control over their health and the factors that shape health (Nutbeam, 2008). This overarching goal to enable people to control their health and health functioning is fundamentally different from the clinical goal of overcoming deficient skills in patients in order to improve their health and ensure efficiency in the system.
The public health view incorporates educational research on literacy, adult learning and skills acquisition, as well as concepts of health promotion (Freebody & Luke, 1990). From this perspective, health literacy is an outcome of health promotion efforts. In the public health asset model, as in the clinical risk model, intervention aims to develop knowledge, but the public health approach goes further. It focuses on promoting health functioning, that is, on putting knowledge into practice to exercise greater control over one’s health and health actions (Nutbeam, 2000).

The public health asset model uses the World Health Organization’s (WHO) definition of health literacy, which reflects a health promotion orientation: “Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (Nutbeam, 1998).

The WHO definition goes on to say, “Health literacy implies the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.”

This alternative perspective extends the concept of health literacy beyond reading to functioning in society, beyond the individual patient to families and social networks, beyond clinicians to broader communities of care, and beyond healthcare to behavioral and lifestyle factors and the social determinants of health4. Therefore, health literacy is seen as equally important in the public sphere and in healthcare settings (Pleasant & Kuruvilla, 2008).

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4 Social determinants of health: the economic and social conditions under which people live which determine their health (WHO, 2003).
If one accepts the idea that health literacy is an independent concept, meaning an idea separate from literacy, which describes the skills and capacities that enable people to exert greater control over their health and health actions, this has important implications for measurement, which are addressed in Chapter 2. To my knowledge, other than the Functional Health Literacy Measures (FHLM say *film*) derived from the Life Skills Progression instrument (LSP) (Wollesen & Peifer, 2006) for this project, no measures have been developed to assess individual health literacy in terms of a person’s ability to use health information in ways that promote and maintain health (Paasche-Orlow & Wolf, 2007).

Conceptualizing functional health literacy by focusing on function opens new directions for intervention. Health education to improve people’s knowledge, understanding, and particularly capacity to act, should be directed not only at improving compliance with prescribed therapeutic regimens, but also at changing personal lifestyle and behaviors and improving health functioning. Further, health education also can raise awareness of the social determinants of health and can be directed towards the promotion of actions which may lead to modification of these determinants (Nutbeam, 2008).

In this study, I take the public health asset approach to functional health literacy. At the same time, with Nutbeam (2008) and others (Baker, 2006; Paasche-Orlow, 2007; Pleasant & Kuruvilla, 2008), I acknowledge the importance of the clinical risk model’s attention to improving information and its delivery, and to increasing health services providers’ sensitivity to the negative impacts of low literacy skills on health and access to healthcare information and services. Both the risk and asset perspectives on health literacy are important and necessary to achieve the common goal of improving health.

Paasche-Orlow and Wolf (2007), working in the clinical risk model, proposed three promising areas for intervention to improve health in persons with low reading skill: access to- and utilization of healthcare, patient-provider interaction, and self-management of disease,
particularly chronic conditions. My intervention, in the public health model, aims to improve health in persons with both higher and lower reading skills by promoting health functioning. I address the goals of both clinical and public health models by promoting and monitoring use of healthcare information and services along with self management of personal and family health at home.

This study further departs from the clinical approach to health literacy by locating the intervention in community-based home visitation programs. I targeted parents in their homes rather than patients in clinical settings. The clinical risk model is restricted to application to patients in clinical settings. Interventions in community settings are rare. I found no reports of health literacy intervention through home visitation in the health literacy literature.

Home Visitation as a Channel to Promote Functional Health Literacy

Home visitation programs intend to promote multiple aspects of functioning in parents of very young children including health functioning (Gomby, 2005). Home visitors are nurses, social workers, health educators, or paraprofessionals who link parents to healthcare and community resources, and provide social support, practical assistance, information, and health and parenting education. Some programs use instruments such as the Life Skills Progression (Wollesen & Peifer, 2006) to monitor progress toward higher levels of functioning, including health functioning. A large national infrastructure is in place to support home visitation. State and national networks of home visiting programs serve over 400,000 families annually (Gomby, 2005). An intervention that effectively incorporates health literacy promotion into the usual activities of home visiting could be efficiently implemented on a national scale through the existing infrastructure.

Beyond the feasibility of national-scale intervention through home visitation, arguments in favor of intervening with disadvantaged families with young children can be made on the grounds of fairness and social justice (WHO, 2003), new understanding of child development (National Academy of Science, National Research Council, 2000), and economic efficiency (Heckman, 2006).
The Emerging Role of Reflection in Functional Health Literacy

Specifically, in this study I examined the impacts of home visitation incorporating the Beginnings Guides Life Skills Development Curriculum on functional health literacy in disadvantaged parents of very young children. A hallmark of the curriculum’s approach is its emphasis on reflection and reflective practices and teaching strategies. Primarily, the curriculum seeks to promote functional health literacy and reflective functioning. During the intervention, I presented these as two separate life skills. In light of literacy theories and the psychology theory of reflective functioning (Fonagy & Target, 1997; Slade, 2005), the study results suggest that functional health literacy and reflective functioning are closely linked.

Reflective functioning refers to the essential human capacity to understand behavior in light of mental states and intentions (Slade, 2005). The curriculum describes reflective functioning as a process of “Think Link & Respond”: Think about the behavior, event, comment, relationship or feelings (Why is the baby crying?); Link to your experience and knowledge (Is he hurt, wet, cold, hungry, scared, sick?); formulate a purposeful Response (I’ll comfort him and take his temperature) (Smith & Wollesen, 2004). Adults who have not learned this process of reflection react based on emotion without thinking about possible sources of their emotional reaction and without linking to their knowledge of the child’s temperament and other potential explanations for the child’s behavior (“Shut up! You are just crying to make me mad!” Parent yells, shakes the baby and leave him alone.) They function at a lower level, particularly in relation to parenting and health. Research in the last decade shows that reactive parents raise reactive children who become reactive adults. Reflective parents raise reflective children who become reflective adults (Grienenberger, Kelly & Slade, 2005). In this project, supervisors and home visitors were trained to promote reflective functioning in themselves and in parents and their infants/toddlers.

5 Reflective functioning: capacity to think about and see the links between events, behavior, feelings, and knowledge, and to formulate a purposeful response. In short, to Think, Link & Respond (Smith & Wollesen, 2008).
Reflection links the concepts of functional literacy, health literacy and reflective functioning. Literacy scholars describe reflection as a higher level literacy skill required to make meaning from information (Longsdale & McCurry, 2004). The concept of health promotion holds that to achieve health, a person must be able to identify and realize aspirations, satisfy needs, and change or cope with the environment (WHO, 1986). Working from the health promotion concept, and realizing that these objectives require reflection, Nutbeam (2000) extends the idea of literacy as reflection to health literacy so that reflection is a higher level of health literacy required to make meaning of health information. Reflective functioning can be understood as basing one’s actions on reflection, (functioning reflectively). If functional health literacy is demonstrated by health related actions and practices (functioning), then reflective health literacy also is demonstrated by reflective functioning. It could be that the process of reflective functioning (Think, Link & Respond) also describes the process of high level functional health literacy, meaning using reflection to make meaning from information (Think, Link) and using information to maintain or promote health (Respond). Reflection, perhaps more than reading, may be central to achieving adequate functional health literacy.

Research Question & Approach

I explored the lens of reflection and used it to understand the conceptualization, measurement and promotion of health literacy, as well as the evaluation reported here. This project of the Home Visitors Research Network6 was envisioned as the initial cycle in a program of action research investigating home visitation as a potentially effective channel for health literacy promotion. Action research, sometimes called "practitioner research", is a reflective process in which practitioners undertake research to improve their own practice by learning from experience. In this project, the home visitor/researchers explored the effectiveness of home

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6 The Home Visitors’ Research Network (HVRN) is an informal collaborative for action research on health literacy and home visitation. HVRN includes the participating sites in this study and other home visitation programs trained in use of the Beginnings Guides curriculum and the Life Skills Progression instrument (LSP) (Wollesen & Peifer, 2006)
visitation in promoting functional health literacy by comparing results of their different program models which differ in a number of ways, including the extent of their use of a reflective approach.

The action research method begins with reflection (What is my concern? Why am I concerned? What evidence can I generate to show the situation as it is and as it unfolds? What can I do about the concern? How can I ensure my conclusions are justified?) and then follows an iterative process of Act, Reflect, Revise (Forest and McNiff, 2007 p. 222). Action research leads to identification of ineffective practices to discontinue, theory-grounded “promising practices” to develop further, and evidence-based “best practices” for rapid dissemination and replication. The process continues until satisfactory solutions and methods are achieved (Koelen, Vaandrager & Colomer, 2001).

The primary research question is this: Does home visitation using the Beginnings Guides Life Skills Development Curriculum promote parental functional health literacy? The null hypothesis is: Home visitation has no significant effect on parental functional health literacy, and there is no difference between participants with higher and lower reading levels.

Exploratory research questions are: Who progresses to higher levels of functioning? What affects progress? Is progress into the target range of functioning related to reading ability, race/ethnicity, age, program factors or home visitor practices? Is progress related to maturation or to community events or policy changes that may have occurred during the observation period? Is progress limited to parents who are higher functioning at the outset?

I addressed these questions through secondary analyses of a database compiled in a previous study by combining data contributed by the participating sites for a field
test\(^7\) of the LSP/Functional Health Literacy Measure (FHLM –say *film*) developed for this project. The field test was a two-year (September 2006 – August 2008) quasi-experimental multi-group cohort study using multiple waves of measurement. Previous analyses demonstrated the LSP/FHLM\(^8\) is reliable and sufficiently valid to warrant further use and testing. In the present study, I evaluate the intervention by examining changes in parents’ FHLM scores over time in home visitation by site, age, ethnicity and reading ability.

A matching process was used to create a “no treatment” comparison group from initial LSP measurements of well-matched parents enrolled in the same programs in the same timeframe. Thus this study used both a longitudinal approach to examine the change achieved over time by the parents in these programs, as well as a matched comparison group. The comparison group permitted me to address a number of differences in the standards of the programs, and known or unknown community level changes unrelated to home visitation (changes in transportation or access to health clinics, or policy changes at a state or national level which could affect parents’ ability to function in the health care system).

Qualitative data from interviews with the home visitors and their supervisors who implemented the intervention and collected the data address adherence to best practices for home visitation (Gomby, 2005). Analyses of these data revealed similarities and differences between the sites’ to elucidate variations in results. Proceedings of the closing reflection conference described interpretations of the data and preliminary findings by visitors and supervisors, funders, researchers, and national experts in home visitation and health literacy.

\(^7\) Grant # RO3 HD055618-01 was jointly funded by the Health Resources and Services Administration Agency for Healthcare Research and Quality, National Institutes of Health Office of Behavioral and Social Science Research and the National Institute for Child Health and Human Development.

\(^8\) The Functional Health Literacy Measure (FHLM), the primary measure used in this study, consists of selected items from the Life Skills Progression instrument (LSP) (Wollesen & Peifer, 2006). For ease of reading, I shorten the acronym LSP/FHLM to FHLM throughout this document.
These qualitative data suggested additional questions and future research regarding promotion of functional healthcare and selfcare literacy practices and the role of critical reflection in improving the health of adults with low literacy.

Summary

In this intervention study, I broke from the prevailing clinical approach to health literacy research in several ways. First, conceptually I worked from a broader understanding of health literacy that includes basic literacy skills and a range of life skills as well as health functioning (actions and practices), and includes both healthcare and community settings. I approached functional health literacy from a public health education standpoint as a personal and community asset to be built, rather than approaching a deficit of literacy skills in clinical settings as a risk to be mitigated. I aimed beyond facilitating understanding or knowledge acquisition to facilitating reflective health functioning.

Secondly, I measured health literacy longitudinally as progressive levels of health functioning, rather than using conventional one-time reading skills tests. Thirdly, I located the intervention in home visitation programs; I targeted parents in their homes rather than patients in clinical settings. Finally, in the evaluation, I made health literacy an outcome of health education and health promotion efforts (an end), as opposed to an independent variable that may influence health or treatment outcomes (a means). These innovations reflect my standpoint (Harding, 2006) in public health education and health promotion.

My study illustrates that, by conceiving health literacy broadly as both function and skill, and measuring health literacy as progress toward higher levels of health functioning, researchers and policymakers can increase understanding of health literacy beyond the current focus on reading ability in a clinical setting and discover new directions and strategies for intervention. It demonstrates that existing national networks of home visitation could be an effective, efficient channel for national-scale intervention to promote functional health literacy in disadvantaged
parents of young children – the healthcare decision makers in growing at-risk families. While the data are insufficient to attribute effects to any particular element of home visitation, results suggests that home visitation using the reflective approach of the Beginnings Life Skills Development Curriculum does promote parental functional health literacy in periods as short as six months, regardless of reading ability. The results suggest further research on the role of reflection in health literacy promotion in community settings, perhaps with implications for clinical settings as well. Further, the Beginnings Life Skills Development Curriculum warrants replication and further evaluation to identify best practices to promote parental functional health literacy through home visitation.

Organization of the Dissertation

Chapter 2 opens with a review of the medical and public health literature on health and literacy summarizing trends from 1970 through the mid 1990s when the term “health literacy” first appeared in the medical literature. Then I explore conceptual, measurement, and intervention approaches to health literacy as they developed over the last 15 years in response to the 1991 National Literacy Act and results of the 1993 National Adult Literacy Survey.

I explore in more detail two distinctive concepts of health literacy: the dominant clinical risk model with roots in clinical care, and the alternative asset model with roots in public health education and health promotion. For each I consider contributions and limitations with particular attention to issues of measurement. This review supports my argument that it is time to expand thinking about health literacy to include not only basic literacy skills but also social and reflective skills and health functioning in order to discover new directions and strategies for measurement and intervention.

Chapter 3 describes the intervention and data collection, which were completed in a previous project. I summarize the evidence base and the policy case for focusing health literacy promotion efforts on disadvantaged families with very young children through the existing national
networks of home visitation programs serving those families. I briefly describe the Functional Health Literacy Measure (FHLM) and its derivation from the Life Skills Progression instrument (Wollesen & Peifer, 2006). The chapter then details the analytical methods I employed to address the research questions through secondary analyses of the previously compiled database and related qualitative data.

Chapter 4 presents the study results and discussion. The evidence supports the hypothesis that home visitation promotes parental functional health literacy for participants with both higher and lower reading skills. Analyses of between-site differences in visitors’ reported practices and parents’ FHLM scores suggest, for further investigation, possible mechanisms by which home visitation produces improved parental functional health literacy, particularly reflective practices and focus on reflective functioning (Fonagy & Target, 1997; Wollesen & Peifer, 2006; McCaffrey et al., 2007; Nutbeam, 2008).

Chapter 5 discusses the study’s implications for health literacy and home visitation. While the data are insufficient to attribute results to any particular element of home visitation, statistically significant progress toward higher levels of functional health literacy among parents in multiple geographically dispersed programs in various program models serving different racial/ethnic populations holds important implications for practice, policy, and research. Notably, the findings support Charner-Laird, Fairman, Park, Soderber and Nune’s (2003) suggestion that reflection is “the mind’s strongest glue” for making connections essential to understanding, regardless of subject matter, so that basic literacy skills are more accurately described as the Four R’s: reading ‘riting, ‘ithmetic, and reflection. And the greatest among these may be reflection.
Chapter 2

Health Literacy Measurement: Toward a Theoretical Framework

The purposes of this review of literature are to examine health literacy concepts, measures and interventions reported in the medical and public health literature; and to establish a theoretical framework for measuring and promoting health literacy as progressive levels of health functioning. I summarize trends in the literature by decade between 1970 when interest in the intersection of health and literacy emerged and 1995 when the term health literacy first appeared in the medical literature. Then I look more closely at the first decade of clinical research specifically addressing health literacy (1995-2004), which closes with research funding agencies calling for innovations in measurement and new directions for intervention. I highlight two limitations underlying the literature of this period: 1) the absence of a theoretical foundation; and 2) the influence of the 1992 National Adult Literacy Survey (NALS) and the 2003 National Assessment of Adult Literacy (NAAL) on the direction and interpretation of health literacy research. Next, I examine the explosion of health literacy research published between 2004 and early 2009 and the current state of health literacy measurement, intervention and policy. Finally, with this background, I propose a theoretical framework for measuring health literacy as progressive levels of health functioning.


Trends in the 1970s & 1980s

Rudd, Moeykens and Colton (1999) found fewer than a dozen articles related to literacy and health in the U.S. medical and public health literature of the 1970s. Two articles focus on barriers posed by low literacy skills, and two on improving health education materials. The
majority focus on assessing the readability of health-related communications. The term health literacy first appeared in the health education literature in a 1974 article titled “Health Education as Social Policy” (Simonds, 1974). In discussing health education as a policy issue affecting the health care system, the educational system, and mass communication, the author calls for minimum standards for health literacy for all school grade levels. The term did not appear in the medical literature until 1995.

The 1980s saw a threefold increase in literacy-related citations (total 37), and a broader scope of topics. The majority of journal articles reported on assessments of written materials. Many relate to patient education materials for a specific disease and a few relate to health education literature for particular population groups. Grosse and Auffrey (1989) authored the first review of international studies and provided evidence of growing scholarly interest in literacy and health (Rudd et al., 1999; AMA, 1999).

**Trends in the Early 1990s**

Health literacy came to the national agenda in the early 1990s following President George H. Bush’s campaign for adult literacy. Bush signed the National Adult Literacy Act of 1991 (Public Law 102-73, Sec.3) which directed the Department of Education to conduct the 1992 National Adult Literacy Survey (NALS). NALS provided a profile of the English literacy of U.S. adults based on their performance of varied literacy tasks using materials and skills needed in everyday life. NALS results showed that about 20 percent of U.S. adults (representing 40 to 44 million people based on 1990 census data) demonstrated skills at the lowest level (NALS Level 1); and about 25 to 28 percent of respondents (representing about 50 million adults) scored in Level 2 (Kirsch, et al., 1993). These results stimulated such broad interest among medical, health services and public health researchers that the first half of the 1990s alone produced more than 100 citations related to health and literacy. Weiss, Hart, and Pust (1991) called for research into the links between literacy and health. However, most of the literature from this period reflects continued interest in printed instructions and medical forms, notably the readability of informed
consent documents (Rudd et al., 1999). This focus on the readability of health and healthcare related materials continued in the second half of the decade reflecting the focus on patients’ low literacy skills as a cause of high costs, low quality and inequities in the healthcare system, as well as the absence of measures of health literacy.

*Trends in the Late 1990s*

A major contribution in this period was the development of assessment tools to identify patients with low literacy. (I address measurement issues later in this review.) The first use of the terms *health literacy* and *functional health literacy* in the medical literature appeared in 1995 in reports on these screening tools and their early use (Williams et al., 1995; Parker, et al., 1995). In these and later articles, the terms were used interchangeably to refer to basic literacy skills in a clinical setting.

The availability of tests of health literacy enabled researchers to investigate links between reading ability and health outcomes and shifted the research focus from materials to patients as readers. Studies in the late 1990s focused on consequences of literacy related barriers to access and the use of information and services, and on issues related to patients’ knowledge of disease and prevention, comprehension of medical instructions, and self-management of chronic disease (Rudd et al., 1999; Berkman et al., 2004). Studies established that low health literacy (measured as reading ability in clinical settings) is associated with higher rates of hospitalization (Rudd et al., 1999), health status and health-related knowledge (AMA, 1999, Berkman et al., 2004). The decade closes with calls for attention to provider-patient communications, strategies to increase disease self-management skills and improve health behaviors, and the causal pathways by which reading ability influences health (Rudd et al., 1999; AMA, 1999; Berkman et al., 2004).

*National Adult Literacy Survey Results (Mis)directed Research*

Reports from this period frequently refer to results of the 1993 National Adult Literacy Survey (NALS). These references should be interpreted in light of evidence that NALS results
have been inaccurately reported and used in unintended ways. Statistics published in 1993 by the Department of Education were widely reported by the media, government and professional organizations. According to the National Academy of Science, National Research Council (NAS/NRS) (2005), early reports were consistent in their misinterpretation of NALS results, and “unsubstantiated inferences” were repeated in many sectors.

NALS scored an adult’s literacy on a scale of 0 to 500 and assigned participants to one of five levels of proficiency (Level 1 (lowest) to Level 5). Statistics were reported as if they represented standards for the level of literacy adults should have to function on the job and in society. Levels 1 and 2 were described as inadequate to hold a job. However, the NALS methodology did not intend and was not able to comment on the level of proficiency adults need to function in society, or in any particular environment (National Academy of Sciences, 2005). NALS only estimated the proficiency respondents had at the time. A National Academy of Science, National Research Council report recommending methods to ensure more accurate reporting of results from the 2003 National Assessment of Adult Literacy (2005) discusses these unsubstantiated inferences:

The procedures used to develop the [NALS] assessment did not involve identifying the level of skills adults need in order to function adequately in society. When findings from the 1992 survey were released, however, the performance levels were interpreted and discussed as if they represented standards for the level of literacy adults should have. The lowest two levels were referred to as inadequate, so low that adults with these skills would be unable to hold a well-paying job. The results of the assessment and these sorts of unsupported inferences about the results provoked widespread controversy in the media and among experts in adult literacy about the extent of literacy problems in the country. (National Academy of Sciences/National Research Council, 2005, p. 2)
After 1993, medical and public health authors frequently reported NALS findings to document the significance and prevalence of low literacy in patient populations, and discussed the NALS literacy levels as standards. For example, an analysis by Friedland (1998) attributed an estimated $29 million in “additional” 1996 health expenditures to inadequate literacy skills defined as NALS Level 1 or 2. A 1999 AMA Council on Scientific Affairs report on health literacy states “The 1992 National Adult Literacy Survey (NALS), the most accurate portrait of English language literacy in the United States, found that 40 to 44 million Americans, or approximately one quarter of the US population, are functionally illiterate and another 50 million have marginal literacy skills. … Inadequate literacy is especially prevalent among the elderly, with almost half scoring in the lowest reading skill level in the NALS” (AMA, 1999, p. 52). The NAS/NRC report (2005) confirmed earlier emphasis by designers of NALS that persons scoring in Level 1 or 2 are not illiterate (Kirsch et al., 1993). Nonetheless, articles in this period have frequently referred to “patients who can’t read” (Morgan, 1993; Miles & Davis, 1995; Weiss & Coyne, 1997) and “illiteracy” in patients (Kefalides, 1999; Weiss, Hart, McGee & D’Estelle, 1992).

Further, most NALS respondents scoring in Level 1 or 2 and often referred to as having inadequate literacy skills, self-reported their literacy as good or very good. This contradiction between the quantitative and qualitative NALS data may mean that adults with low literacy skills are unaware of their problem or hiding it, that they avoid environments that exceed their capacity, or that NALS overstates their handicap. Health literacy researchers have interpreted the contradiction to mean that persons with low literacy skills cannot be relied on to report their deficit (Hironaka & Paasche-Orlow, 2008), so that testing is needed to identify patients with low literacy.

Subsequent writings repeated and extended inferences from official reports of NALS results. For example, a 2004 Institute of Medicine (IOM) report assigns a reading grade level equivalent (below high school level) to NALS proficiency Levels 1 and 2 despite the expressed intent of NALS designers to move away from reporting adult literacy in this way since the practice is uninformative and often misleading (Kirsch et al., 1993). The IOM report (2004) continues the
erroneous practice of using NALS proficiency levels as standards of literacy and infers a standard for using the healthcare system:

*About 90 million Americans, an estimate based on the 1992 NALS, have literacy skills that test below high school level (NALS Level 1 and 2). Of these, about 40 – 44 million have difficulty finding information in complex texts such as newspaper articles, editorials, medicine labels, forms, or charts. Because the medical and public health literature indicates that health materials are complex and often far above high school level, the committee notes that approximately 90 million adults may lack the needed literacy skills to effectively use the U.S. health system.* (IOM 2004, p. 8)

Later this report drops the qualifier and refers to “90 million American adults who lack the functional literacy skills in English to use the U.S. health care system” (Institute of Medicine, 2004a). This statement is repeated frequently in the literature. In this way, NALS levels inadvertently became known, erroneously, as standards for adequate health literacy. This use of the NALS literacy levels as proficiency standards carried over into development of health literacy testing methodology developed during this period, which equates NALS levels to reading grade equivalents and infers standards for adequate functioning in the healthcare system.

In addition, the NAS/NRC report (2005) pointed out the inaccuracy of statements common in the medical literature and elsewhere that misinterpret the NALS proficiency levels. For example, Moon and colleagues (1998) reported: “It is estimated that 20% of American adults [in NALS Level 1] lack basic reading and writing skills (ranging from signing one’s name to identifying basic information from a simple form), and an additional 25% [in NALS Level 2] are marginally literate (cannot fill out an application or interpret instructions for an appliance)”. The NAS/NRC report (2005) indicates that a NALS assignment to Level 1, for example, does not mean a person cannot perform tasks at higher levels. In fact, NALS data indicated that adults might be able to perform more than half of tasks at higher levels. Individuals at every score point
and each performance level have some probability of responding correctly to each item; they simply could not perform them with an 80 percent probability of success. The decision to use the 80 percent “response probability” was not explained in the NALS technical manual and was the subject of debate centering on whether it led to underestimating adult literacy levels. I found no reports addressing these issues related to the NALS findings in the medical or public health literature. Nonetheless, research designers, intervention planners and policymakers should read critically and interpret studies from this period with awareness that national literacy surveys may underestimate adult literacy, and that health literacy studies and cost estimates may be based on unsupported inferences about what constitutes adequate reading ability in a clinical setting.

Health Literacy in the Literature 2000-2009

Trends 2000 to 2004

In the late 1990s, with the introduction of clinical screening tests to estimate patients’ ability to read medical and healthcare documents, evidence began to emerge about the prevalence of low literacy in healthcare settings and its adverse influence on health outcomes (Williams et al., 1995; Gazmararian et al., 1999). In a 2004 systematic review of medical and educational literature published between 1980 and 2003, Berkman and colleagues (2004) further examined the evidence of a relationship between literacy and health outcomes. The evidence report, commissioned by the Agency for Healthcare Research and Quality at the request of the American Medical Association, intended to inform clinical practice and health policy and lay a foundation for the next wave of research. Confirming findings of earlier reviews (Rudd et al., 1999; AMA, 1999), the authors concluded poor reading ability is associated with a range of

9 Response probability: In test design, the chance of responding correctly. The choice of response probability affects the value of the scores used to separate proficiency levels. NALS designers chose an 80% response probability to estimate the difficulty of NALS questions, and so determine the literacy level of test participants.
adverse health outcomes. About one-third of reviewed studies used knowledge as the outcome and evidence of patients’ ability to understand information (e.g. knowledge of disease, preventive services, discharge instructions, health behaviors). Most of these studies found a significant positive relationship between patients’ reading ability and knowledge. However, the reviewers suggest knowledge is a less meaningful outcome; it offers little direction for practice. Another third of the studies reviewed by Berkman and colleagues (2004) addressed the relationship between reading ability and health outcomes. Limited literacy skills have been consistently associated with worse health outcomes (i.e., poor physical functioning, poorer quality of life, late-stage disease detection) in some conditions such as asthma and cancer, hospitalization and mortality. However, limited health literacy skills (reading ability in clinical settings) have yielded mixed results in diabetes, HIV, and depression, and medication adherence studies.

Reviewers note a number of limitations in the evidence. Most studies were cross-sectional; many used multiple comparisons and many failed to adequately address confounding factors. Factors underlying both literacy and health that may distort their association include occupation, income, social support, culture, language, age, education, vision and hearing, racism and lack of access (Paasche-Orlow & Wolf, 2007). Reviewers recommended more rigorous methods to better define the relationship between adult literacy (reading ability) and outcomes and to guide new interventions (Berkman et al., 2004; Sanders, 2009). These limitations of the literature give researchers and policymakers’ additional reasons to interpret studies with caution and to seek more comprehensive and informative measures of health literacy.

Berkman and colleagues (2004) also conducted the first systematic review of interventions (1980-2004) to promote health in persons with low literacy. They conclude that limitations in study design, interventions tested and outcomes assessed make drawing conclusions about effectiveness difficult. Intervention studies are still relatively rare in this period.

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10 Confounding refers to interference by a third variable so as to distort the association being studied between two other variables, because of a strong relationship with both of the other variables.
Most examined the effect of improved information or its delivery on health knowledge; and found mixed results. Reviewers conclude that improved information leads to short-term knowledge gains for participants with both higher and lower reading levels. However, it remained unclear whether the association between low literacy and adverse health outcomes is mainly direct (meaning outcomes would be improved by interventions designed to overcome limited reading skill) or indirect (such that interventions addressing underlying causes such as poverty, racism and lack of access to care would be more effective). Reviewers call for future studies that link knowledge gain to important, longer-term health outcomes that matter to patients and families (e.g. tasks required for effective selfcare and ability to perform those tasks, effects on outcomes of teaching people to read better, and effects of structural changes in health services delivery).

Influence of NAAL & the Health Literacy Component

The 2003 National Assessment of Adult Literacy (NAAL) was conducted with the same methodology as the 1993 NALS. In 2005, after the data were collected, to help assure accurate use of the results for public policy and program design, the Department of Education requested assistance from National Academy of Science, National Research Council (NAS/NRC) to determine a means for reporting results that would be useful and understandable for varied audiences. Because the NAAL was not designed to provide information about what proficiency level adults need to function adequately in society, there was no way to develop performance levels that would support such inferences. NAS/NRC attempted to improve reporting and use of the results by developing five performance levels using a less stringent response probability of 67 percent, as generally recommended in test development literature. Health experts argued, unsuccessfully, for retaining the 80 percent response probability used in the 1993 NALS to reflect the importance of correctly using health related materials.

The 2003 NAAL performance levels are: Nonliterate in English, a new category based on an assessment that was absent from NALS, Below Basic, Basic, Intermediate, and Proficient. Basic literacy consists of having skills to perform simple and everyday tasks. Intermediate
literacy consists of having skills to perform moderately challenging literacy activities. Proficient literacy consists of having the skills to perform more complex and challenging literacy activities (White & Dillow, 2005; IOM, 2005).

NAS/NRC emphasized these levels are not intended to represent standards for what is required to perform adequately because the data cannot support such inferences; and their precision should not be overestimated. Since the assessment does not cover the upper end of the distribution of literacy skills, NAAL does not allow for detection of problems at the post-secondary level and above (NAS/NRS, 2005). Adult literacy scores showed no significant change between 1993 NALS and 2003 NAAL (Rudd, 2007).

At the urging of health literacy researchers, the 2003 NAAL included 28 questions related to clinical, prevention and navigation skills. These questions used healthcare documents and intended to gauge health literacy, meaning applying reading skills to healthcare related tasks (story problems). The questions were used to calculate the Health Activities Literacy Scale (HALS). Findings are reported as follows: the majority of adults (53 percent) had Intermediate health literacy. An additional 12 percent of adults had Proficient health literacy. Among the remaining adults, 22 percent had Basic health literacy, and 14 percent had Below Basic health literacy. Reported health literacy scores are very similar to prose literacy (use of continuous text) scores. Critics suggest the health literacy findings reflect the known complexity of materials as much as participant’s health literacy skills (Rudd, 2007).

The Health Activities Literacy Scale (HALS) comes closer to a comprehensive test by including different health-related competencies in five domains – health promotion, health protection, disease prevention, health care and maintenance, and systems navigation (Educational Testing Service, 2006). Baker (2006) points out that the HALS is new, its properties are unknown, and the full-length test takes up to an hour to administer. If it is to be more widely used, the HALS will need to be made more accessible to researchers (questions are not available
for additional studies), and an abbreviated version will need to be developed. Despite its improvement over less comprehensive measures, the HALS test reflects a view of health literacy as reading skill in a clinical context and amounts to a reading skills test. Due to its length and unknown validity, it has received little attention from researchers and has had little influence on health literacy measurement or intervention.

In 2009, researchers are expressing concerns over the NAAL sampling methods and usefulness of the data for research (Weiss, 2009). Due to remaining issues of methodology and reporting, the planned 2013 national adult literacy survey has been delayed to 2016 or later, leaving no means for measuring progress toward Healthy People 2010 health literacy goals (U.S. Dept of Health and Human Services, 2000) and no foundation for setting new health literacy goals for 2020.

*Trends 2004 -2009*

The literature on health literacy is expanding rapidly with increasing interest among researchers, clinicians, policymakers, insurers, politicians and the public. A PubMed search on “Health Literacy” returned over 600 citations published in English between 2004 and 2009. These were reviewed from abstracts. For the purposes of this project, I excluded articles on other functional literacies (media, financial, science and computer literacy) as well as reports on reading disorders and reading science since these are not directly relevant to health literacy. I excluded studies set in developing countries and those limited to the elderly or persons with a specific diagnosis, except pregnancy, since my study is primarily concerned with parental health literacy in the U.S. I excluded articles related solely to provider communications training, or to the readability, reading level, or design of materials since these subjects are well covered elsewhere and numerous guidelines have been published (Smith & Gonzales, 2005).

For the most part, research continues in the direction established in the 1990s, with primary attention to measurement. Nearly 300 studies published between 2004 and 2009 report
on experiments with ever more convenient versions of the standard health literacy screening tests to identify patients with low reading ability. A few report on a new reading test (Weiss, Mays, Castro, DeWalt, Pignone, et al., 2005; Osborn et al., 2007). One reports on a test of oral literacy, meaning listening skill (Downey & Zun, 2007). Debate rages over the value of routine screening (Paasche-Orlow & Wolf, 2008).

A few of studies have attempted to estimate the cost of low health literacy to the healthcare system (Baker et al., 2002, Baker et al., 2004; Cho, Lee, Arozullah, & Crittenden, 2008; Howard, Gazmararian, & Parker, 2005). Since these calculations are based on imprecise estimates of reading ability in clinical settings and unsubstantiated inferences of proficiency standards from national literacy surveys, their accuracy and utility must be questioned.

Intervention studies increased in number in this period but remain focused on efforts to improve information and its delivery. Nearly 200 articles report on reducing cognitive demand of materials or on experiments with delivering content in a variety of print, audio and electronic media. There is growing recognition of patients’ need for “oral literacy”, described as ability to understand spoken instructions, in addition to “print literacy”, ability to understand written information. Emphasis seems to be shifting from patients’ deficient reading skills to barriers in the healthcare system (Paasche-Orlow, Schillenger, Green & Wagner, 2006).

Overall, the recent literature shows little progress toward increasing understanding of literacy and health, reducing health disparities, or improving patients’ and healthcare consumers’ use of information and services. Calls for new directions in health literacy research and intervention from funders and professional organizations have inspired new conceptual and theoretical work.
A Tale of Two Literacies\textsuperscript{12}

Our research standpoint, meaning the outlook and attitudes that determine the way we think about an issue based on training, experience and motivations, determines our research approach, what we choose to measure, and how we interpret results (Harding, 2006). In turn, measurement drives intervention. What we measure and how we measure it determines what we find out about what works, what is worthy of doing, and who should do it (Schorr, 1997, p. 141).

In Chapter 1, I introduced two distinct research standpoints: the dominant standpoint rooted in clinical care in the U.S., and the emerging alternative standpoint rooted in international public health education and health promotion. Here I examine more closely these two standpoints, their contributions and limitations, with particular attention to measurement issues.

\textit{Health Literacy from the Clinical Standpoint}

Nearly all studies of health literacy reported in the U.S. medical and public health literatures have been conducted from a clinical standpoint. The clinical approach developed mainly in U.S. academic medical centers during the 1990s. Its overarching aim is to help physicians more effectively communicate instructions and to help patients understand and comply (Pleasant & Kuruvilla, 2008). In Chapter 1, we saw that the clinical perspective views adult literacy narrowly as basic literacy skills (reading and numeracy\textsuperscript{13}), and views health literacy simply as basic literacy skills in a clinical setting. In this view, the goal of health literacy is for patients to obtain, process, and understand basic health information in order to make appropriate health decisions (IOM, 2004a). Basic health information refers to commonly used healthcare documents such as medication labels, informed consent instruments, insurance materials, and more recently, spoken instructions. Appropriate health decisions involve proper utilization of preventive, primary care and emergency healthcare services, adherence to medication regimens, and compliance with treatment and follow-up instructions. In this view, failure to comply with

\textsuperscript{12} From Pleasant & Kuruvilla, 2008
\textsuperscript{13} Numeracy refers to use of numbers.
Contributions of the Clinical Standpoint

The prevailing clinical approach has been fundamental to health literacy research. It has established a strong science related to screening patients for low literacy, and has increased sensitivity among healthcare professionals. Response can be observed in a range of adaptations to patient education methods in print, broadcast and electronic communication, as well as improved interpersonal communication between health care providers and patients (Coulter & Ellins, 2007; Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005). A few studies have addressed the cost of patients’ low literacy to the healthcare system (Baker et al., 2002; Baker et al., 2004; Howard et al., 2005; Cho et al., 2008). This work has brought health literacy to organizational (American Academy of Pediatrics, 2009\textsuperscript{14}, America’s Health Insurance Plans, 2009\textsuperscript{15}), state (MO, NC, WI, MN), and national policy agendas (National Health Literacy Act of 2007\textsuperscript{16}). However, there are several limitations to the clinical orientation in health literacy research.

Limitations of the Clinical Conceptualization of Health Literacy

Deficit approach limits understanding. The clinical perspective’s narrow view of adult literacy has limited understanding of health literacy to reading ability in a clinical setting. The literature suggests this narrow view arises from the deficit approach inherent in the clinical standpoint, which raises further conceptual, theoretical, measurement and intervention issues.

Deficit approach is disempowering. Conceptually, the deficit approach dictates a focus on low health literacy as a cognitive deficit in patients. While researchers acknowledge that patients’

\begin{footnotesize}
\begin{enumerate}
\item[14] http://www.aap.org/research/hlp.htm
\item[15] http://www.ahip.org/content/default.aspx?bc=39|341|22050
\end{enumerate}
\end{footnotesize}
difficulty in understanding healthcare information and documents is exacerbated by the complexity of the systems (Paasche-Orlow, 2007) and information, and ineffective communication (Mettger & Stableford, 2007), the clinical standpoint tends to characterize health literacy as a problem that patients have and physicians need to overcome (Pleasant & Kuruvilla, 2008). In my view, this conceptualization is disempowering to both patients and providers since it places providers in the untenable position of holding patients as unable to do what is required to regain or maintain their health.

*Without a theoretical framework, measures drive research.* Perhaps more problematic, in the clinical deficit model, low health literacy constitutes a risk to patients and the healthcare system that physicians need to identify and manage (Nutbeam, 2008). From the outset, the perceived need to enable clinicians to identify patients with low literacy directed researchers to aggressively pursue clinically feasible measures of low health literacy. Reading and comprehension tests were readily available and adaptable with medical vocabulary and healthcare documents and fit the narrow concept of functional literacy as ability to perform basic literacy tasks. Thus, school-based literacy skills tests formed the basis for the current standard measures of health literacy, the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991) and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995). We will consider these tests in detail shortly. At this point, it is notable that development of these measures preceded development of the clinical definition of health literacy.

The first use of the terms *health literacy* and *functional health literacy* in the medical literature appear in 1995 reports on development of the TOFHLA (Williams et al., 1995; Parker et al., 1995). In these and subsequent articles, the terms are used interchangeably.

The most widely used definition of health literacy is the clinical definition published in 2000 (U.S. Dept of Health and Human Services, 2000) and again in 2004 (IOMa), years after testing methods became established. Since early studies had focused on developing clinically feasible measures of patients’ cognitive (in)ability to process and understand commonly
distributed health information, nearly all studies operationalized health literacy as reading ability in a clinical setting and measured it by the available reading tests (Berkman et al., 2004).

Consequently, health literacy became defined as *ability to obtain, process and understand basic health information in order to make appropriate health decisions*. Thus, convenient measures, rather than any theory of literacy and health, adult learning, or health behavior have defined the meaning of health literacy, the direction of research and interpretation of findings. The absence of a theoretic framework is reflected in the quality of the evidence (Pignone et al., 2005; DeWalt et al., 2004; Paasche-Orlow, & Wolf, 2007; Sanders, 2009) and lack of progress toward the common goals of all concerned with health literacy: effective use of health information and services, good selfcare, and positive health outcomes (Berkman et al., 2004).

**Limitations of Clinical Health Literacy Measures**

Health literacy researchers rely on two standard tests of health literacy as reading ability in a medical setting. Most frequently used is the Rapid Estimate of Adult Literacy in Medicine, (REALM) (Davis et al, 1991), a medical-word recognition test administered in two to three minutes. Various authors have experimented with shorter forms of the REALM (Bass, Wilson & Griffiths, 2003; Shea et al., 2004). The most recently validated version consists of seven words (behavior, exercise, menopause, rectal, antibiotics, anemia, jaundice) and requires about seven seconds to administer (Arozulla et al., 2007). The patients' task is to read the words aloud. Scoring is based on the number of correctly pronounced terms and reported as a school grade equivalent: 3rd grade or less (0 correct pronunciations); 4th to 6th grade (1-3 correct), 7th to 8th grade (4-6 correct) and 9th grade or higher (7 correct). Since the REALM is designed to detect low literacy, it measures up to a 9th grade reading level equivalent. This implies, without substantiation, that 9th grade reading ability is adequate to access and obtain the benefit of healthcare information and services. However, over 300 studies have documented that most health information is written at tenth grade level or above (Mettger & Stableford, 2007); and the
National Network of Libraries of Medicine (Glassman, 2008) suggests anyone with high school education or less is vulnerable in the healthcare system.

The original REALM was validated against the reading section of the Wide Range Achievement Test (WRAT-R) (Jastak & Wilkinson, 1993) and two other academic reading tests. Short forms of the REALM are validated against the original and other reading tests. The REALM is available only in English.

The Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995) is a reading comprehension test using cloze testing methodology. Cloze testing is frequently used to test acquisition of foreign language. It involves deleting from a sample of text every fifth or seventh word. The patients’ task is to fill in the blanks thereby indicating comprehension from surrounding context (Smith & Gonzales, 2005). The TOFHLA, in English and Spanish, uses excerpts from common healthcare documents such as a medication label, instructions for gastrointestinal surgery, and the Medicaid Bill of Rights. A short form (S-TOFHLA) has been in use since 1999 (Baker et al., 1999).

The TOFHLA reports scores as inadequate, marginal or adequate health literacy inferring standards for health functioning. Cutoffs for these levels are based on age and education levels, both of which are considered unreliable predictors of reading ability in individuals (Doak, Doak & Root, 1996). The scores are correlated with the REALM’s grade level equivalents so that less than sixth grade reading level is deemed inadequate; seventh to eighth grade level infers marginal health literacy; and a ninth-grade or higher reading level is presumed adequate to function in the healthcare system. No theory or evidence is offered to support the inference of inadequacy or adequacy of reading ability indicated by TOFHLA scores. There is little evidence to indicate what school grade level reading skill may be necessary or sufficient for adequate or optimal health functioning (Pignone et al., 2005).

While the TOFHLA is validated against the REALM, there are significant differences in results. TOFHLA authors claim the REALM both overestimates and underestimates reading ability. Some patients are able to pronounce words on the REALM but score poorly on the
TOFHLA comprehension test. Conversely, some patients who are unable to pronounce words in the REALM test score well on TOFHLA where words appear in context. The TOFHLA has been shown to be an independent predictor of disease knowledge, but shows little association with health services utilization, self-care skills, or health. The TOFHLA is used only for research since its short form takes too long (seven to 10 minutes) to be clinically feasible. It is rarely used in intervention studies.

Up to 40 percent of participants taking these tests, particularly those who score poorly, have reported feelings of shame, embarrassment and alienation (Parikh, Parker, Nurss, Baker & Williams, 1996; Wolf et al., 2007). Recently, the negative impact on test participants has led to a flurry of experimentation with single- and multiple-question screening tests that produce proxy REALM or TOFHLA scores (Chew, Bradley & Boyko, 2004; Bennett, Robbins & Haeker, 2003; Wallace, Rogers, Roskos, Holiday & Weiss, 2005; Garcia, Hanly & Souffrant, 2008).

A recently developed reading and comprehension test designed to feel less like an academic test and so more acceptable to patients is the Newest Vital Sign (NVS) (Weiss et al., 2005). It uses the nutrition label from an ice cream carton accompanied by six questions. The test takes three minutes to complete. Scoring is calculated by the number of correct answers and validated against the TOFHLA and the REALM (Osborn et al., 2007). The authors conclude that patients with more than four correct responses are unlikely to have low health literacy, meaning they are unlikely to score in the “inadequate or marginal” category on the TOFHLA or below seventh grade reading equivalent on the REALM. Fewer than four correct answers indicates the “possibility of limited literacy”, meaning they might score below the “adequate” range on the TOFHLA or below seventh grade on the REALM. The NVS significantly overestimates low literacy as measured by the REALM and TOFHLA although at different rates. This makes the NVS too imprecise for research, but useful as a screen to identify those who may have difficulty understanding medical information (Osborne et al., 2007).

Downey & Zun (2007) report on a new instrument to test understanding of verbal instructions. The Basic English Skills Test (BEST) was validated against the TOFHLA short form.
All these established and new health literacy tests are validated against each other. The original standard form of the REALM produces similar results to three recognized academic reading tests categorized by school grade level equivalent. The TOFHLA produces results in line with the REALM inferring the relative adequacy of reading grade levels for health functioning. All subsequent health literacy tests produce results more or less similar to the REALM or the TOFHLA.

Critics have long argued that school grade level equivalents are irrelevant for adults and are misleading since reading ability varies widely within grades (Flesch, 1948; Perrin 1989; Smith & Gonzales, 2005). The 1992 National Adult Literacy Survey specifically intended to move away from reporting literacy as a school grade level (Kirsch et al., 1993). There is no evidentiary basis for the inferred adequacy or inadequacy of reading grade levels for health functioning. None of the available health literacy tests is considered a comprehensive measure of literacy or health literacy (Rogers, Ratzan & Payne, 2001; Berkman et al., 2004; Baker, 2006). None adequately captures the meaning of health literacy as a risk to patients, the public or the healthcare system.

Do we need to test patients’ health literacy? The name “Newest Vital Sign” suggests the position of the tests’ authors in the current debate over the value of routine health literacy testing. Proponents argue that clinicians need to identify poor readers in order to offer them special assistance, usually by tailoring communications to their needs (Weiss et al., 2005). Critics reply that none of the available tests are comprehensive measures of literacy in clinical settings since they address only one literacy skill and cannot capture systemic or social factors in patients’ understanding and decision making (Baker, 2006). I have argued previously that testing is unnecessary since it is clear from national adult literacy studies and over a decade of health literacy testing that nearly everyone has difficulty understanding and acting on healthcare information, regardless of reading ability, particularly when they are in need of medical care (Smith, 2000). Further, hundreds of studies conducted over 30 years have documented the wide gap between the literacy demands of healthcare information and the literacy skills of U.S. adults.
These findings have led national and international policy leaders to advocate universal precautions such as using plain language in all health and healthcare related communications (Smith, 2000; Smith & Gonzales, 2004; Baker, 2006; Mettger & Stableford, 2007).

Critics argue further that routine health literacy testing carries significant risks (alienation of patients) and has demonstrated no benefits (Paasche-Orlow, 2008). Few health-focused organizations or training programs have committed significant resources to retool workforce communications skills or prepare the next generation of healthcare professionals to offer the special assistance that patients identified with poor reading skill are thought to need (Mettger & Stableford, 2007). Most physicians consider health literacy beyond their purview (Parker & Kindig, 2006). With Paasche-Orlow (2008), I maintain that screening may be useful when effective interventions become available.

Clinical measures restrict intervention, fail to inform practice. Perhaps the most significant limitation of available health literacy measures is that they do not inform practice. What we measure determines what we find out about what works and what is worth doing (Schorr, 1997). Using available measures and the clinical definition of health literacy, nearly all interventions have aimed to make healthcare and medical information easier to read and comprehend. Thus, convenient measures have dictated intervention aimed at improving the health of patients with low literacy skill.

Findings from health literacy intervention research show that improved information (printed materials, multimedia, and oral explanations) leads to increased knowledge of disease, prevention, and treatments for participants with both higher and lower reading levels. However, skilled and unskilled readers alike struggle to act appropriately on acquired knowledge17. As Figure 2 illustrates, the literature makes clear that basic literacy skills do not readily translate to

17 The prevailing clinical definition of health literacy is ability to “obtain, process and understand basic health information in order to make appropriate health decisions (IOM, 2004)” The definition leaves open what constitutes an appropriate decision and who determines appropriateness by what criteria. The definition is typically operationalized as treatment compliance or medical adherence. Non-compliance is usually interpreted as cognitive deficit or disregard for health rather than the result of a decision based on reflection.
functioning in the healthcare system. Conversely, people with poor reading ability are sometimes able to function in the healthcare system. Scholars speculate that some level of basic literacy (mental processing skills) may be necessary to use the healthcare system, and skills beyond that level do not contribute to health functioning or to clinical outcomes (Pignone et al., 2005). While higher reading ability is clearly associated with better health status and increased longevity, people at all reading levels have difficulty adhering to treatment regimens, using medical devices, using preventive services, and managing chronic conditions (Berkman et al., 2004).

Figure 2. Basic literacy skills do not readily translate to functioning in the healthcare system. Unskilled readers may miss the context and so misinterpret instructions.

According to the National Network of Libraries of Medicine (Glassman, 2008), anyone with a high school education or less is vulnerable to limited access to preventive and medical services, misdiagnoses, unnecessary testing and procedures, medication errors, repeat hospitalizations and adverse treatment outcomes. Still, every day people with “inadequate or marginal health literacy” do successfully fill out forms, describe their symptoms, take medications and recover from illness.
Clinical research on health literacy has achieved little progress toward establishing a causal pathway between reading ability and health outcomes (Paasche-Orlow, 2007), or toward enabling individuals to effectively access and benefit from healthcare services, prevent illness, or self-manage disease (Berkman et al., 2004). In 2004, and again in 2007 and 2009, research funding agencies called for new measures of health literacy to increase understanding beyond the focus on reading ability in a clinical setting, and for effective channels to promote health literacy. The Institute of Medicine (2009) and the American College of Physicians (2008) are actively seeking new directions for measurement and intervention. Researchers, practitioners and policymakers are renegotiating the meaning and measure of health literacy. In this climate, an alternative research standpoint is emerging.

*Health Literacy from the Public Health Standpoint*

Authors are beginning to explore health literacy from the public health standpoint as a personal and community asset. This perspective has its roots in public health education, an interdisciplinary field that integrates adult learning and health promotion with biostatistics, epidemiology, environmental health sciences, health policy and the social and behavioral sciences.

In the public health model, the primary aim of health literacy is to enable people to exert greater control over their health and the range of personal, social and environmental factors that shape health (Nutbeam, 2008). Health literacy is seen as an empowerment strategy equally important in community and healthcare settings (Pleasant & Kuruvilla, 2008). While Nutbeam takes a Frierean (1994) approach to health literacy as socio-political empowerment of the oppressed, in this project we are not concerned with political empowerment but rather with personal empowerment to exert greater control over personal, child and family health.
While clinical interventions aim to increase understanding of information and knowledge acquisition, public health education interventions aim further to develop the self-efficacy\(^{18}\) (confidence) necessary to put knowledge into practice in ways that promote health (Nutbeam, 2000). From this public health perspective, health literacy is seen as an asset to be built, and as an outcome of health education and health promotion efforts that support greater empowerment in health decision-making and health actions (Nutbeam, 2008).

This understanding of health literacy identifies it as a distinct concept, rather than more simply as literacy in a clinical setting. In the previously described clinical model, health literacy begins with an assessment of the individual’s reading ability and knowledge, which directs tailored education and communications, which lead to better compliance and self-management of disease and ultimately to improved clinical outcomes (Baker, 2006). The purpose of communication in this model is compliance with prescribed therapeutic regimens, which focuses on transferring knowledge from expert to patient and keeps control of the patient’s health and health actions with the healthcare professional. Paasche-Orlow (2007) added to this model system factors such as providers’ communication skills and access issues.

The public health model begins in the same way with tailored health education and communications. However, it focuses on development of interpersonal, social and reflective ability to personalize relevant information and apply it in context to shift the locus of control of health and health actions (Wallston & Wallston, 1978) to the patient. Thus, in the public health model, health literacy is the *outcome* of health education and communication, rather than a factor that may influence clinical outcomes. More developed health literacy enables a person to engage in a wider range of health enhancing actions including personal behaviors and practices. The results are not only improved health outcomes, but also a wider range of options and opportunities for health (Nutbeam, 2008).

\(^{18}\) Self-efficacy: confidence. The most significant factor in behavior change (Badura, 1986)
Contributions and Limitations of the Public Health Standpoint

The principle contribution of the public health approach has been conceptual (Pleasant & Kuruvilla, 2008). Research to support the ideas around health literacy as an asset is at a developmental stage. It emanates mainly from the U.K., Australia, and Canada (Coulter & Ellins, 2007; & Nutbeam, 2001; Rootman & Ronson, 2005). Like the clinical perspective, the emerging public health perspective lacks a meaningful measure. My study is, to my knowledge, the first to test the public health approach in intervention and to establish its practicality for implementation (Nutbeam, 2008). In addition, this study contributes the Functional Health Literacy Measure (FHLM), a useful measure of health literacy as health functioning.

The conceptualization of health literacy as an asset offers significant promise in terms of potential impact on health and the range of actions it may enable, including efforts to address the social determinants of health. In addition, this asset approach lends itself to a broader application beyond health care settings (Nutbeam, 2008; Pleasant & Kuruvilla, 2008).

A few authors have taken a population-based approach (as opposed to an individual-based approach) and experimented with assessment of health knowledge in the public (Pleasant & Kuruvilla, 2008); and with use of demographic data combined with area estimates of literacy levels based on the NAAL for targeting resources and interventions in areas of greatest need (Hanchat, Ash, Gazmararian, Wolf & Paasche-Orlow, 2008; Lurie & Parker, 2007).

A Theoretical Framework for Measuring Health Literacy as an Asset

If we accept that health literacy is an independent concept, rather than simply literacy in a clinical setting, that implies a different approach to measurement. For example, in the clinical model, asking for assistance in reading hospital materials is taken as an indicator of low literacy skill (Chew, Bradley, & Boyoko, 2004). In the public health education perspective, asking for assistance can be viewed as an interactive health literacy skill employed to access and understand information and to improve functioning. Similarly, Katz, Jacobson, Veledar & Kripalani
(2007) use asking the physician to repeat as an indicator of limited cognitive ability. In the asset model, assuming the patient is not hard-of-hearing and the physician is not mumbling, this so-called deficit may indicate using social skills to access information.

Nutbeam (2008) suggests a measure of individual health literacy as a personal asset would need to take into account different ages and stages in life, and the social contexts in which health literacy is relevant. It would recognize both the clinical definition of health literacy as reading ability to understand health information and the broader public health definition of health literacy as ability to use information in ways that maintain and promote health. It would capture the impacts of improved information as well as improved health functioning. Such a measure would not test technical skills but rather would assess ability to 1) access age- and context-specific information from a variety of sources, 2) discriminate reliable sources, and 3) personalize and appropriately apply relevant health information for personal benefit. He suggests several instruments may be necessary to assess health literacy in various age groups (children, elderly), contexts (medical care, dental care, home, school) and conditions (pregnancy, cancer, asthma).

Expanding Thinking about the Function in Functional Health Literacy

The public health education perspective incorporates research into literacy and adult learning. A number of literacy scholars characterize the practical application of literacy skills as "types" or "layers" of literacy ranging from functional (fundamental, autonomous, technical) skills (reading and writing) used to independently perform tasks of everyday living, to interactive (social) skills used in applying knowledge to familiar situations and changing circumstances, to reflective skills applied to exert greater control over life events and situations (Freebody & Luke, 1990; McCaffrey et al., 2007).

Following this line of thinking, Nutbeam (2000) categorized health literacy into levels that reflect progressively greater autonomy, personal empowerment, and engagement in a wider range of health actions that extend from personal behaviors to healthcare practices and lifestyle

![Diagram of Types & Layers of Literacy]

Figure 3. Nutbeam (2000) applied Freebody & Luke’s (1990) conceptualization of “types” or “layers” of literacy to health literacy.

*Functional (technical, autonomous) Health Literacy.* In the Freebody/Nutbeam model of health literacy, function relates to doing tasks. Nutbeam assigns two meanings to the term. Sometimes he refers to functional health literacy as “reading and writing” (2008) - basic literacy skills, and associates it with literacy tasks like word recognition and comprehension. This usage reflects the current dominant approach to measuring health literacy.

Alternatively, Nutbeam and others (Freebody & Luke, 1990; McCaffrey et al., 2007) refer to functional health literacy as fundamental literacy associated with practical everyday tasks. Researchers and clinicians operate from this use of the term when considering healthcare tasks, such as comprehending a medication label or evaluating risk, as “everyday” tasks.

*Interactive Health Literacy.* Interactive health literacy requires social skills such as speaking and listening to complete more complex interactive tasks like making an appointment.
and getting there, describing symptoms and listening to treatment instructions. This is analogous to what recent health literacy reports call oral literacy (Baker, 2006). Using interactive literacy, people develop social practices (McCaffrey et al., 2007) that involve many tasks and skills, for example, the practice of monitoring symptoms and triggering timely intervention.

_Health Literacy as Reflection._ Critical reflection (Freire, 1994; Freebody & Luke 1990; Nutbeam, 2000; McCaffrey et al., 2007) is a higher level literacy skill needed to make meaning from information and use it to control one’s health and health actions and to change the determinants of health. For example, a mother hears from the pediatrician that her baby should sleep on his back to prevent Sudden Infant Death Syndrome\(^ {19} \) (SIDS). She hears from the grandmother that the baby should sleep on his stomach to prevent aspiration.\(^ {20} \) This mother needs reflection to discriminate information sources, reconcile conflicting advice, manage the power differentials, control her child’s sleep position, and so manage his health.

Without reflection, the mother may comply with the pediatrician’s instruction without question. But in the grandmother’s presence, the mother may similarly comply with the grandmother’s conflicting direction, or simply allow her to determine the child’s sleep position. In both cases, without reflection, the mother relinquishes control of her child’s health and her own health actions to external authority. In this example, simple compliance without reflection results in inconsistent practices that place the child at increased risk for SIDS.

With reflection to personalize the pediatricians’ information to her “real life”, the mother may consciously choose to comply, and require the grandmother to comply as well, in order to exert control over her child’s health. On the other hand, she may choose not to comply. For instance, she may judge the risk of defying the grandmother, and so losing a safe place to live, to be greater than the risk of the baby sleeping face-down. At the same time, she might begin to consider alternative living arrangements. In any case, in the public health model, she has

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\(^ {19} \) SIDS: death of an infant while sleeping that is not explained by other causes.
\(^ {20} \) Aspiration: Choking on vomit
increased health literacy through reflection by achieving greater control over her health and health actions, whereas in the clinical model her non-compliance would typically be interpreted as inability to understand the instruction or disregard for her child’s health (Selden, Zorn, Ratzen, & Parker, 2000).

This story illustrates that like reading ability, compliance is fundamental to functional health literacy, a first step toward optimal health functioning; but like reading ability, unquestioning compliance is rarely sufficient to maintain and promote health. Even on those occasions when compliance without reflection leads to better health (e.g. the medication works), in clinical terms, it precludes patient activation, patient responsibility and patient-centered care. In public health terms, unquestioning compliance precludes the patient exerting control over his/her own health and health actions. Compliance without reflection demonstrates and encourages dependence on the healthcare professional as the producer of health. In terms of reflective functioning, the mothers’ unquestioning compliance with the pediatricians’ instruction constitutes a reaction rather than a purposeful response, it suggests no attempt to understand the pediatrician’s intent or personalize the meaning of changing the baby’s sleep position in her particular circumstance. Without reflection, the mother will likely be surprised and upset (reaction) by the grandmother’s reaction.

The story further illustrates that the prevailing clinical conceptualization and measurement of health literacy as reading skill in a clinical setting miss much of the deeper meaning and purpose of literacy for health that extends beyond individuals to families and beyond the healthcare system to home and community. Reading skill may increase the mother’s understanding of the instruction and so increase her ability to comply; but reading and understanding may be neither necessary nor sufficient for her to comply. Further, neither reading skill nor unquestioning compliance, nor reading skill and compliance together are sufficient to achieve optimal health functioning.
Charner-Laird and colleagues (2003) describe reflection as one of the “Four R’s”: reading, ‘riting, ‘rithmetic, and reflection. They describe reflection as “the mind’s strongest glue” for making connections essential to understanding, regardless of subject matter. This suggests, for future investigation, that reflection, perhaps more than reading, may be key to understanding health information in context, making appropriate health decisions, achieving optimal health functioning, and improving clinical outcomes.

**Extending the Concept of Functional Health Literacy**

One could infer from the use of the term *functional* in Nutbeam’s model of health literacy described above, that interactive and reflective health literacy are not functional. Rather, it is useful to extend the concept of functional literacy to include all three types/levels of health literacy. I posit that Nutbeam’s (2000) progressive levels of health literacy correspond to Wollesen & Peifer’s (2006) progressive levels of functioning, so that, for example, a functionally (fundamentally) health literate person finds a clinic phone number. A *more* functionally health literate person makes and keeps an appointment. And an *optimally* functional person maintains a medical home\(^{21}\) and asks questions. Figure 4 incorporates Nutbeam’s progressive levels of health literacy with this idea of progressive levels of functioning.

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\(^{21}\) Medical home: a single consistent source of preventive and acute healthcare services, typically a personal physician or group practice.
Figure 4. Progressive levels of health literacy correspond to progressive levels of health functioning. In this theoretical framework, health literacy can be measured as progressive levels of health functioning.

This theoretical framework gives us a way to measure the function in functional health literacy. It makes functional health literacy a concept separate from literacy that describes the practical application of a wide range of cognitive and non-cognitive skills in real life, rather than simply reading ability in a clinical setting. It captures how people use literacy for health as patients, and as parents and family members.

In this framework, a fundamentally health literate person completes tasks for a practical purpose, such as filling out a form to apply for insurance or taking aspirin to get over a headache. Further, a more functionally literate person develops social practices such as getting regular checkups or adhering to a medication regimen. An optimally health literate person reflects critically to, for example, personalize and contextualize information, manage the health of family
members, or change personal lifestyles and living conditions. By characterizing the progressive tasks and social practices that demonstrate progressive levels of health functioning for groups (parents, persons living with chronic disease), it may be possible to measure functional health literacy and monitor progress over time toward optimal functioning.

In this frame, functional health literacy is an outcome of health education and health promotion efforts, rather than a variable that may affect health outcomes. Nutbeam (1996) identified health literacy as an outcome of health promotion interventions which can be measured as improvements in attitudes, motivations, health actions, self-efficacy, and knowledge. These short term health promotion outcomes are the immediate targets of health education and skills development. They lead to improvement in intermediate outcomes (modifiable determinants of health) such as healthy behaviors and lifestyles (tobacco, alcohol and drug use), effective use of health information and services (immunizations, medical home), and healthy environments (safe home and car). Intermediate outcomes in turn lead to ultimate or end-stage outcomes (infant mortality, healthy school ready children). Thus, the effects of an intervention to promote functional health literacy can be measured as improvement in health promotion outcomes and intermediate health outcomes.

By characterizing the progressive tasks and social practices that demonstrate progressive levels of health functioning for groups of individuals (e.g. parents, or persons living with chronic disease), it is possible to measure functional health literacy and monitor progress over time toward optimal functioning. This strategy responds to scholars’ calls to address longer-term health outcomes that matter to patients and families particularly tasks required for effective selfcare and ability to perform those tasks (Berkman et al., 2004). No measure of health literacy in the public health model has been reported (Paasche-Orlow, 2007; Pleasant & Kuruvilla, 2008). I applied the theoretical framework described here as the basis for deriving the Functional Health Literacy Measure (FHLM—say *film*) from the Life Skills Progression instrument (Wollesen & Peifer, 2006) used in this study.
In Chapter 3, I describe the instrument and data collection as well as analytical methods used to evaluate the impacts of an intervention to promote functional health literacy as an asset in parents of disadvantaged children through home visitation. This includes presentation of the evidence base supporting home visitation as a feasible, potentially effective channel for health literacy promotion and the policy case for focusing national scale health literacy intervention on disadvantaged families.
In Chapter 2, I considered functional health literacy from the public health standpoint as a personal and community asset to be built through health education and health promotion interventions (Nutbeam, 2008). I discussed the Nutbeam (2000) model of progressive “levels” of health literacy demonstrated through health actions and practices. These levels (functional, interactive and reflective) reflect progressively greater autonomy, personal empowerment, and engagement in a wider range of health actions that extend from personal behaviors to healthcare practices and lifestyle changes (Nutbeam, 2000). Following this thinking, I extended the idea of functional health literacy, meaning engagement in health actions and practices, to encompass not only fundamental health literacy, (which Nutbeam and others label *functional health literacy*), but also interactive and reflective health literacy; so that progressive levels of health literacy correspond to progressive levels of health functioning. With this theoretical framework, one can measure improvement (or decline) in functional health literacy over time as progress (or regression) toward higher levels of health functioning. Higher level literacy skills (social interaction and reflection) show up as higher levels of health functioning.

This Chapter describes a community based intervention to promote functional health literacy. Previous intervention studies have focused on overcoming patients’ low reading and comprehension skills in clinical settings by improving information and its delivery, and recently by mitigating system-level barriers to understanding and complying with therapeutic regimens. While the goal of these interventions has been to improve health in persons with low literacy, the most common outcomes of interest in intervention studies have been knowledge gain (about disease,
treatment, or prevention) and treatment adherence (following a medication regimen; e.g. taking all the antibiotics despite feeling better after a few doses).

The intervention reported here aims beyond acquiring knowledge to using knowledge in ways that maintain and promote health. It applies health education and health promotion methods to promote functional health literacy, measured as health functioning, in both skilled and unskilled readers, particularly in disadvantaged parents during the prenatal to preschool period.

Focus Intervention on Disadvantaged Young Families

Arguments in favor of intervening with disadvantaged families with young children can be made on the grounds of fairness and social justice (WHO, 2003), new understanding of early child development (National Academy of Science, National Research Council, 2000), and economic efficiency (Heckman, 2006). The Institute of Medicine’s (2004b p. 4) definition of child health is closely linked to concepts of literacy expressed in the National Literacy Act of 1991:

*Children’s health should be defined as the extent to which individual children or groups of children are able or enabled to (a) develop and realize their potential, (b) satisfy their needs, and (c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments (IOM, 2004a p.4).*

This definition is rooted in an emerging scientific consensus that health is not endowed at birth but instead develops over time. Health is the product of dynamic lifelong interactions between risks (poverty, low parental literacy), protective factors (safe environments, parental functional health literacy) and health promoting influences (preventive healthcare services, safe stimulating environments) that affect long term health trajectories. Disadvantage during childhood diminishes future prospects by reducing a child’s health potential, which in turn directly harms educational outcomes and future social competence and accelerates the acquisition and severity of health problems in later years. Therefore, effective approaches to developing health
seek to minimize risks, maximize protective factors, and optimize health promotion (Halfon, DuPlessis & Inkelas, 2007; IOM, 2004b; WHO, 2003).

Intervention to promote functional health literacy in disadvantaged families can contribute to each of these objectives. It can minimize risks of negative health outcomes for children associated with maternal low literacy such as poor development, low immunization rates, low-birth-weight and infant mortality (Robinson & Wharrad 2000; Arya & Devi, 1991; Browne & Barrett, 1991; Kogan, Alexander, Kotelchuck & Nagey, 1994). Preventable low birth weight\textsuperscript{22} is one example of how the negative impacts of parents’ low health literacy extend to their children, and how maximizing health promotion can minimize risk and improve health outcomes. Kogan et al., (1994) reported that in a large nationally representative sample, mothers who recalled learning about specific health behavior topics during pregnancy had a significantly reduced chance of delivering a low-birth-weight child compared to mothers who were not able to access information on those topics. Mothers with inadequate pregnancy health information were more likely to have a low-birth-weight baby despite lower risks. Low birth weight is the leading cause of infant mortality and poor child development. Other examples of how parents’ functional health literacy (health actions) may simultaneously affect parent health and child development include: establishing a medical and dental home (regular sources of care) for parent and child; arranging and completing well-child checkups and immunizations; recognizing the child’s illness and injury, providing appropriate home-care, triggering timely intervention, administering medications and follow treatment regimens; recognizing their own depression and accessing treatment.

Because the scaffolding for physical, cognitive and socio-emotional health is built in the early years of life, early investments in prevention and health promotion can greatly improve long-term health, behavior, economic and civic outcomes (National Academy of Science/National Research Council, 2000). Low literacy and low health literacy are closely associated with poverty,\textsuperscript{22}Low birth weight refers to newborn weight less than 5.5 pounds. It is the leading cause of poor child development and infant mortality, that is, death before the child’s first birthday, and the most significant indicator of quality prenatal care.
racism and poor education (Rudd, 2007) and a growing body of literature documents how health disparities originate during early childhood and compound over time (IOM, 2004b; WHO, 2003). Therefore, interventions that promote parents’ functional literacy serve social justice and fairness.

It is a rare public policy initiative that promotes fairness and social justice and at the same time promotes productivity in the economy and in society. Investing in the development of disadvantaged children is such a policy (Heckman, 2006 p. 2). The reason lies in the importance of skills in the modern economy and the dynamic nature of the skill acquisition process.

Early inputs greatly affect the productivity of later inputs. A large body of social science and neuroscience research shows children are born learning; stimulating early childhood environments support skill development; and skill begets skill. Conversely, impoverished environments, those that lack cognitive and non-cognitive stimulation regardless of income, are powerful predictors of adult failure. Early family environments are major predictors of both cognitive and non-cognitive skills in adults. Early interventions can partially compensate for early disadvantage (National Academy of Science, National Research Council, 2000; Heckman, 2006). Efforts to enhance early family environments and parenting skills promote child development, including children’s emerging literacy and school readiness benefitting individuals, families, communities and society. Similarly, efforts to promote parents’ functional health literacy prepare the next generation of parents, healthcare consumers and family health managers.

**Pregnancy and Early Parenting: A Unique Opportunity to Promote Health Literacy**

Pregnancy is a life transition that triggers independent learning (Orr, 1990) and use of significant health services, often for the first time, notably prenatal, obstetric, pediatric and preventive services. Lacey (1988) found that pregnant women and new mothers exhibit readiness to learn well above national norms. Figure 5 illustrates how the 0 to 3 period (preconception to the child’s third birthday) presents a unique opportunity to establish appropriate health services
utilization and personal health practices among primary health decision makers in growing families with potential lifelong benefits for several individuals and the healthcare system.

Figure 5. This logic model of health literacy promotion in the prenatal to preschool period illustrates how pregnancy and early parenting present a unique opportunity to establish appropriate health services utilization and personal health practices among primary health decision makers in growing families with potential lifelong benefits for entire families, the healthcare system and the schools.

Taken together, the concepts of functional health literacy, health functioning, reflective functioning, health promotion, early child development, and life skills acquisition suggest that an intervention to promote parental functional health literacy among disadvantaged families with very young children has the potential to produce significant short- and long term health, economic and social benefits for entire families, the healthcare system and the schools.
Visitors Promote and Monitor Health Functioning

Home visitation programs intend to promote multiple aspects of functioning in parents of very young children including health functioning. Home visitors are nurses, social workers, health educators or paraprofessionals who link parents to healthcare and community resources, and provide social support, practical assistance, information, and parenting and health education (Gomby, 2005).

Studies show that home visitation exerts a positive effect on women’s and children’s health and health functioning. Kitzman, and colleagues (1997) reported improvements related to home visitation by nurses, including reductions in prenatal cigarette smoking and hypertensive disorders; reductions in children's healthcare encounters for injuries; fewer unintended subsequent pregnancies, improvements in birth spacing and in children's school readiness. Wollesen and Peifer (2006) reported significantly reduced depression and violence in families participating in home visitation programs.

Lee and colleagues theorize that social support buffers or mitigates the adverse effects of low health literacy (Lee, Arrozulla & Cho, 2004). Considerable evidence links social support with increases in health promoting behavior and decreases in health compromising behavior, including adherence to medical regimens (Jackson, 2006). Social support is a cornerstone of the rationale for home visiting. Home visitors provide support directly and strive to strengthen natural support networks (Gomby, 2005).

In contrast to clinical settings characterized by short episodic encounters, the home setting is conducive to health education tailored to particular everyday living conditions. The frequency (1 to 4 per month) and duration (1 to 2 hours) of home visits enables ongoing monitoring and support of parents’ goals, behavior change and health practices. Length of services (six to 36 or 60 months) is sufficient to achieve lifestyle and behavior change.
A trusting relationship is essential to changing behaviors, lifestyles, and environments (Heaney & Israel, 1997). While production pressures in clinical settings may preclude relationship development, home visitors are especially skillful at establishing rapport and developing trusting relationships with parents, especially those made cautious and reluctant by past disappointments. Home visitors are selected for their aptitude and attitude. They are non-judgmental, respectful and motivated by a desire to work with disadvantaged parents. Home visitors frequently are recruited from the service population and so are culturally and linguistically competent.

*Home Visitation Networks Can Support a National Response to Health Literacy*

Healthy People 2010 23 Objective 11.2 (U.S. Dept of Health and Human Services, 2000) is “to promote the health literacy of persons with low literacy skills”. According to the 2003 National Assessment of Adult Literacy, only 13 percent of U.S. adults have proficient literacy skills. And according to the National Network of Libraries of Medicine (Glassman, 2008), low health literacy makes anyone with a high school education or less (about three-quarters of the adult population) vulnerable in the healthcare system. Therefore, the objective calls for a nationwide response. A large national infrastructure, including training and technical assistance mechanisms, is in place to support home visitation. State and national networks of home visiting programs serve over 400,000 families annually (Gomby, 2005). Some programs use instruments such as the Life Skills Progression (Wollesen & Peifer, 2006) to monitor progress toward higher levels of functioning, including health functioning. My study demonstrates the readiness of home visitation programs to collaborate to increase their effectiveness and their hunger for data to inform practice. An intervention that consciously and effectively incorporates health literacy promotion into the usual activities of home visiting could be efficiently implemented on a national scale through the existing infrastructure. Home visitation is a feasible and potentially effective channel to promote health literacy in parents.

23 Healthy People 2010: Public health objectives for the Nation set every 10 years with mid-course evaluation every five years. In 2009, setting of 2020 objectives is in progress. Health literacy is considered a factor in all the 416 objectives. See http://www.healthypeople.gov
For these reasons, this early attempt to implement the public health model of health literacy promotion aimed to increase functional health literacy in disadvantaged parents during the prenatal to preschool period through home visitation. Success suggests a national intervention strategy to embed literacy and health literacy in growing families as they enter the healthcare and school systems by embedding literacy and health literacy promotion into home visitation goals, practice and evaluation.

**Intervention Description**

**Background**

Beginning in 2004, a number of home visitation and case management programs around the country obtained training and implemented the Beginnings Guides Life Skills Development Curriculum (Smith & Wollesen, 2004-8) including the Life Skills Progression instrument (Wollesen & Peifer, 2006). The primary aim of the curriculum is to promote functional health literacy and reflective functioning in disadvantaged parents of very young children. The curriculum development was funded by grants from the Zero To Three National Center for Infants Toddlers and Families. In the trained programs, home visitors/case managers integrate the curriculum materials and reflective practices and teaching strategies into their usual activities. They tailor the curriculum to individual families and use the Life Skills Progression instrument (LSP) to observe and document parents’ progress over time on multiple aspects of family functioning. Each program collects and organizes their LSP data into a database for internal evaluation purposes.

In 2006, I recruited six of these trained home visitation programs and one telephonic case management program to contribute their de-identified LSP databases for secondary analyses by University of Washington researchers under the direction of four institutional review boards.\(^\text{24}\) I selected programs to be broadly representative of various models of home visitation, service

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\(^{24}\) University of Washington, University of Indiana, Virginia Polytechnic Institute, Medical College of Georgia
populations and geographic areas. The participating programs’ contributed data including all LSP records (up to seven completed LSPs) for cases open at the start of the study period (September 2006) and all cases opened as late as March 2008. The programs’ LSP databases were combined, resulting in a single analyzable database (N=2532 parent/child pairs who received 6 to 36 months of service). Since the telephonic case management program (New Mexico) did not conduct home visits and is only recently established, the analysis focuses on the six home visitation programs.

The Functional Health Literacy Measure (FHLM)

In a previous project, the research team conducted statistical analyses to assess the reliability and validity of a measure of functional health literacy derived from the LSP. The Functional Health Literacy Measure (FHLM –say *film*) consists of two scales: The Functional *Healthcare* Literacy Scale (FHcL) rates parents’ use of healthcare services and information, and the Functional *Selfcare* Literacy Scale (FScL) rates self-management of personal and child health at home. The internal consistency of items comprising each scale was assessed by calculating Cronbach’s alpha using all initial LSP records with complete data. Alphas of .60 would indicate scale items are adequately consistent with one another and measure related skills (Dooley, 1985 p.83). Analysis of the FHcL scale used 279 records and produced an alpha of .76. Analysis of the FScL used 538 records and produced an alpha of .74.

Repeated administration of the LSP allowed examination of test-retest reliability for the scales by computing correlations between the first and second observation for each scale, which occurred about six months apart. While we anticipate visitation increases parental functional health literacy, we expected that parents with lower initial scores relative to the other parents would have lower scores at the second assessment as well. Similarly, the highest scoring parents would be expected to remain among the highest scoring parents, even if some improved more
than others. The analysis showed substantial correlation between first and second observations of the same scale. As expected, those correlations are larger than other correlations between the scales.

In a previous independent review, rating of five case studies by 12 home visitors produced an estimated inter-rater reliability of 90% (Richardson, 2000). This finding indicates that different reviewers can be expected to score the same case very similarly.

I used logical analysis and expert review to establish content validity of the scales, meaning key elements, and no inappropriate elements, are included (Adcock & Collier, 2001). I developed the healthcare and selfcare scales separately since they represent different functions, skills, and environments. All LSP items were previously reviewed in a rigorous process (Wollesen & Peifer, 2006)

The research team conducted criterion validation in which one measure is used as a standard of reference to evaluate an alternative measure. Since there are no true measures of functional health literacy, we sought evidence of association between FHcL and FScL scores and several other indicators that conformed to theoretical expectations about their inter-relationship (Adcock & Collier, 2001). Reference criteria included the ELF literacy screen (Bennett et al., 2003) described in Chapter 3, and well established measures of parental life skills, notably the Community Life Skills Scale (Barnard, 1991) and the HOME Infant Toddler Inventory (Caldwell, 1984). We also compared FHLM scores to data on actual child health services utilization (n= 800) collected concurrently with the LSP by home visitors in two participating sites using the Home Visitors Information Tracking System. Correlation coefficients showed the expected agreement or disagreement between FHLM scores and each of the reference criteria indicating sufficient validity to warrant further use and testing.

For this intervention trial, further analyses of FHLM scores were conducted to evaluate home visitation as a channel to promote functional health literacy; specifically to address the
research question: Does home visitation incorporating the Beginnings Guides Life Skills Development Curriculum promote parental functional health literacy?

Specific Aims

This intervention aims to improve parental functional health literacy, demonstrated by progress toward higher levels of health functioning, among disadvantaged parents of young children, in the healthcare system and in health contexts at home, through home visitation.

Study Population

Families served in home visitation programs are economically disadvantaged, socially isolated and/or at risk for child maltreatment. Participating programs recognize low adult literacy and low health literacy as significant barriers to parents’ goals for their children and to the goals of home visitation. Their service populations are medically underserved and socially complex, including non-English speaking/limited English proficiency families (primarily Spanish speakers), racial minorities (primarily African American and Hispanic/Latino), and both urban and rural populations. The cohort is 32% African American, 29% Caucasian, 18% Hispanic/Latino, 2% other ethnicities, and 20% unknown or missing. Screening estimated 30-36% of the cohort had reading skill equivalent to sixth grade or lower, compared to about 20% in clinical populations (Bennett et al., 2003)

Participating Sites

The participating sites are:

- Healthy Families Indiana MOM Project, Indianapolis, IN
- Healthy Families of Grant County, Marion, IN
- Child Health Investment Partnership of Roanoke Valley, VA
- Enterprise Community Healthy Start, Augusta, GA
- Partnership for Strengthening Families, Bozeman, MT
- Early Head Start of Monterey County, Salinas, CA
Presbyterian Health Services Maternity Case Management, Albuquerque, NM

These sites are broadly representative of national networks of home visitation programs including Healthy Families America, National Healthy Start, Early Head Start, Parents as Teachers, Strengthening Families, and the state of Virginia’s public-private partnership model of home visiting, plus a telephonic case management service for isolated families in rural New Mexico.

Program models differ in their specific goals and approaches, service areas and populations, staffing models, and use of supplemental curricula. The participating programs are differentiated from most other programs in their model by their specific intent to promote parental functional health literacy and reflective functioning, and by their routine use of the Beginnings Guides Life Skills Development Curriculum including the Life Skills Progression instrument.

*Parental Functional Health Literacy*

This project was conceived as an investigation of maternal health literacy defined by Renkert and Nutbeam (2001 p. 382) as:

*The cognitive and social skills which determine the motivation and ability of mothers to gain access to understand and use information in ways that promote and maintain their health and that of their children. (Emphasis added)*

Since the database included a significant number of fathers, the consensus among the research team, the home visitors, program and research funders, and experts was to change the language to include fathers by addressing parental health literacy. Accordingly, I adapted Renkert and Nutbeam’s (2001) definition to define parental functional health literacy as:

*The cognitive and social skills which determine the motivation and ability of parents to gain access to, understand, and use information in ways that promote and maintain their health and that of their children.*
Intervention Activities

To promote parental functional health literacy, home visitors integrated use of the Beginnings Guides Life Skills Development Curriculum (Smith & Wollesen, 2004-8) into their usual activities. They were free to tailor their use of the curriculum to the needs, goals and capacities of each family. This section describes key elements of the intervention including goals, training, materials, reflective teaching strategies and tools (reflective questions, reflective drawings and reflective supervision), the Life Skills Progression instrument as a guide to tailoring the intervention, and referral to literacy enhancing services.

The Beginnings Guides Life Skills Development Curriculum

The Beginnings Guides Life Skills Development Curriculum is a strengths-based family support and parent education curriculum that helps home visitors promote reflective functioning in parents and their infants/toddlers, and promote parents’ functional health literacy. A hallmark of this curriculum is its emphasis on reflection and reflective practices and teaching strategies. Goals include enhancing parents’ knowledge of health and healthcare, increasing their ability to access and benefit from healthcare information and services, use community resources, maintain health at home, and support child development. The curriculum incorporates the Life Skills Progression instrument (LSP), which monitors progress toward developing the life skills that the Beginnings Guides materials and content promote. The LSP enables visitors and case managers to establish parents’ baseline profiles, identify strengths and needs, tailor interventions to promote specific capacities, monitor parents’ progress/regression, and assess program effects (Wollesen & Peifer, 2006).

Training for a Reflective Approach

The Beginnings Guides Implementation Training is an on-site one-day (8 hours) interactive intensive for home visitors/case managers and their supervisors on effective, efficient use of the Beginnings Guides Life Skills Development curriculum. Focus is on learning to support
parents’ development of reflective skills and functional health literacy. The reflective approach represents a significant shift for many home visitors and supervisors who as “helping professionals” or “natural helpers” are inclined to “rescue” or “fix” families, and for programs whose funding sources may mandate a quick fix. While it may produce favorable statistics, rescuing defeats the purpose of promoting higher level functioning by holding the parent as a victim unable to do what is required of her/him and “doing the heavy lifting” for them. The reflective approach aims to enable parents to do for themselves. This tendency to rescue is addressed in the training through modules on Stephen Karpman’s (1968) drama triangle, which explains dysfunctional relationships as dynamics among Victim (parent), Persecutor (The System, poverty, abuser) and Rescuer (visitor, boyfriend). In David Emerald’s (2006) antidote to the drama triangle, *The Empowerment Dynamic (TED)*, parties in the relationship shift to new roles as Creator (parent exerting control over his/her life), Challenger (persecutor viewed differently), and Coach (visitor). An important distinction is made between being *victimized*, which is common for many disadvantaged parents, and living in *victimhood*, which is a state of mind. The reflective process enables the visitor to step out of the rescuer role, which in turn requires the parent to step out victimhood and begin to exert control over his/her life and health.

At completion of the training, participants feel confident using the *Beginnings Guides* and ready to begin implementing the practice tools and teaching strategies. This implementation training is a companion to the one-day (8 hours) Life Skills Progression Training on reliable use of the LSP to collect data and use it to 1) monitor multiple aspects of family functioning, including functional health literacy; and 2) to tailor reflective interventions to support continued progress in specific families.

*Materials: Beginnings Pregnancy Guide and Beginnings Parents Guide*

The *Beginnings Pregnancy Guide* (Smith, 1989-2008) consists of six booklets (total 96 pages) referenced by gestational age to facilitate staged learning. The *Pregnancy Guide*
translates the health promotion content of prenatal care (U.S. Dept. of Health and Human Services, 1989) into practical guidance for healthy pregnancy. First published in 1989 and now in its seventh edition, it reflects guidelines of the Public Health Service, American College of Obstetricians and Gynecologists, Obstetricians and Gynaecologists of Canada, and American Academy of Family Physicians. The Spanish edition was produced through a grant from the Agency for Healthcare Research and Quality with direct participation of parents and home visitors representing multiple Spanish-speaking cultures in the US (Smith & Gonzales, 2005).

The *Beginnings Parents Guide* translates the science of early child development into practical guidance for parents of children to age 3. It consists of 8 booklets (total 196 pages) referenced by child age. First published in 1999 through a ZERO TO THREE fellowship with the National Center for Infants Toddlers and Families, and now in its third edition in English and Spanish, the *Parents Guide* reflects guidelines of the American Academies of Pediatrics and Family Physicians.

Curriculum materials are specifically designed for low-skill learners and demonstrated acceptable, attractive and persuasive to both college-educated and under-educated parents. Field testing showed these materials are easy to read and comprehend *independently* for 50% of participants with 6 to 8 years schooling and 80% of those with 9 to 12 years education. Designed to serve both as teaching guides and for independent learning, the *Beginning Guides* incorporate findings from research on health behavior, health education and health promotion; readability, interaction, typology and graphics, plain language and materials design. Art by Laurel Burch conveys the purpose and importance of the information, compels even disinterested parents to pick up the material, and leads them into the learning (Smith, 2008).

Specific checklists and self-assessments aid parents’ use of health information and services. For example, warning signs for the current period of pregnancy or early childhood are located on the back cover of each booklet with space to write in providers’ contact information.
Visitors review the warning signs with the parent each time they introduce a new booklet, (increases health knowledge and skill with printed information). The visitor invites the parent to read aloud the warning signs (practice reading in a non-judgmental supportive setting, increases comprehension and vocabulary, stimulates discussion). She then asks the parent which of the warning signs s/he has seen already or is worried about and these are discussed (personalizes information and applies to new circumstances, problem solving and planning for health crises). The parent writes in the physician contact information and decides where to keep the information for easy reference (increases facility with printed information, provides permission, encouragement and knowledge to trigger timely intervention). If the parent has no telephone, s/he and the visitor discuss how to contact the doctor (e.g. arrange to use a neighbor’s phone) (increases social support, problem solving). They may discuss what information the doctor will need if the child has a particular problem (e.g. temperature readings for a fever). They may role play a call to report a suspected warning sign and decide what to say if an answering service responds or if their concern is not taken seriously (practice interacting with health professionals, advocacy). In these ways, these deceptively simple activities and conversations promote fundamental, interactive and reflective health literacy and health functioning.

Reflective Questions

While the focus of clinical interventions is on transmission of facts and instructions from experts to patients, in this intervention, home visitors were trained to “teach by asking” using reflective questions. The Beginnings Guides Life Skills Development Curriculum includes scripted reflective questions to personalize and apply key health messages, knowledge of which research shows to be directly related to outcomes. Home visitors learn to formulate questions that lead a parent to reflect; that is to observe and frame his/her situation, (Think) and draw on his/her experience and knowledge and personalize information (Link) to devise solutions (Respond). Worksheets are provided to encourage parents to write out answers as an aid to thinking, learning and literacy skills development, and provide qualitative data for programs.
Home visitors use Reflective Questions to support development of functional health literacy, particularly critical reflection. For example, a parent might hear from the pediatrician that her infant should sleep on his back to prevent SIDS\textsuperscript{25}, and from the grandmother that the baby should sleep on his stomach to prevent aspiration\textsuperscript{26}. The parent needs critical reflection to reconcile conflicting advice, discriminate sources of information, and to decide how she will position her child for sleep. A parent’s ability to reflect critically affects her/his health practices and capacity to navigate the healthcare system and maintain personal and child health. Promoting health literacy and promoting reflection are inseparable. Support of reflection may be a critical missing piece for health literacy promotion in both community and clinical settings.

Visitors practice using and formulating Reflective Questions for various situations. Basic questions aim to initiate self-observation and lead a parent to identify needs and draw on experience: \textit{What did you notice about…? What have you tried; how well did that work? Have you asked for what you need?}

A relationship question focuses a parent’s thinking on a particular relationship; it presents an opportunity to consider things from the perspective of others and implies the possibility of changing assumptions or behavior. For example, \textit{Why do you think your mother says you’ve ruined your life?}

An exception question focuses on alternatives to “the way it is”. It identifies exceptions to things that feel “always” there and leads to seeing possibilities. For example: \textit{Can you think of a time when you were not depressed?} A coping question leads to discovery of personal resources and family strengths: \textit{How have you been able to cope so well?}

Miracle questions break though hopelessness and fear. They lead parents to create a possible future or establish a goal. For example: \textit{Imagine you are waking up tomorrow morning. A}

\textsuperscript{25} SIDS- sudden infant death syndrome; also called crib death. Death of an infant while sleeping that cannot be otherwise explained.

\textsuperscript{26} Aspiration – choking on vomit.
miracle has happened and things have changed. What is the first thing that will tell you something is different?

Scaling questions also relate to goal setting and problem solving. They lead parents to identify do-able steps toward a goal and recognize progress. For example: On a scale of 1 to 10, where 1 is the worst it’s ever been and 10 is the day of a miracle, where are you now? What would it take to move from there to …? (Smith & Wollesen, 2004-8).

Figure 6 illustrates how home visitors using the Beginnings Guides and reflective questions support parents’ development of health literacy skills and health functioning, and simultaneously support child development and school readiness.
The Gift of a Reflective Question

Home Visitor Asks

- Demonstrates it matters what a mother knows
- Builds mother’s confidence
- Creates a teachable moment
- Suggests a way to think about a current problem
- Presents the mother opportunity to recognize & apply her knowledge & experience - to use her power
- Presents the mother opportunity to notice gaps in her knowledge & to seek info
- Teaches responsively - leaves the power with the mother by supplying info only in response to her request
- She empowers the mother

Mother Reflects

- Feels respected, knowledgable, self-confident in caring for herself & Baby
- Taps into her experience, uses her knowledge
- Evaluates her experience, values, knowledge, feelings
- Applies and so learns from her experience
- Recognizes her need to know & need for info
- Asks for info - takes charge of her learning
- Increases knowledge
- Develops her life skills - problem solving, resource utilization, info seeking
- Changes behavior
- Improves baby care, interaction, teaching
- She is empowered

Baby Benefits

- Has his/her needs met
- Establishes trust in the mother
- Achieves secure attachment
- Enjoys improved health & well being
- Learns appropriate behaviors
- Reduced risk of abuse & neglect
- Innate curiosity is supported
- Improved school readiness

Figure 6. In the "Teach by Asking" model, reflective questions facilitate development of skills for effective use of health information and services, increase self-efficacy, support child development and school-readiness.

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Reflective Drawings

To assist learners who are unaccustomed to learning by reading, with Wollesen, I commissioned a series of line drawings to convey key messages of the *Beginnings Guides* without words. In a side-by-side “coloring conversation” between visitor and parent, or in a group of parents, coloring a Reflective Drawing initiates deep thinking and intimate sharing about the concepts it illustrates. This art therapy technique is powerful in eliciting repressed feelings, previously unrecognized needs, and new information about significant health risks such as low literacy skills, depression, domestic violence, or substance abuse. Reflective Drawings promote functional health literacy by increasing understanding, influencing attitudes and supporting behavior change. For example, they have been used to promote breastfeeding, seeking social support, responsive parenting and support of child development, and to facilitate peer teaching among parents. See Figure 7.

![Reflective Drawing](image)

**Figure 7.** This reflective drawing by Laurel Burch from the *Beginnings Parent’s Guide* promotes family literacy and raises issues related to reading. Reflective drawings and "coloring conversations" convey key messages without words, increase understanding, influence attitudes, and support behavior change.
Reflective Supervision

Supervisors and staff were trained to utilize Reflective Supervision in which the supervisor models reflective practices to assess and support visitors’ reflective practices in the field. This sets up a parallel process in which the supervisor models reflection and planning for the visitor who models for the parent who models for the child.

Supervision is reflective when both supervisor and visitor consider it a time for supported self-observation and learning from insight and experience. It focuses on program content and process, and the quality of the visitor’s relationships with families. It is strength-based, meaning it notes what is effective and done well by the visitor, the family, and the program and considers goals, needs, and blind spots of each. Reflective supervision is most beneficial when it is regular (time is protected), frequent (weekly is ideal), collaborative (reflects a shared vision and commitment), and topics of discussion are prioritized by the visitor.

In reflective supervision, the home visitor’s goals include the following:

- To obtain personal support for the heartbreak and frustration encountered in difficult family situations and heavy caseloads
- To notice and celebrate effective interventions, family progress and successes
- To gain new perspective on families and situations through collaborative reflection with an experienced supportive person
- To obtain expert information
- To plan strategies, tailor intervention, identify resources and formulate reflective questions to help parents focus their reflection on particular issues or blind spots
• To promote in visitors a habit of useful self-awareness and to use awareness of successes and disappointments to improve skills, detect personal blind spots that diminish effectiveness, learn by insight, self-observation and self-nurturing.

• To prevent burnout

The supervisor’s goals in reflective supervision include:

• To support the home visitor

• To reflect and validate the visitor’s strengths

• To build and maintain a trusting relationship with the visitor

• To support collaborative and individual reflective thinking

• To support planning of family-specific interventions and reflective questions

• To offer expert knowledge, guidance, resources

• To encourage self-assessment and professional growth

• To identify training needs and program service issues.

Supervisors use reflective questions such as Does this parent notice and take pride in his/her skills? How can you encourage that awareness and pride? Can you see needs that you are concerned about but are not a priority for the parent now? What do you want to do about them? What reflective questions are you thinking of to encourage the parent to bring the baby’s immunizations up to date? In what ways have you been effective with this family? If you had one wish for this family, what would it be? (Wollesen & Piefer, 2006).
The Life Skills Progression Instrument (LSP) and the Functional Health Literacy Measure (FHLM)

Participating programs administered the full LSP for each family at initiation of service, every six months and at close of service to establish baseline client profiles, identify strengths and needs, plan interventions, and monitor progress/regression toward optimal functioning. The LSP includes the Functional Health Literacy Measure (FHLM), two scales that rate parents’ functional health literacy. Use of the LSP must be considered part of the intervention, as well as the primary data collection method. The LSP guides reflective supervision and tailoring of the intervention for each family. For example, home visitors and supervisors use the LSP to jointly assess a particular parent’s strengths and develop strategies to build those strengths in order to address that parent’s needs and goals. Use of the LSP reduces visitor burnout, points to effective teaching strategies, and assures that sensitive topics (e.g. drug misuse, family violence) are addressed (Wollesen & Peifer, 2006).

Literacy Screening

Intervention for health literacy is inextricably linked to promotion of basic literacy skills in adults. In this intervention, home visitors were trained to use a brief (three-question) screening tool (Bennett et al., 2003) to identify parents likely to lack fundamental literacy skills and to refer them to community-based literacy enhancing services, such as adult basic education, English language learning programs, or tutors. The screening tool was validated with disadvantaged parents of children to age 6 in pediatric primary care. A panel of home visitation experts agreed that professional and paraprofessional visitors could reliably administer the ELF literacy screen and that it would be useful practice. A one-year pilot test conducted at the Medical College of Georgia confirmed this judgment.
Research Methods

*Action Research to Improve Health Literacy Promotion Practice*

My study was conceived as the first cycle in an ongoing program of action research, an iterative process of action and reflection in which practitioners undertake research activities in order to improve practice by learning from experience. The action research approach is particularly suited to health promotion research (Koelen, Vaandrager & Colomer, 2001), such as my study, which is conducted in the field, and involves collaborators from different organizations and disciplines. Health promotion outcomes, including health literacy promotion outcomes, are behavior changes that support health. Health behavior is the product of the interaction of multiple factors found in many facets of biological, social, environmental and cultural exposures. The health promotion researcher’s goal is to understand ways in which these factors might interact to yield certain behavior changes under certain conditions (Glanz, Lewis & Rimer, 1997, p. xvi), in order to guide practice. Traditional biomedical research methodologies (e.g. the randomized control trial), which value precision and parsimony and aim to isolate the contribution of single elements to any observed change in outcome, can reduce the effectiveness of health promotion interventions since they run counter to the processes of health promotion.

Following the action research design described by Kemmis (in Hopkins, 1985), the participating program staffs initially reflected individually on the potential impacts of limited literacy and health literacy in their service populations. They engaged in training to develop an understanding of adult literacy, particularly functional health literacy and its impacts on the goals of home visitation, specific program goals, and parents’ goals for their families. In view of research showing that home visitation has produced only moderate outcome effects (Gomby 2005), the training led the program staffs to conclude that specific attention to promoting parents’ functional literacy, particularly health literacy, may be prerequisite to achieving their program and family goals.
To address health literacy in their service populations, the participating programs independently determined to implement the Beginnings Guides Life Skills Development Curriculum and to track families’ progress toward optimal functioning using the Life Skills Progression instrument (LSP). Implementation of the intervention constituted the action in this first cycle of action research. I recruited the participating programs to collaborate in this study by sharing their LSP data for aggregate and comparative analyses. The collaborative became known as the Home Visitors Research Network.

In the reflection step of the iterative action research process, the home visitor/researchers compared and reflected on the observed results of their action. At the close of the study period, the directors and home visitor representatives of each program met for a day and a half with the research team, program funders, and national experts in home visitation and health literacy. This group of 40 collaborators together took a first look at the data. In a series of facilitated round-table conversations, they reflected collaboratively to make meaning of findings and between-site differences in results, plan next steps and future research, and make recommendations for policy (the revision step in action research). The Home Visitors Research Network is now poised for the second cycle of action research, meaning dissemination of promising practices and implementation of planned revisions to the intervention.

**Analytical Methods**

**Study Design**

The intervention was field tested in a two-year (September 2006 – August 2008) quasi-experimental multi-group cohort study using multiple waves of measurement. The intervention trial was funded jointly by the Health Resources and Services Administration Agency for Healthcare Research and Quality, National Institutes of Health Office of Behavioral and Social Science Research, and the National Institute for Child Health and Human Development.
**Instruments**

*LIFE SKILLS PROGRESSION AND THE FUNCTIONAL HEALTH LITERACY MEASURE.* The primary data collection instrument was the Life Skills Progression instrument (Wollesen & Peifer, 2006). Home visitors in the participating programs routinely use the LSP to document changes on 43 aspects of parents’ functioning and the literacy screen. For this project, they shared their data with researchers at University of Washington for secondary analyses.

To measure parents’ functional health literacy specifically, in a previous project, I derived the Functional Health Literacy Measure (FHLM- say film) from the LSP. The FHLM consists of two scales, the Functional Healthcare Literacy Scale (FHcL) and the Functional Selfcare Literacy Scale (FScL). On both scales, each item is Likert scale that characterizes progressive levels of health functioning from inadequate (score of 1), indicating health-harming behavior (chain smoking) or practices (no participation in the healthcare system), to adequate to optimal functioning (score >4, the target range) indicating health-promoting behaviors (not smoking) and practices (maintaining a medical home). The scales are intended to represent a continuum rather than absolute categories. Reflection and reflective functioning are embedded in the scales with higher scores indicating improving health functioning indicative of increased reflective skills.

Figure 8 shows the Functional Healthcare Literacy Scale completed for a hypothetical parent. It combines nine items from the LSP (Wollesen & Peifer, 2006) to rate parents’ use of health information and healthcare services for both parent and child.
### The LSP Functional Healthcare Literacy Scale

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
<th>Healthcare Literacy</th>
<th>NA</th>
<th>Inadequate</th>
<th>1</th>
<th>1.5</th>
<th>2</th>
<th>2.5</th>
<th>3</th>
<th>3.5</th>
<th>4</th>
<th>4.5</th>
<th>Competent</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>3</td>
<td>Use of Information</td>
<td></td>
<td>Refuses information from HV or HC</td>
<td>Uses inaccurate information from information sources</td>
<td>Passively accepts some information from HV or HC</td>
<td>Accepts/uses most information from HV or HC</td>
<td>Actively seeks/uses information from HV, HC &amp; other sources</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>2</td>
<td>Prenatal Care</td>
<td>No prenatal care</td>
<td>Care starts in 2nd-3rd trimester. Keeps some appointments</td>
<td>Care starts 2nd-3rd trimester. Keeps most appointments</td>
<td>Starts care in 1st trimester. Keeps most appointments</td>
<td>Keeps postpartum appointments</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>3</td>
<td>Parent Sick Care</td>
<td>Acute/chronic conditions go without Dr/Tx. No medical home</td>
<td>Seeks care only when very ill. Uses ER for care. No medical home</td>
<td>Seeks care consistently. Inconsistent Tx follow-up. Has medical home</td>
<td>Seeks care appropriately. Follows Tx recommended. Has medical home</td>
<td>Seeks care appropriately. Care or control obtained. Has medical home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>3</td>
<td>Family Planning</td>
<td>No PP method used. Lacks information about PP</td>
<td>FP method use is rare. Limited understanding of FP</td>
<td>Occasional use of FP methods. Good understanding of FP</td>
<td>Regular use of FP methods. Good understanding of FP</td>
<td>Regular use of FP methods. Plans/spaces pregnancies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>3.5</td>
<td>Child Well Care</td>
<td>None; no medical home</td>
<td>Seldom; no medical home</td>
<td>Occasional appointments; Child does not receive home</td>
<td>Has annual exam only</td>
<td>Has stable medical home</td>
<td>Keeps regular Check/Well-child appointments with same provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>3</td>
<td>Child Sick Care</td>
<td>Medical neglect. No Dr/Tx for acute or chronic conditions</td>
<td>Has care only when very ill. Uses ER for care</td>
<td>Timely care for minor illness but inconsistent Tx/Tx</td>
<td>Timely care for minor illness. Follows Tx recommended</td>
<td>Obtains optimal care for acute or chronic conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>0</td>
<td>Child Dental Care</td>
<td>No dental home or care at serious ECC. Poor hygiene</td>
<td>No dental home or care with some ECC and inadequate Tx/hygiene</td>
<td>Has dental home and hygiene but late Tx of ECC</td>
<td>Has dental home. Some preventative care. Inconsistent Tx</td>
<td>Has dental home. Regular preventative care and timely Tx</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>2.5</td>
<td>Child Immunizations</td>
<td>None or refused</td>
<td>IZ history unclear. Records lost</td>
<td>IZ’s begun, but no return appointment</td>
<td>IZ delayed, has return appointment</td>
<td>Complete or up-to-date IZ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>3</td>
<td>Medical/Health Insurance</td>
<td>No/unable to afford care or coverage</td>
<td>Medicaid for pregnancy or emergency only</td>
<td>Medicaid for pregnancy or emergency only</td>
<td>State-subsidized or partial-pay coverage</td>
<td>Private insurance with or without co-pay for self/others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Average 2.9 Healthcare Literacy**

Figure 8. The LSP Parental Functional Healthcare Literacy Scale (FHcL), one of two scales comprising the FHLM, rates parents’ use of healthcare services and health information. The shaded area represents the target range characterizing adequate to optimal functioning in the healthcare system.

In this hypothetical case, child dental care is not scored since the child is too young to have teeth. The scale score is the average of the item scores. This mother scored 2.9, below target range. Her interest in information from her doctor and her visitor is developing (Item 10 Use of Information). She has established a regular source of care for the child (Item 20 Child Well Care), but not herself (Item 18 Parent Sick Care), and is beginning to use services, albeit inconsistently.
Figure 9 illustrates the Functional Selfcare Literacy Scale, which combines seven LSP items to rate parents' management of health at home including maintaining a healthy life style and safe environments, using community resources, and supporting child development.

**The LSP Functional Selfcare Literacy Scale**

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
<th>Functional Selfcare Literacy</th>
<th>NA</th>
<th>Inadequate</th>
<th>Inadequate</th>
<th>Planned but unprepared</th>
<th>Planned, prepared, welcomed</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>0</td>
<td>Attitude to Pregnancy</td>
<td>1</td>
<td>Unplanned and wanted, Abortion or adoption plan</td>
<td>Planned but unprepared</td>
<td>Planned, prepared, welcomed</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>2.5</td>
<td>Support of Development</td>
<td>1</td>
<td>Poor knowledge of child development. Unrealistic expectations. Ignores or refuses information</td>
<td>Open to child development information. Provides some toys, books and play for age appropriate role</td>
<td>Applies child development ideas. Interested in child’s development skills, interests and play</td>
<td>Anticipates child development changes; Uses appropriate toysbooks; plays &amp; reads with child daily</td>
</tr>
<tr>
<td>11</td>
<td>2.5</td>
<td>Use of Resources</td>
<td>1</td>
<td>Resource needs unrecognized. Community resources not used or refused; hostile</td>
<td>Resource needs unrecognized. Limited use when assisted by others. Misses most appointments</td>
<td>Identifies needs. Uses resources with little resistance. Keeps most appointments</td>
<td>Identifies needs. Uses resources independently. Keeps or reschedules appointments</td>
</tr>
<tr>
<td>24</td>
<td>5</td>
<td>Substance Use or Abuse</td>
<td>1</td>
<td>Chronic Hx drug and/or alcohol abuse with addiction</td>
<td>Drug/alcohol binge or intermittent use, without apparent addiction</td>
<td>Rare or experimental use of drugs or clean. In recovery group or Tx program</td>
<td>Occasional use of legal substance; stops if pregnant</td>
</tr>
<tr>
<td>25</td>
<td>5</td>
<td>Tobacco</td>
<td>1</td>
<td>Chain smokers; &gt;2 pk/day; uses smoking; heavy second-hand exposure</td>
<td>Non-chrown use or some second-hand exposure</td>
<td>Decreases amount when pregnant. Controls second-hand exposure</td>
<td>No use or second-hand exposure in past six months or current pregnancy</td>
</tr>
<tr>
<td>28</td>
<td>2</td>
<td>Self-Esteem</td>
<td>1</td>
<td>Poor self-esteem. Anticipates criticism from others. Rarely initiates; avoids trying new skills</td>
<td>Copes sometimes; but not limited competence and flat affect. Limited initiative for learning new skills</td>
<td>Irritable/defensive. Makes excuses, blames others. Initiates; starts using new skills but gives up easily</td>
<td>Beginning to actively initiate. Develops skills &amp; recognizes own competence. Emerging confidence visible</td>
</tr>
</tbody>
</table>

Figure 9: The LSP Parental Functional Selfcare Literacy Scale (FScL), one of two scales comprising the FHLM, rates parents’ ability to exert control over their personal health and health actions, their children’s health. The shaded area represents the target range characterizing adequate to optimal functioning in the healthcare system.

In this hypothetical case, Item 4 Attitude to Pregnancy is not scored since either the pregnancy has ended, or the parent is a father. This mother scored 3.3 on FScL, below target range. She is beginning to identify needs & access resources and information.
Literacy Assessment. To tie this study to previous research, parents’ health literacy skills were assessed conventionally as reading skill in a clinical setting using Bennett and colleague’s (2003) literacy screening tool described above. I dubbed the screen “the ELF” as a mnemonic acronym. Two ELF items not already included in the LSP were added to the primary data collection instrument. The ELF screen produces dichotomous proxy REALM scores (Rapid Estimate of Adult Literacy in Medicine, the most commonly used conventional health literacy measure (Davis et. al., 1991)). Bennett reported the screen correctly flagged 84% of parents with REALM scores at or below 6th grade level and also flagged 46% of parents with higher REALM scores. The study database includes one or two literacy measures on 2,145 parents. Figure 10 illustrates the screening instrument. Less than 12 years education and one No answer predicts 84% of parents with < 6th grade reading level. Follow-up questions further indicate low fundamental literacy skills and set up referral to literacy enhancing services. Visitors provide ongoing support and encouragement for participation.

<table>
<thead>
<tr>
<th>ELF Literacy Screen</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ How many years of Education have you completed?</td>
</tr>
<tr>
<td>□ Is your child’s other parent Living with you now?</td>
</tr>
<tr>
<td>□ Do you ever read for Fun?</td>
</tr>
</tbody>
</table>

**Follow-up Referral Questions**

| □ Do you think your reading could be better? |
| □ Would you like to get some help with your reading? |

(Bennett et al., 2003)

Figure 10. The primary purpose of the brief literacy screen (ELF) is to refer parents to literacy enhancing services. The data estimates reading level by producing proxy REALM scores.
Analyses

Quantitative Analyses

Controlling for low reading ability, an Analysis of Variance with Repeated Measures examined the patterns of change in FHLM scores over six to 36 months of home visitation. The null hypothesis of no change in parental functional health literacy over time and no difference in the pattern of change for those at highest risk of low literacy would be rejected if this analysis showed a significant change from baseline, or a significant interaction between change from baseline and reading level.

A threat to the validity of a positive finding on this question is the possibility that improvements are due to events unrelated to the intervention that occurred during the intervention period. For example, the changes could be due to simple maturation in the parents, or to changes in the community, such as the availability of public transportation or a local medical clinic. Another possibility is a change in the local economics resulting in large scale employment or unemployment among participating families. Or changes in public policy might affect access to healthcare by these families. It may be that the parents’ functional health literacy did not increase; they simply became “older and wiser” with time, or the community changed so that it was easier or harder to access health care, or a policy change affected access.

Since ethical considerations preclude withholding services or wait-listing needy families, there is no randomly assigned control group. However, we were able to create comparison groups within the cohort, using a matching process in which an “experimental parent” was matched with a “comparison parent”. At intake into the program, this “comparison parent” was a close geographic and demographic match for an “experimental parent” by the time the comparison parent had received 12 to 18 months of home visitation services. In this way, if the observed longitudinal effects are not due to the intervention, but instead result from some other factor such as simple maturation or unrelated environmental factors, the comparison parent’s
baseline FHLM score (before home visitation services) should be the same as the experimental parent’s “post” FHLM score, after the ineffective treatment. That is, the comparison parent’s baseline score represents what one would expect the experimental parent’s FHLM score to be if she had not obtained home visitation services or if the home visitation services were ineffective, even if other factors worked together to create an apparent effect. This design allowed me to attribute any difference between the experimental parent’s “post” home visitation FHLM score and their matched comparison’s “pre” home visitation score to the intervention.

**Qualitative Analyses**

Qualitative data from interviews with the home visitors who implemented the intervention and collected the LSP data and their supervisors address adherence to best practices for home visitation (Gomby, 2005). Interviews were audio recorded and transcribed. Responses were tabulated and analyzed for themes and comparison of between-site differences.

Analysis of the transcripts and tabulated responses revealed similarities and differences between the sites’ to elucidate variations in results. In addition, proceedings of a project closing reflection conference revealed meanings assigned to the data and preliminary findings by visitors and supervisors, funders, researchers, and national experts in home visitation and health literacy. The proceedings informed conclusions and implications reported in Chapter 5.
Chapter 4
Home Visitation: Promoting Health Literacy as an Asset

This chapter presents findings of aggregate and comparative analyses of FHLM scores. Since the data are insufficient to comment on the relative effectiveness of program models, here I refer to the programs by their state. Since the New Mexico program did not conduct home visits, only telephone visits, and it is too recently established to be included in the matched comparison analyses, the analyses focus on the six home visitation programs.

Descriptive Statistics

Study Population

Participating sites contributed useable Life Skills Progression (LSP) records of 2532 parents who obtained home visiting services for up to 36 months in one of seven programs representing various home visitation models and serving racially/ethnically different low-income urban and rural populations in the Northwest, Southwest, Mid-Atlantic, and Midwest regions of U.S. Figure 11 shows the number of families followed at each site.

![Figure 11. Number of parent-child pairs followed at each site.](image-url)
Parents’ age ranged from 13 to 68 years (in a few cases, grandparents served as parents), with an average of 25.4 years (SD=7.4 years). About one-third (32%) of the study population were African American, 29% were Caucasian, 18% were Hispanic/Latino, two percent were other ethnicities, and 20% were unknown or missing. The families are Medicaid-eligible (they meet their state’s means test for poverty assistance) and/or at risk for child maltreatment. High school completion rates in the sites ranged at intake from 33 to 53 percent, and higher education rates ranged from 4 to 26 percent.

Figure 12 shows the diversity of the study population by site. The Virginia and Indianapolis sites had the most diverse populations. The California site’s population is all Latino/Hispanic; the Montana program serves a nearly all Caucasian/white population; and the Georgia site’s population is 85 percent African American.

![Ethnicity/Race distribution by site](image)

Figure 12. Race/ethnicity distribution by site. The diversity of the study population strengthens the study.
**Literacy Estimates**

Using the brief literacy screening tool (ELF) described in Chapter 3, the home visitors obtained useable baseline literacy estimates for 2145 parents. Of these, 73% had scores suggesting reading skill above sixth grade level; 27% have scores suggesting reading skills at or below sixth grade level. Another 11% had less than 12 years education and missing data for the other two screening questions. If these parents read at or below sixth grade level, it brings the percentage of the cohort at risk for reading ability \( \leq 6^{\text{th}} \) grade to 36%, compared to about 20% in clinical populations.

**Functional Health Literacy before Home Visitation**

Figure 3 below shows that at baseline (before obtaining home visitation services), only 42 percent of parents scored in the target range on functional healthcare literacy. Nearly six in 10 (58%) parents scored below target range, indicating they were not adequately accessing and obtaining the benefits of healthcare information and services when they entered home visiting services. This distribution is comparable to national estimates of health literacy in U.S. adults with less than high school education (Rudd, 2007).

Parents demonstrated stronger baseline selfcare literacy compared to healthcare literacy with 57% in the target range at initiation of service. Still, more than four in 10 (43%) scored below target range, suggesting attitudes and practices that compromise family health. See Figure 13.
Figure 13. Functional Health Literacy Scores at Initiation of Home Visitation Service show at baseline, only 43% of parents had adequate functional healthcare literacy; 59% had adequate selfcare literacy.
Results

*Does Home Visitation Promote Parents’ Health Literacy? Yes*

Parents demonstrated statistically significant improvement on both Functional Health Literacy Measure (FHLM) scales after six months of service. They showed a linear increase over time that slowed after the initial increase seen at six months. See Figure 14.

**Figure 14.** Change in Functional Healthcare Literacy and Selfcare Literacy for parents with four observations. Functional health literacy increases over time with home visitation (p<.001).

Parents continued to progress toward optimal functioning even after starting in or attaining the target range indicated by scores >4 (p<.001). Modest, highly significant changes across a large population represent a major impact.
Is Change Due to Maturation, Community Events or Policy Changes? No

Maturation and external events occurring during the intervention that may affect study outcomes are the greatest threat to the validity of the finding that home visitation promotes parents’ functional health literacy. To rely on this finding one must rule out the possibility that parents are simply becoming older and wiser with time or that something other than the intervention produced the observed effects.

So far, the analyses have compared parents with themselves over time. To separate individual maturation, or unrelated community events or policy initiatives, from the effects of home visitation, I compared “experimental” parents who were visited for 12 to 24 months by the time of comparison with matched “comparison” parents who had just entered service. The 832 “comparison” parents matched 621 “experimental” parents in 480 blocks defined by age at the time of the comparison, race, gender, reading level, site, and assessment date. At the time of the comparison, the “comparison” parents have had only one or two visits, and “experimental” parents have been visited for one to two years. Analysis confirmed the groups were well matched on the variables, increasing confidence in the between-group comparisons. Figure 15 illustrates that after 12, 18 or 24 months of service, scores of the “experimental” parents are significantly higher than scores of the matched “comparison” parents at baseline for both functional healthcare literacy and functional selfcare literacy(p<.001). Therefore, the null hypothesis of no difference in parental functional health literacy is rejected.
Figure 15. After 12, 18, or 24 months of home visitation, "experimental" parents have significantly higher scores for Functional Selfcare Literacy (p<.001) and Functional Healthcare Literacy (p<.001) than matched "comparison" parents who have not yet had home visits.
What Affects Progress?

Does Reading Level Explain Differences? No

Functional Healthcare Literacy. Figure 16 shows change in functional healthcare literacy at baseline and with 6, 12 and 18 months of home visitation for those with lower estimated reading levels (ELF Negative, < 6th grade) and higher estimated reading levels (ELF Positive, > 7th grade). Parents made statistically significant progress regardless of reading ability (p<.001).

![Graph showing change in Functional Healthcare Literacy over time by reading level.](image)

**Observation**

- ELF: F(1,211)=24.3; p<.001
- Time: F(3,209)=9.9; p<.001
- Linear: F(1,211)=15.4; p<.001
- Quadratic: F(1,211)=10.9; p<.01
- Linear*ELF: F(1,211)=5.2; p<.05

Figure 16. Change in Functional Healthcare Literacy over time by reading level. Parents with lower estimated reading level made significantly greater gains in functional healthcare literacy than those with higher estimated reading level (p<.001).

Those with lower estimated reading levels made significantly greater gains in functional healthcare literacy. This finding suggests that everyone benefits from information support, particularly from personal assistance to understand information (Think), personalize and make
meaning from it (Link) and use information in “real life” (Respond). Greater gains for low-skill readers could be expected since they are less likely than better readers to have prior knowledge or other sources of information.

This finding suggests that reading ability, and estimates of health literacy as reading ability in a clinical setting, do not predict the amount of improvement in use of information, that is, in health functioning. Reading ability may or may not improve with home visitation, but ability to gain and apply knowledge is not dependent on reading ability. The finding supports Lee, Arozullah & Young’s (2004) theory that social support mitigates or buffers the negative impacts of low literacy in a clinical context, as well as my hypothesis that reflection may be as important as reading ability in making meaning from information and applying it in context. Analysis of change in ELF status over time may elucidate this point.
**Functional Selfcare Literacy.** For Selfcare Literacy, both unskilled and more skilled readers progressed ($p<.001$) at about the same rate. Matched analyses confirmed this finding.

See Figure 17.

---

Figure 17. Change in Functional Selfcare Literacy over time by estimated reading level. Parents made significant progress in self-managing personal and child health, regardless of reading level.
Does Race/Ethnicity Explain Differences in Functional Health Literacy Scores? No

Functional Healthcare Literacy. Figure 18 shows no statistically significant difference in parents’ functional healthcare literacy attributable to race/ethnicity. However, the pattern of change over time was different for different ethnic groups. Hispanic/Latino parents improved the most; African American/black parents improved the least. Matched analyses confirmed these findings.

Figure 18. Change in Functional Healthcare Literacy over time by race/ethnicity. Overall, parents in home visitation programs achieved a significant increase in healthcare literacy over time (p<.001).
**Functional Selfcare Literacy.** Figure 19 shows that scores for functional selfcare literacy demonstrated overall race/ethnicity differences (p<.05). Overall, all groups improved; but the African American/black parents increased at a lower rate and did not follow the pattern of significant initial improvement in the first six months of service. Hispanic/Latino parents had the highest Functional Selfcare Literacy scores (p<.001), while Caucasian/white parents had the lowest scores (p<.001).

![Change in Functional Selfcare Literacy over time by race/ethnicity](image)

**Figure 19.** Change in Functional Selfcare Literacy over time by race/ethnicity. Overall, all groups improved, but patterns of change in Functional Selfcare Literacy varied by race/ethnicity (p<.05).

**Does Age Account for Differences in Functional Health Literacy Scores? No**

**Functional Healthcare & Selfcare Literacy.** The main statistical finding related to age is that the younger group (16-21 years) achieved marked improvement between the initial and second observations. This departure from the pattern in the other age groups indicates that...
younger parents who start at a disadvantage can make immediate gains in healthcare literacy to achieve par with their older counterparts in the first six months of home visiting. The younger group demonstrated the largest initial gains and then leveled off (p<.05). Patterns of functional selfcare literacy change showed no statistically significant difference by age group (not shown).

**Figure 20.** Change in Functional Healthcare Literacy over time by age group. Younger parents start at a disadvantage and can make immediate gains in functional healthcare literacy to achieve par with their older counterparts in the first six months of home visiting.

---

**Who Progresses to Higher Levels of Health Functioning?**

**Is Progress Limited to Higher Functioning Parents? No**

A central criticism of interventions, sometimes correct, is that observed improvements come from increases among those already better off. To gauge whether a reflective model of home visitation promotes functional healthcare literacy among lower functioning parents, I examined the correlation between baseline FHLM scores and change in FHLM scores by the third measurement (after 12 months of home visitation).
**Functional Healthcare Literacy.** Scores >4 on the FHcL scale indicate adequate to optimal functioning related to use of healthcare services and health information; those with baseline scores >4 (in target range) are considered higher functioning; those with baseline scores <4 (below target range), are considered lower functioning. Among the lower functioning parents, 63 to 88% improved their healthcare literacy; compared to 23 to 41% of higher functioning parents. These figures suggest that the lower the starting point, the bigger the gain. See figure 21.

Figure 21. The correlation between initial FHcL score and change in FHcL after 12 months of home visitation: $r = -.49; p<.001 (n=577)$ indicates home visitation seems to have greater impact on the Functional Healthcare Literacy scores of lower functioning parents.
Functional Selfcare Literacy. Results of the analysis were similar for Functional Selfcare Literacy, self-management of personal and child health at home. Lower functioning parents (those with baseline scores ≤4) improved 68 to 82%, compared to 31 to 56% of higher functioning parents: \( r = -0.49; p < 0.001 \). See Figure 22.

Figure 22. The correlation between initial FScL score and change in FScL after 12 months of home visitation: \( r = -0.40; p < 0.001 \) (n=614) shows home visitation also seems to have greater impact on the Functional Selfcare Literacy scores of lower functioning parents.

Who Moved from Lower to Higher Functioning? Who Regressed?

To further examine patterns of parents’ progress/regression, I plotted baseline FHLM scores with scores after 12 months of service to see who moved up from below target range (scores ≤4, lower functioning category) into target range (scores >4, the higher functioning category); who remained in the same category, and who regressed.

Functional Healthcare Literacy. After one year of home visiting, 18% of the parents (n=105) moved up, meaning they progressed from low functioning (below target range) into the
higher functioning category. These parents were less likely to be higher skilled readers (69% vs. 73% overall; 31% with estimated reading level ≤ 6th grade). They are more likely to be from the Montana site (11% vs. 6% overall); and less likely to be from the Georgia program (12% vs. 9% overall) or the Virginia program (51% vs. 61% overall).

Another 28% of parents in this analysis (n= 162) started and stayed low functioning; they entered below target range and were still below target after the first year of service. However, most made progress; 58% (n=94) of these parents improved their use of health information and services; while 31% of the low functioning group (n=51) regressed. Parents in this group were less likely to be higher skilled readers (45%; 55% with estimated reading level ≤ 6th grade). They were more likely to be from the Virginia program (78% vs. 61% overall) and less likely from California (5% vs. 15%), Georgia (4% vs. 9% overall), or Indiana (5% vs. 10%).

About 43% (n= 246) of parents in this study stayed strong. They were functioning well in the healthcare system (scores in the target range) when they entered service and were still functioning well a year later. Most of these (87%) were higher skilled readers (13% with estimated reading level ≤ 6th grade. They also were older (27 yrs. vs. 25 overall.) and more likely to be from the California program (22% vs.15% overall).

About one in 10 parents (11%, n=64), regressed; they started with Functional Healthcare Literacy scores in the target range, indicating competent use of healthcare, but regressed to below target range indicating lower functioning after one year. These parents were more likely to be higher skilled readers (76%; 24% with estimated reading level ≤ 6th grade), younger (24 yrs. vs. 25 overall.) and from the Georgia site (16% vs. 9% overall).

Functional Selfcare Literacy. Parents were somewhat higher functioning on selfcare compared to healthcare functioning. About 17% of parents (n=102) moved up from low functioning as managers of health at home (scores below target range) to competent functioning (scores in the target range), about the same proportion that moved up on healthcare functioning.
These parents are less likely to be higher skilled readers (64% vs. 73% overall; 36% with estimated reading level ≤ 6th grade). They are less likely to be African American/black (31% vs. 41% overall) and more likely to be Caucasian/white 53% vs. 44% overall). Parents who moved up in Functional Selfcare Literacy are more likely to be from the Montana program (13% vs. 7% overall).

Another 19% of parents (n=115) stayed low functioning, a significantly smaller proportion than for healthcare functioning; their scores started and stayed below target range. These parents were equally likely to be higher or lower skilled readers (52% vs. 48%). They are more likely to be older (29 yrs vs. 25 overall), Caucasian/white (58% vs. 44% overall), and from the Virginia program (80% vs. 57% overall). They are less likely to be Hispanic/Latino (6% vs. 15%) or from the Georgia site (5% vs. 12% overall) or the California site (3% vs. 14%).

Almost six in 10 (57%, n= 340) stayed strong; they started and stayed within the target range indicating adequate to optimal self-management of health at home. These parents were more likely to be skilled readers (79%; 21% with estimated reading level ≤ 6th grade. They were more likely to be African American/black (45% vs. 41% overall) or Hispanic/Latino (19% vs. 15% overall); and less like to be Caucasian/white (36% vs. 44% overall). They were more likely to be from the California site (21% vs. 14% overall) and less likely from the Montana program (4% vs. 7% overall).

Only 5% (n=29) regressed out of the target range indicating they started in the high functioning category and slipped to the lower functioning category. Of these, 75% are higher skilled readers (25% with estimated reading level ≤ 6th grade). These parents are more likely to be from the Grant County Indiana program (14% vs. 5% overall). They are less likely to be Hispanic/Latino (4% vs. 15%) or from the California program (3% vs. 14%).

Parents with higher estimated reading levels had higher baseline scores for both Functional Healthcare Literacy (FHeL) and Functional Selfcare Literacy (FScL). Increases in
FScL scores were the same for those with higher and lower estimated reading levels ($p < .001$). Those with lower estimated reading levels demonstrated significantly larger increases in FHcL ($p < .01$). Reading level estimates predicted baseline FHcL but did not predict who would progress (or regress) or to what degree.

**Between-sites Differences**

**Differences in Impact on Functional Healthcare Literacy**

Longitudinal analyses of changes in FHLM scores (no comparison group) revealed significant between-site differences in the rates and patterns of change on the two FHLM scales. First, consider functional healthcare literacy scores which rate use of healthcare services and information. While parents in all sites improved their functional healthcare literacy scores with home visitation, those served by Virginia site ($p<.001$) and the Montana site ($p<.01$) had initial scores lower than the others. Virginia parents showed flatter, steadier progress compared to Montana parents who entered with the lowest scores and made steep gains. Parents in the Grant County (IN) program showed gains similar to the Montana group but started and ended with slightly higher scores. Parents in the California program had the highest baseline scores and achieved modest gains to attain the highest end scores ($p<.01$). Modest gains may be a ceiling effect, that is, there was little room on the scales to demonstrate improvement. See Figure 23.
Matched comparison analysis confirms between-sites difference. Analysis of the gap between "experimental" parents who obtained one to two years of service and their matched "comparison" parents who obtained no service confirms that functional healthcare literacy scores and increases over time differ significantly by site (p< .001) See Figure 24.
Figure 24. Between-site differences in FHcL scores of Experimental parents after 12-24 months of service and Comparison parents who had not yet obtained home visitation. Matched comparisons analyses confirmed FHcL scores differ by site (<.001). Further analysis showed that parents in three sites (GA, CA, and MT) made statistically significant gains.

**Between-sites Differences in Impact on Functional Selfcare Literacy**

As with the functional healthcare literacy scores, functional selfcare literacy (management of personal and child health at home) scores varied significantly by site (p<.001). Again, the parents in the California program had the highest baseline and 12 month scores. In all programs, parents achieved the largest gains in the first six months of service; this is especially so for the
Montana site. Parents at the Georgia site continued to increase after the second observation (six months of service), while at other sites progress tended to level off. These findings should not suggest that intervention be limited to six months of service. This apparent leveling off may reflect that easy changes are made first. For example, home visitors place a priority on assisting parents in eliminating obvious safety risks in the home and obtaining a car seat for the child. Further, overall mean scores suggesting leveling off in progress may reflect regression in individual scores; however, such apparently negative changes should be interpreted with caution. They are frequently due to a more established visitor/parent relationship (a highly positive development) that facilitates disclosure of previously suppressed sensitive information such as drug or alcohol abuse, inability to read, or family violence. Also, exerting control over these factors (avoiding second-hand smoke, eliminating violence) is more difficult and requires more time, as well as resources that may be unavailable in some communities (mental health counseling, drug treatment programs, public transportation). Analysis of differences in functional selfcare literacy improvement for “experimental” parents (having one to two years of visits) compared to matched “comparison” parents (having only one or two visits) shows that although scores vary significantly across sites, the impact of home visitation is similar. See Figure 25.
Figure 25. Matched comparison analyses of parents’ Functional Selfcare Literacy scores shows scores differ significantly by site (p<.001); but the difference between groups is similar p<.001.

Qualitative Analyses of Between-Site Differences

Changes in selfcare literacy were similar across the sites. However, impacts on healthcare literacy (use of healthcare information and services) varied significantly across the sites (p<.001). Qualitative data from interviews with staff and supervisors of the participating sites offer some possible explanations for between-site differences in results and suggest further study to discover health literacy promoting practices to replicate, or on the other hand, conditions that hamper progress.
Parents in the Virginia program started below target and made little progress (3.93 to 3.96 $p > .05$). Parents at both Indiana sites started in the target range and made insignificant progress (4 to 4.1; $p>.05$ and 4.09 to 4.1; $p>0.5$).

Parents in the Georgia and Montana sites achieved statistically significant progress moving from below target range into target range (GA: 3.87 to 4.2 $p<.001$; MT: 3.58 to 4.0 $p<.01$). California parents started in the target range and continued to improve (4.08 to 4.36 $p<.001$).

*What Might Explain Differences in Impacts on Functional Healthcare Literacy?*

How do the healthcare literacy promoting sites (Georgia, Montana and California) differ from the sites that achieved significant improvements in functional selfcare literacy, but not in functional healthcare literacy (Virginia and two in Indiana)? I used qualitative data to examine differences in staffing (professional vs. paraprofessional); intensity of service (frequency, duration, caseload); prevalence of low literacy (as estimated by site staff); service population size and diversity; experience with the curriculum and integration of reflective practices; and service priorities.

Here I discuss improvement in healthcare literacy scores only; parents in all the sites achieved significant improvements in their management of personal and child health (functional selfcare literacy), although in some sites parents made more limited progress in use of healthcare services (functional healthcare literacy).

*Staffing model.* Previous research on home visitation suggests staffing may be a primary factor and that professionals would be expected to produce better overall results than paraprofessionals (Kitzman et al., 1997). Findings seem to confirm the previous studies, but inconsistently. The Montana site, which produced the greatest improvements, uses only professionals (nurse/social worker teams). However, the California site achieved the highest overall scores using paraprofessionals only. The Georgia site which produced improvements similar to Montana’s and sustained improvement better than other sites, used nurses in teams.
with paraprofessionals. Of the three sites that did not achieve significant gain in FHcL, two used nurse/paraprofessional teams and one used only paraprofessionals. Parents at all sites showed improved selfcare literacy regardless of staffing model. Level of staff of education (rather than professional vs. other degrees), and type and amount of specialized training are factors for further study. Discussion at the closing reflection conference suggested that visitor training is critical, as well as the match between visitor skills and family needs. A related factor may be the consistency of home visitors since turn-over disrupts the trusting relationship which all participants stressed is the foundation for the work of home visiting.

*Rescue vs. support.* Home visitors and their supervisors are professional helpers. Some are inclined and encouraged by funding mandates to “rescue” or “fix” low functioning families. Rescuers may produce positive outcomes in families, especially early in the intervention, by doing “the heavy lifting” for parents. However, these improvements are likely to be unsustainable in the visitor’s absence, and so promote dependence rather than increased capacity. This may explain in part why some sites produced more change than others and why the rate of improvement tended to flatten. It may also explain in part the failure of home visitation overall to demonstrate more than modest outcomes (Gomby, 2005).

Another possible explanation for apparent reduction in the rate of improvement after the first six months is that “easy” changes are made early. For example, home visitors place priority on assisting parents to obtain healthcare coverage and prenatal care, and to bring immunizations and well-baby check-ups current. Other changes, like establishing a medical home for the parent, organizing resources needed to keep appointments, negotiating regular use of family planning methods, or learning to interpret medical documents take more time and may depend on availability of community resources (accessible healthcare services, especially dental care; public transportation; literacy enhancing services) or policy issues like insurance coverage for contraceptives.
Intensity of service. Another likely explanation is intensity of service, yet this does not clearly explain between-site differences in rates of improvement. Home visitors in the healthcare literacy promoting sites have caseloads of 10-12 (MT) and 28 families (GA) while visitors in the lower performing sites carry caseloads of 14 (IN) to 42 (VA) families. This may suggest a limit to the number of families a visitor can effectively serve.

Sites that showed significant improvements in functional healthcare literacy (MT, CA and GA) visited each family on average 12 to 18 times per year for 15 to 24 months (15-36 visits), compared to six to 24 visits per year for 11 to 30 months (6 to 60 visits). This is an area for further study, especially frequency of visits and frequency of visits combined with staffing model. The success of the Montana site suggests a combination of professional staff, smaller case loads and more frequent visits increases effectiveness.

Size and diversity of service population. The healthcare literacy promoting sites are midsize (GA=229, CA=300, MT =268) and have little racial/ethnic diversity. The Georgia site’s service population is 85% black/African American; the California site’s is 100% Hispanic/Latino, and the Montana site’s is 98% Caucasian/white. The sites that did not significantly promote FHcL are the two largest (VA=951, Marion Co IN=510), and the smallest site (Grant Co IN=137). These sites are ethnically diverse. These differences may reflect the added challenges of consistently delivering culturally relevant services in a multi-cultural setting.

Experience with the reflective approach. Experience with the curriculum, particularly use of reflective practices, is another factor for further study. Qualitative data from interviews with home visitors and their supervisors suggest that the three healthcare literacy promoting programs more fully embraced reflective practices and use of the LSP for intervention planning and supervision. Two of the higher performing sites were early adopters of the LSP and so had more experience with the instrument and reflective practices. The Montana site initially obtained training in 1999 and the California site was trained in 2002. The Georgia site was trained in 2005,
as were the rest of the sites; however, the Georgia site invested in additional consultation and training on reflective practices and reflective supervision. Participants in the closing reflection conference strongly concurred that use of reflective practices, particularly reflective questions is important.

*Health Literacy Promotion as a Goal.* Goals and priorities are similar among the sites. However, there may be more attention to health services utilization in the healthcare literacy promoting sites. Home visitors in the Georgia site specifically listed improving use of the health system and clinical outcomes among their goals. The Montana site, a public-private partnership including the city-county health department, collaborates with the local hospital to address health literacy in physician practices and participates in a local coalition on language barriers in healthcare. The California site focuses on family health and literacy. All sites specifically intend to promote child health and development and all achieved significant improvements in selfcare literacy. Specific intent among leadership and staff to promote functional healthcare literacy may be an important factor.

*Comparison of Sites with Highest and Lowest Functional Healthcare Literacy Scores*

In further analyses to identify differences in practices or communities that could potentially explain differences in results, I compared the site with the lowest FHLM scores (VA) to the site with the highest scores (CA). This provides a starker comparison.

*Intensity of service.* The California program provides more intense service with 36 to 40 visits per year compared to 6 to 12 in the Virginia program. Average caseload for California visitors is 17 families compared to 42 families for each Virginia visitor. Actual length of service is six months longer in the California program. This comparison suggests intensity of service is more important than staffing model since the healthcare literacy promoting California program uses all paraprofessional staff while the Virginia site uses nurse/paraprofessional teams. However, since parents enrolled in the California program had higher baseline scores for
functional healthcare literacy, some of the difference is related to context rather than service. The California and Virginia programs’ estimates of low literacy rates in their populations are similar (39% and 42%), as are their high school graduation rates (33% and 42%). Literacy screening placed 87% of California parents in the higher reading level category compared to 62% of Virginia parents. The California parents may be higher functioning parents. Hispanic/Latino cultural factors may offer more social support. Community resources (transportation, accessible services) may be more plentiful in California than in Virginia.

*Size and diversity of the service population.* The California program is much smaller than the Virginia program (300 vs. 951 parent/child pairs). Its service population is the least diverse of all the sites with 100% Latino/Hispanic families. In contrast, the Virginia population is the most diverse with 9% Latino/Hispanic, 48% Caucasian/white, and 43% African American/black; and healthcare literacy scores did not change significantly in any of these groups at that site. This was also the case in the second largest and most diverse site (Indianapolis). The added challenges of serving a larger more diverse population require further study.

*Program goals.* The California site, along with the other healthcare literacy promoting sites, maintains family health as a priority whereas the Virginia and Indiana sites focus more narrowly on preventing child maltreatment. The California and Georgia sites, both healthcare literacy promoting programs, specifically work to enable parents to advocate for health services and to work with healthcare professionals. This observation suggests inclusion of literacy in program goals and standards may be a powerful stimulus to promote literacy in disadvantaged families and that the combined explicit focus on literacy and health is powerful for promoting healthcare literacy. The observation supports the consensus of all the participating programs that the goals of home visitation may depend on specific attention to parents’ literacy and health literacy, and that lack of such attention may explain in part why home visitation overall has been able to demonstrate only moderate outcome effects.
Experience with the reflective approach. Finally, it is notable that the California program had more experience with the curriculum having implemented it three years ahead of the Virginia site. The California site is the only one of the participating programs that required all staff to use the *Beginnings Guides* materials exclusively, to mandate reflective practices, and to fully integrate reflective supervision. Directors of other sites indicated some home visitors were resistant to changes in materials and practices and some supervisors resisted reflective supervision. These findings suggest the usefulness of additional studies comparing results in sites adhering to a defined protocol with those free to adapt the curriculum as they choose, or comparing results within sites by caseloads of visitors who maintain fidelity to a protocol with those who do not.

Other possible explanations. Other potential factors in the difference between the highest and lowest performing sites warrant additional analyses. There may be between-site differences in scoring the LSP. Although the tool has exhibited strong (90%) inter-rater reliability (Richardson, 2000) this warrants further examination. Community factors may explain differences; for example, the Virginia site reports lack of public transportation and other access issues prevent parents from obtaining healthcare services they want and need. The Virginia site may serve higher risk and/or harder to reach families; for example, a portion of parents in the Virginia program participate involuntarily, meaning services are mandated by the courts and Child Protective Services. This also may be a factor in the two other lower performing sites; both focus on prevention of child maltreatment and serve families known to be at risk for child maltreatment.
Limitations

Instruments

Literacy Assessment. I relied on a brief screening tool (Bennett et al., 2003) for literacy assessment. The tool is relatively new and its validity is not fully established. However, our findings strengthen its validity. The screen is intended primarily to facilitate referrals to literacy enhancing services and that was its primary use in the intervention. The screen has a relatively high false positive rate\(^\text{27}\) (46%), making our findings related to reading levels imprecise.

Since more commonly used clinical tests of literacy are known to produce feelings of shame and alienation in participants (Parikh et al., 1996), and since the research team was committed to protect the visitor/parent relationship, I elected not to use the REALM or TOFLAH. In addition, the intervention aimed to integrate health literacy promotion into the usual activities of home visitation with minimal burden on visitors and families. The ELF literacy screen, described in detail in Chapter 3, provided a reasonable estimate of each parent’s reading ability without adding to visitors’ or parents’ burden and without risk to their relationship. The research may be strengthened somewhat by administration of the REALM in a subsample of the population, and the newest seven-second short form may be feasible for use during home visits. However, preservation of the visitor/parent relationship must remain the primary consideration and use of other instruments must demonstrate significantly more precise results.

Functional Health Literacy Measure. The FHL is new. It shows good internal consistency. Face validity requires acceptance of the public health view of health literacy as an asset and an outcome of health promotion demonstrated by health functioning. Since there is no other measure of functional health literacy, strict criterion validity cannot be established. As described in Chapter 2, initial validity testing indicates good criterion validity using the ELF and

\(^{27}\) False-positive rate: the rate at which the test incorrectly identifies parents with higher reading levels as having lower reading levels.
several measures of health functioning as reference measures, and suggests the FHLM warrants further use and testing to firmly establish validity.

Home visitors complete the LSP and FHLM on their own clients. This raises the potential that visitors may be unduly influenced by the need to show improvement. However, the LSP has shown strong (90%) inter-rater reliability (Richardson, 2000), and bias has not become apparent in 10 years of use. Despite consistent training by the same trainers, it is possible that scoring parameters differ by individual visitor or by program.

**Analyses**

The scope of this study was limited to analyses of the FHLM scores. A fuller understanding of functional health literacy in growing disadvantaged families will be achieved by analyzing the full LSP database. For example, it would be useful to explore links between FHLM scores and other LSP data such as social support, depression, and child development. Also, univariate analyses of the FHLM scales may further inform results and could possibly lead to a refined, more parsimonious measure.

**Data Issues**

The study population was large (n=2532) and diverse and from multiple urban and rural sites and multiple home visitation program models. Still, differences in state policies that affect access to healthcare services, differences in availability of community services (healthcare, dental care, transportation, insurance) and differences in relative risks in service populations that cannot be accounted for in this study could affect overall outcomes and between-site variations.

Information on sensitive topics (violence, alcohol and drug abuse) may not be readily observable by visitors and may be suppressed or falsified by parents, or revealed only after a trusting visitor/parent relationship has been firmly established. This can skew the picture presented by the FHLM and the LSP, and require interpretation by visitors and their supervisors. Some of the ethnicity data (20%) and some of the literacy screening data were missing.
Fidelity to Protocols

Beyond training the home visitors to use the LSP and Beginnings Guides Life Skills Development Curriculum and requiring the *Beginnings Guides* materials for parents, I intentionally took a hands-off approach to the intervention. This approach allowed me to test the hypothesis that the usual activities of home visitation promote health literacy, even if as a side effect. The evidence supports this idea and suggests factors that may increase the effect and warrant further investigation with stricter protocols.

Home visitors worked in various models of home visitation; they were free to integrate the intervention into their program model and to tailor it for individual families. All sites used the Beginnings Guides Life Skills Development Curriculum to varying degrees and all, except the California site, also used other curricula. All reported routine use of reflective questions, but the data do not reveal the degree to which visitors implemented “teaching by asking”, reflective supervision, and other reflective practices. Therefore, the data are insufficient to attribute improvements in functional health literacy to the curriculum or any particular aspect of home visitation. Further, the data are insufficient to comment on the relative effectiveness of various models of home visitation in promoting functional health literacy. To do so will require further studies with broader representation of each model.

Strengths

The size and diversity of the study population and the variety of program models, the use of multiple waves of measurement for a longitudinal view, and the use of matching to create comparison groups within the cohort made for a robust study and increase confidence in the results. Findings may be more generalizable than is usually expected from a cohort study.
Discussion & Conclusions

Home Visitors Promote Functional Health Literacy

The primary finding of my study is this: Home visitation promotes functional healthcare literacy and functional selfcare literacy across program models and service populations, regardless of reading ability.

Public Health Model of Health Literacy Promotion is Practical for Implementation

This study demonstrated it is practical to implement the public health model of health literacy as an asset and an outcome of health education and health promotion efforts. It suggests further that a national public health intervention to promote health literacy in disadvantaged growing families may be feasible through the existing networks of home visitation programs.

Disparities Questions Raised

Parents in all programs demonstrated statistically significant improvement in functional selfcare literacy (self-management of personal and family health). A surprising finding that warrants further investigation is that Latino/Hispanic parents had the highest starting and ending functional selfcare literacy scores. It is well known that health behaviors and health status among immigrants deteriorates with time in the U.S. (Lansford, Deater-Decker, Bornstein & Suarez-Orozco, 2007). This finding suggests that home visitation might prevent or mitigate such deterioration. Also surprising is African American/black parents’ departure from the common pattern of improvement in the first six months of service. The analyses showed differences in the patterns of improvement by race/ethnicity. Further research is needed to explain these differences. One possibility for future study is that the Curriculum is well suited to Latino/Hispanic families but less well suited to African American parents.
Between-sites Differences are Multifactoral

In three programs (CA, GA, MT), parents also achieved statistically significant improvement in healthcare literacy (use of healthcare services and information). More research is needed to elucidate between-site differences in results. Variations could mean that visitors or methods in some sites are more effective than visitors or methods in other sites. But it also could indicate that visitors in some sites are doing the “heavy lifting” for parents so that results will not be sustained when visiting ends. Or some service populations may be more complex, higher risk, or harder to reach. Results also reflect availability of community services and awareness of health literacy among local healthcare providers and public health departments, adult education programs, and other community agencies. The qualitative data suggest that specific intent and focus on promoting appropriate use of healthcare information and services may be key to improving functional healthcare literacy. Other factors for further investigation include size and homogeneity of the service population and fidelity to the curriculum, particularly use of reflective practices.

Progress is Unrelated to Reading Level

The analyses of patterns of progress showed parents do progress from inadequate (below target range, score ≤4) to competent functioning (in target range, score >4), regardless of reading ability. To a lesser extent, they also regress from higher to lower functioning, regardless of reading ability. The finding that reading level is a predictor of baseline functional health literacy scores, but not of whether or how much a person might improve or regress, makes clear that functional health literacy encompasses social and environmental skills and other factors beyond basic literacy skill. The evidence supports the concept of measuring functional health literacy by monitoring function over time rather than relying solely on testing reading skill in the clinical setting.
Regression suggests intervention points. A skilled readers' regression from the target range into the lower functioning category points to numerous avenues for possible intervention beyond improving individual reading ability or reducing the cognitive demand of information. Regression in healthcare functioning could mean, for example, that a mother lost access to care because she was eligible for public insurance only during pregnancy, a state and national policy issue. It may mean the local clinic closed, or the clinic is open only during times when parents are working, a resource allocation issue. Another possibility noted by several participating programs is lack of public transportation and child care services in the community, which prohibits parents from seeking the preventive and acute healthcare services families want and need, a condition the program can affect only indirectly.

Further, when interpreted in context, regression in FHLM scores may be expected. For example, when a child or a parent develops a serious condition that the family is just learning to manage, regression is expected. When a child approaches his/her second birthday and begins to talk and exert independence, scores predictably go down while the parent adjusts to new challenges.

Some apparent “backsliding” may actually represent improvement. Regression on some items in the healthcare literacy scale (family violence, alcohol and drug abuse) could represent the parent’s increased trust of the visitor and disclosure of previously suppressed or falsified information, an important positive step toward change. A woman who leaves an abusive relationship, representing a significant breakthrough in self-efficacy and increase in her ability to exert control over her health, her children’s health and her health actions, is likely to experience a period of transition and lower scores. The reduction in scores does not necessarily indicate reduced functional health literacy. This gap in mapping between reality in context and inflexibility of a standardized measure is inherent in all tools. The advantage of the FHLM is that scores are interpreted by home visitors and supervisors who can reflect on the scores linked to context and
respond constructively. Any regression in scores alerts the visitor to a need for specific intervention, which can be designed by the visitor based on knowledge of the family.

Home Visiting Addresses Personal, Social, Economic Factors in Health Literacy

That parents in all participating programs made statistically significant gains in functional selfcare literacy indicates that home visitation successfully addresses the social determinants of health and functional health literacy that are not visible in a clinical setting and not amenable to clinical interventions.

National Database for Ongoing Effectiveness Evaluation of Home Visitation

This study established for the first time a database of comparable data on home visitation programs in various models and locations, and a structure for collaboration among programs that have historically been insular, proprietary and competitive. This makes possible and feasible ongoing evaluation of home visitations’ effectiveness for functional health literacy promotion, including identification and rapid dissemination of best practices. Thus, an added benefit of the intervention may be improved overall quality of home visitation services.

Summary

The evidence supports the hypothesis that home visitation promotes parental functional health literacy for participants with both higher and lower reading skills. Analyses of between-site differences in visitors’ reported practices and parents’ FHLM scores suggest, for further investigation, possible mechanisms by which home visitation produces improved parental functional health literacy.

The intervention worked quickly. Parents, especially young parents (16-21 yrs), demonstrated statistically significant progress in the first six months. They continued to progress over time with home visitation, regardless of reading ability. All ethnicities progressed, but
displayed different patterns. Statistical analyses using a matching process to create comparison
groups within the cohort ruled out maturation, community events and policy changes as
alternative explanations for improvement and confirmed findings of the longitudinal analyses. The
data are insufficient to attribute effects to any particular element of home visitation, however
statistically significant progress toward higher levels of functional health literacy among parents in
multiple programs and various program models, serving different ethnic populations in disparate
regions indicates home visitation is an effective channel to promote functional health literacy in
parents. Chapter 5 explores implications for practice, policy and research.
Chapter 5

New Directions in Health Literacy

Does home visitation promote parental health literacy? That inquiry led me to initiate a program of action research on health literacy promotion beginning with a two-year federally funded project conducted with the Home Visitors Research Network between August 2006 and August 2008. The question raised complex issues related to the meaning and measure of health literacy and the potential role of home visitation in health literacy promotion. The intervention and the research process were groundbreaking for both health literacy and home visiting.

There is strong consensus among the stakeholders that the most significant finding from my research is this: home visitation promotes functional health literacy in disadvantaged parents of infants and toddlers regardless of reading level. This final chapter of the dissertation discusses implications for research, practice and policy in health literacy and home visitation. The discussion of implications and priorities for future research are informed by the proceedings of a 1.5 day conference featuring a series of facilitated reflective round-table conversations among the home visitor/researchers, the academic research team, national experts, and executives and funders of several national home visitation models represented in the Home Visitors Research Network.

Implications for Health Literacy Research

Traditional Research Approach is Unsuitable to Health Literacy Promotion

The public health model, in which health literacy is the outcome of health promotion efforts, presents dilemmas and challenges for health literacy research (Koelen, Vaandragr & Colomer, 2001). The traditional biomedical research methods that characterize health literacy
studies, and the associated standards by which the quality of the evidence is judged, run counter to health promotion practice and can reduce the effectiveness of health promotion interventions.

While health promotion practice assumes synergy among elements, clinical research methods aim to isolate the contribution of single elements to any observed change in outcome. The outcome of health literacy promotion is behavior change, which is the product of the interaction of multiple personal, social and environmental factors. Any one of these factors may be powerful; and none acts independently (Glanz, Lewis & Rimer, 2007, xvi). Therefore, attempts to isolate single effective factors and control for interactions are self-defeating. The traditional solution to multiple intervention components, phased implementation, would reduce the effectiveness of the intervention since no single component alone is likely to be effective. The working methods of the clinical paradigm are insufficient to capture the success of health literacy promotion efforts.

Further, community-based health literacy promotion is carried out in the field where external factors can interfere with the intervention. For example, in my study at one site a hospital program addresses health literacy in physician practices and a local coalition addresses language barriers in healthcare at the same time the home visitation program promotes parental health literacy. Traditional methods control for such “interference” through randomization, in which the intervention is implemented only with randomly selected participants so that effects of external factors also will be random. In a health promotion effort such as home visiting, “external factors” are likely to be the desirable contributions of collaborators rather than interference. Furthermore, the traditional solution, randomization, is usually impossible and arguably unethical in needy families. Traditional biomedical research methods usually are infeasible in community settings.

Health promotion research is oriented to improving practice. Similarly, health literacy promotion research should aim primarily to guide practice, particularly since intervention research remains relatively rare in health literacy studies and offers little to inform practice beyond
improving information and its delivery. The research needs to produce knowledge about effectiveness (how well the intervention worked), as in the biomedical model. In addition, in order to guide practice, the research needs to produce knowledge about how and why an intervention worked. Therefore, the research goal is to understand the complex workings of many forces, rather than control, precision and parsimony (Glanz et al., 1997).

This does not mean that health literacy promotion research is not, or need not be rigorous. My study, to my knowledge the first intervention study in health literacy promotion, is robust due to a combination of qualitative and quantitative methods, multiple sources (2532 parents), sites (seven in six regions), and investigators (researchers in three universities and 71 home visitors). The cohort is racially/ethnically and geographically diverse representing urban and rural populations. Participating programs represent several models of home visitation. While ethical considerations precluded a traditional comparison group, a matching process produced reliable comparisons within the cohort and ruled out environmental or policy factors unrelated to the intervention as alternative explanations for observed effects. These elements contribute to a reliable rich picture of what works for whom under what circumstances and ensure quality of findings.

Action Research Approach Guides Practice

Since traditional research methods are insufficient to capture health literacy promotion outcomes and infeasible in community settings, I conceived this study as the first cycle in an ongoing program of action research. The action research approach is particularly suited to health promotion studies (Koelen, Vaandrager & Colomer, 2001), and to investigation of an intervention that uses reflective strategies to promote reflective skills and functioning.

Action research is an iterative and cyclical process of action and reflection in which practitioners undertake research activities in order to improve practice by learning from experience. The protocol is similar to the iterative Think, Link & Respond process of reflection
that home visitors adopted in this project. The process starts with conceptualizing the problem (Think), and particularizing it (Link), and then moves through several interventions/actions (Respond) and evaluations/reflections. The process produces “best practices”, meaning demonstrated effective strategies, and continues until a sufficient solution is fully developed (Gabel D, 1995).

Reflective Questions for Action Research

In alignment with the intervention, Forrest and McNiff (2007 p 222) offer these reflective questions for action researchers:

- **What is my concern?** (Parental literacy and functional health literacy)

- **Why am I concerned?** (Parents need literacy and health literacy skills to achieve their goals and goals of home visiting.)

- **What evidence can I generate to show the situation as it is and as it unfolds?** (LSP/FHLM data)

- **What can I do about the concern?** (Integrate into practice the Beginnings Guides Life Skills Development Curriculum.)

- **How will I ensure any conclusions I come to are reasonably fair and justified?** (Use multiple methods, sources and sites. Seek diversity to learn by comparison and contrast. Draw from related disciplines. Involve multiple investigators and stakeholders.)

- **How do I modify my ideas and my practice in light of my evaluation?** (Revise as the evidence directs or suggests; act again but differently.)

Action Research Creates Commitment to Change and Diffusion
The action research approach also offers explanations of how and why the practice has improved, how the validity of knowledge claims is demonstrated, and how the significance of the research for future practice and theory can be communicated (Forrest & McNiff, 2007). My study demonstrated that action research is a suitable paradigm for health literacy promotion research in community settings and is useful for creating active support for the result of the process of inquiry, commitment to change and greater likelihood that findings will be diffused (Koelen, Vaandrager & Colomer, 2001).

To advance as a field, health literacy research must make relevant contributions to both science and practice. So far, health literacy research has built a strong science for testing reading skill in patients and improving information and its delivery, but offers little guidance for intervention to promote health literacy. Fifteen years of research demonstrates that only a limited range of health literacy interventions is discoverable through traditional biomedical research methods. The value on precision and parsimony limits intervention to single elements or judges the use of multiple elements as a weakness in the intervention research (Pignone et al., 2005). Research funders and policymakers who rely solely on evidence produced by traditional biomedical methods (e.g. randomized controlled trials) will unwittingly eliminate many workable health promotion interventions and community based programs that traditional methods are insufficient to investigate.

Collaboration is Essential to a Health Literacy Solution

Given that health literacy is complex, related to individual and systems-level factors (Paasche-Orlow, 2008), as well as social, economic and environmental factors (Nutbeam, 2000, 2008); routes through which positive outcomes are to be achieved also are complex and intersectoral. Health literacy intervention research is in an embryonic stage. To travel the route to a health literate society (IOM, 2004a), it will be necessary to “build the bike while riding it” (Hansen, 2009). Success will depend on intersectoral collaboration and understanding of the interactions of multiple factors, two reasons health literacy researchers, funders and policymakers
should reconsider the research approach and methods for investigating health literacy interventions.

Public Health Concept Opens a New Approach to Health Literacy Intervention

The most significant finding of this project is that home visitation promotes functional health literacy. The finding demonstrates that the public health concept of health literacy promotion (Nutbeam, 2008) is practical for implementation. It is possible to promote functional health literacy. This opens a new approach for health literacy intervention.

The emerging public health model of health literacy promotion increases understanding beyond the current focus on reading in a clinical setting. By incorporating concepts from literacy studies, adult learning, and health promotion, this interdisciplinary view overcomes several limitations of the narrower clinical conceptualization of health literacy.

In approaching health literacy as a personal asset to be developed, rather than a deficit to be overcome, the public health model holds individuals as able to do what is required to regain, maintain, and promote their health. It avoids blaming patients for systemic problems in healthcare (high cost, low quality, and inequities in access, treatment and outcomes). Therefore, it supports overarching health system goals of patient-centered and family-centered care, patient activation, self-management of chronic conditions, and adults functioning as effective patients and healthcare consumers. Since the public health model includes the range of personal, social and environmental determinants of health as factors in health literacy, it addresses disparities in access and outcomes (Nutbeam, 2008).

The clinical model of health literacy is driven by convenient measures developed in the absence of supporting theory. As a result, evidence from intervention studies has been difficult to interpret (Berkman et al., 2004; Sanders, 2009) and offers little direction for health literacy improvement. By taking a broader view of adult literacy and health literacy as progressive levels of skill and functioning, combined with concepts and methods of health promotion, the public
health model applied in this project provides a theoretical framework for promoting functional health literacy. The aim of health literacy promotion is to enable individuals to exert greater control over a range of factors that determine health in both community and clinical settings.

In this framework, health literacy is an independent concept, the outcome of health promotion efforts. This is fundamentally different from the clinical model in which health literacy is viewed simply as an extension of pre-existing literacy skills (the Three Rs) into clinical settings; health literacy (reading ability) is seen as an independent variable; and the aim is to increase compliance with therapeutic regimens.

Further, by including reflection as a health literacy skill, the broader view opens the possibility of reflection as an underlying construct perhaps as essential as reading to achieving optimal functional health literacy. Literacy scholars view reflection as a higher level literacy skill necessary to make meaning from information (Longsdale & McCurry, 2004). Health promotion scholar Nutbeam (2008) extends this idea to make reflection a higher level health literacy skill necessary to control one’s health and health actions and to maintain or promote the health of others. Education scholars Charner-Laird, Fiarman, Park, et al. (2003) posit that reflection is so fundamental to personalizing information and using it in real life that it should be counted as one of the Four R’s – reading, ‘riting, ‘rithmetic, and reflection. The findings of this study suggest that reflection may be fundamental to attaining and promoting functional health literacy.

**Clinical & Public Health Approaches are Complementary**

This emerging public health/health promotion approach to health literacy should be viewed and pursued as complementary to the clinical approach. The latter recognizes and seeks to mitigate the negative impacts of low literacy skills (reading, listening, numeracy) on effectiveness of care; it increases sensitivity of clinicians and health and social services managers, and improves patient education and health services delivery. It has brought health literacy to local, state and national policy agendas. The public health conceptualization of health
literacy as an asset is promising in terms of the range of interventions it enables and in terms of potential impact on health and health practices. With Nutbeam (2008), I advocate improved interaction between researchers and advocates of the clinical and public health approaches to enrich both.

Through this project, health literacy research in the clinical model sensitized home visitation practitioners and leaders to the negative impacts of parents’ low literacy on the effectiveness of home visiting services. Home visitation programs could benefit by following clinicians’ lead and methods to ensure information they provide to parents orally and in print is attractive, acceptable, comprehensible and memorable (Smith & Gonzales, 2005). In addition, a clinically feasible measure of health literacy as reading skill in a medical setting enabled the home visitors to identify parents at high risk for low literacy and refer them to literacy enhancing services, a fundamental step in promoting functional health literacy in the public health model. In turn, clinicians can learn from home visitation the value of focusing on function as well as skill. The functional perspective may be especially useful as clinical interventions are directed to making healthcare services more user friendly.

**Implications for Health Literacy Measurement**

*The FHLM is a Meaningful Measure of Functional Health Literacy*

Until now, no measure of health literacy in the public health model has been reported (Nutbeam 2008; Pleasant & Kuruvilla 2008). A major contribution of this study is demonstration of the utility of the Functional Health Literacy Measure (FHLM) derived from the Life Skills Progression instrument (LSP) (Wollesen & Peifer, 2006) for this project. If one accepts the public health concept of health literacy as progressive levels of an array of skills (Nutbeam 2008), and my extension of the notion of functional literacy beyond the fundamental level to interactive and reflective literacy, then the FHLM provides a reliable measure of functional health literacy with demonstrated validity sufficient to warrant further use and testing. The FHLM captures the
impacts of both systems-level interventions to improve information and services, and health promotion efforts to improve use of information and services.

In addition, FHLM results are immediately available for intervention planning. The data are useful to those who collect them and measurement directly benefits participants. This represents a significant advantage over commonly used clinical measures of reading skill, which many participants find embarrassing and alienating. Perhaps the greatest contribution of the FHLM is that it immediately and directly informs practice, and so it opens new avenues for health literacy intervention. This approach to measuring functional health literacy may be adaptable for use in clinical settings, particularly for families living with chronic disease. In addition, the FHLM could be instructive for re-orienting health services to reduce inequities in health and healthcare.

**FHLM Rates Parents’ Ability to Exert Control over Health and Health Actions.** Items in the FHLM scales (see Figure 8 for the Functional Healthcare Literacy Scale; Figure 9 for the Functional Selfcare Literacy Scale) intend to describe health actions, attitudes, behaviors and practices that characterize progressive levels of health functioning in parents of infants and toddlers. The levels are not absolute but rather represent a continuum. It would be inaccurate to infer that scores simply reflect degrees of compliance with proscribed behavior. Scoring intends to guide tailoring of intervention strategies to support parents’ reflective process (Think, Link & Respond) and efforts to achieve greater control over their health and health actions. The FHLM’s progressive levels of functioning intend to reflect the two part purpose of health literacy: 1) to use health information and services, 2) in ways that maintain or promote health. Using information and services implies applying literacy skills, particularly reflective skills, to make meaning from them, that is, to process and understand them (Think) and personalize them (Link). Using information and services in ways that maintain or promote health (Respond) implies engaging in progressively more healthful practices. The two FHLM scales use multiple inter-related items to reflect multiple aspects of health functioning.
For example, consider a pregnant woman who has reflected on information that smoking is harmful to her child. The question is how she will choose to use this information in the context of her real life to exert greater control over her health and health actions and her child’s health. Her response will be documented on the Functional Selfcare Literacy Scale, see Figure 9, on the “Tobacco” item. 28 The most healthful response (optimal functioning, score of 5) to the smoking information is that she does not and never has smoked. She may choose to quit smoking and successfully convince others in the household not to smoke so that she is smoke-free for the current period (adequate functioning, score of 4). Or, upon reflection, she may realize that she cannot quit now, but she can cut back and manage second-hand exposure (marginal functioning, score of 3). She might cut back her tobacco use, but be unable to prevent second-hand exposure (low health functioning, score of 2). Or, her response to the information may be that, at least for now, the addiction is too strong and she is surrounded by smokers; she will continue to chain smoke and endure heavy second-hand exposure (dysfunctional, behavior harmful to health, score of 1).

Still, this mother may set other health goals while she continues to smoke. She may stop using drugs, so her scores would increase on the “Substance Use or Abuse” item. She may accomplish this improvement by recognizing the need and beginning to use community resources, so her scores also would increase on the “Use of Resources” item. The accomplishment may lead her to start trying new skills, so that her scores improve on the “Self-Esteem” item as well. Progress in one area may lag or regress while it proceeds in other areas, and all the items are inter-related. The health literacy promotion approach and the FHLM recognize that health behavior change is complex and challenging, requiring more than information and knowledge. The measure does not intend to specify appropriate behavior for a particular parent. Rather it intends to reflect developing health literacy skills and changing levels of parents’ control over their health and actions. Reflectivity is embedded in the scales; a more

28 Recall the instrument is completed every six months and covers only the last 6 months; sequential scores show change over time.
A reflective parent is more likely to make meaning from information and find ways to apply it to increase control of his/her health and health actions.

**Continue to Establish the Validity of the FHLM**

Additional validity studies should be conducted to verify the utility of the FHLM, hone and simplify the instrument to achieve a desirable balance of comprehensiveness and parsimony, and increase confidence in the measure. This will set the stage for experiments to adapt the FHLM for use in other settings, particularly for families living with chronic conditions.

**Criterion validity testing.** The analyses reported here suggest that reflective skill and functioning are underlying constructs embedded in the LSP/FHLM. Criterion validity testing could address this issue by comparing FHLM scores and LSP item scores with results of tests of reflectivity such as the Matching Familiar Figures Test (MFFT) (Kagan, Rosman, Day, Albert & Philips, 1964).

Future studies might include paying a subsample of parents in the existing database to take a battery of tests, and paying home visitors to administer those tests to parents who are not in their caseload. Tests might include the REALM (newest short form) and TOFHLA, the two most commonly used measures in clinical health literacy studies; plus selected tests of various aspects of functioning, and tests of reflectivity (MFFT). Scores on these tests can be compared to FHLM scores to test aspects of validity and hone the instrument.

**Inter-rater reliability testing.** Although the developers of the LSP tested this form of reliability with good results, some questions remain as to whether between-site differences in outcomes found in this study might be explained in part by differences in scoring parameters. The sites expressed a desire to test this by having participating visitors score standard cases. These standard cases also would be useful in training.
Future psychometric testing of the FHLM might include data clustering and path analysis to confirm or question already completed multivariate analysis (Ary, Jacobs & Razavieh, 2002). Univariate analyses should examine effects of home visitation on single FHLM items, particularly to address the pattern of improvement in the first six months.

Implications for Health Literacy Intervention

Focus on Function

The public health concept of health literacy promotion has not been previously implemented (Nutbeam, 2008). Until now, no one has demonstrated that functional health literacy can be promoted. This project showed that the public health model is practical for implementation; health literacy can be promoted in diverse community settings and populations, particularly among disadvantaged (poor, under-educated, minority) hard-to-reach families, regardless of reading level, in periods as short as six months. Further understanding of the mechanism(s) by which home visitation promotes functional health literacy, especially among those with lower estimated reading level and initial lower functioning, might reveal methods adaptable to promoting health literacy in clinical settings and opportunities for collaboration between clinicians and home visitors and their community partners. Reflective skills and functioning and reflective health education strategies emerged as potential mechanisms for further study.

The Role of Reflection

The intervention focused on promoting higher level health literacy skills, particularly reflection. The home visitors worked to increase their own reflective skills and to model reflection in their work with parents. They used reflective teaching strategies (e.g. reflective questions) to enable parents to make meaning from curriculum materials and other sources, and to use that information to develop health promoting practices (e.g. use of preventive healthcare services) that will serve them and their children over their lifetimes.
Literacy - and health literacy-promoting practices were embedded in home visitors’ usual activities. The only added activity was use of the Life Skills Progression instrument (LSP) (Wollesen & Peifer, 2006), which includes the FHLM and the literacy skills assessment. The visitors completed the full LSP on each parent every six months; the process takes about 10 minutes. Completing the LSP is itself a reflective process in which the visitor synthesizes and summarizes an array of routinely administered formal and informal assessments of multiple aspects of family functioning. In reflective supervision, home visitor and supervisor together review the LSP to reflect on a parent’s/family’s progress, needs and strengths, and tailor services for them. At the same time, they reflect on the visitor’s progress, strengths and professional development needs.

Emphasis on reflection was a common element in six disparate programs serving various populations. Success across programs suggests that reflection may be an underlying construct that is fundamental to functional health literacy promotion. It further suggests a role for home visitors and other community health workers in addressing health literacy on a broad scale. It suggests collaboration among clinicians\(^{29}\), home visitors\(^{30}\), and community partners of home visitation programs\(^{31}\) in a concerted effort to promote functional health literacy on a national scale, especially in disadvantaged young families, and potentially in families living with chronic conditions or recovering from major injury or illness.

\(^{29}\) Pediatricians; family physicians, obstetricians and other prenatal and primary care providers

\(^{30}\) Public health nurses, health educators, social workers and paraprofessional community health workers

\(^{31}\) Public health professionals, school officials and pre-school teachers, librarians, adult education programs, and others
Implications for Home Visitation Research

Reflection May Buffer Impacts of Poor Reading and Support Improved Health Functioning

This project demonstrated that the public health concept of health literacy as a personal asset to be developed through health education and health promotion efforts fits well with the usual activities of home visitation. Due to their unique access and perspective, home visitors are well positioned to promote functional health literacy skills and practices that affect parents’ ability to control their health and health actions. Other community health workers may be able to apply this approach to promote functional health literacy in other populations, for example, in families living with chronic conditions.

Functional health literacy is conceived here as progressive levels of skill and functioning, including reflective skills and functioning. The psychology concept of reflective functioning (Fonagy & Target, 1997) describes a life skill at the core of parenting (Slade 2005), the essential human capacity to make sense of self and others by understanding (reflecting on) their mental states and intentions, and to respond (function) mindfully; in short, to Think, Link & Respond (Smith & Wollesen, 2004). Reflective functioning is opposed to emotional reaction or inaction. My study suggests reflective functioning and reflective literacy are overlapping and complementary concepts central to health-promoting parenting and to attaining optimal functional health literacy. Results suggest further that reflective practices and teaching strategies and reflective supervision effectively promote both. The ability to reflect (Think, Link & Respond) may buffer or mitigate the negative impacts of low reading skills and support improved health functioning. Another possibility is that reflection is necessary to make meaning of information and so should be considered a basic literacy skill, rather than a higher order skill (Charner-Laird et al., 2003).

The reflective approach in home visitation worked quickly to significantly improve parents’ functional health literacy within the first six months of service (p<.001). Parents continued to improve their health functioning over time with home visiting. Additional research is
needed to identify the specific mechanisms by which improvement is achieved, particularly in the first six months of service, and sustained. Reflective practices in supervisors, home visitors, and parents are a promising explanatory factor.

Future theoretical inquiry should explore links between Nutbeam’s (2008) levels of health literacy, Wollesen’s (2006) levels of health functioning, and levels of reflection described by Habermas (1973), Zeichner and Liston (1987), Mezirow (1981) and others. A potentially rewarding inquiry asks: Do parents visited by more reflective visitors progress toward functional health literacy at different rates or in different patterns compared to parents with less reflective visitors? To address this question, researchers could use methods and instruments from the field of teacher training to rate reflectivity in home visitors who participated in this initial project; and then compare FHLM scores of parents in the existing database by visitor. In addition, it would be worthwhile to investigate reflection-promoting strategies that might be adapted from the fields of teacher training, nurses training, or psychoanalysis.

Measurement in Home Visitation Research

LSP and FHLM Make Routine Program Evaluation and Action Research Feasible

Home visitors showed themselves to be capable researchers using multiple waves of measurement to track parents’ progress (regression) toward higher levels of functioning using the Life Skills Progression instrument (LSP), particularly tracking progress to higher levels of health functioning using the Functional Health Literacy Measure (FHLM). These measurement tools served to ensure that difficult topics were addressed regularly, to summarize in one place the multiple formal assessments, interviews and observations that visitors use to assess parents’ functioning; to identify family strengths and needs, to plan interventions, and to guide reflective practice and reflective supervision, while providing data for evaluation.

In addition, the measurement tools make possible ongoing action research at visitor, program, community and network levels to identify and disseminate best practices, guide
recruitment and training, and inform policymaking. Home visitors in the participating programs collected reliable useable data on over 2500 parent/child pairs. This combined database can now be used to provide comparison groups for future health literacy intervention studies.

Priority for Future Research: Complete Analysis of the Project Database

The FHLM is derived from the Life Skills Progression instrument (LSP) (Wollesen & Peifer, 2006). The participating sites contributed data on all 35 aspects of family functioning and eight aspects of child development included in the LSP. The scope of this project was limited to analyses of the FHLM scales, which incorporate only selected LSP items. Analyses using the project’s full LSP database would further explain between-site differences in health literacy improvement and elucidate links between health literacy and other determinants of health. It could suggest intervention points for home visitors and clinicians, as well as direction for policymakers. The first priority for future studies is to complete analyses of data collected in this project, particularly links between health literacy and depression, social support, and child development. I anticipate each of these factors is independently related to health literacy, and the factors are inter-related.

Health Literacy & Depression. Forty to 60 percent of low-income mothers of young children and pregnant/parenting teens report depressive symptoms. Maternal depression threatens ability to foster healthy relationships and to carry out the management functions of parenting, including managing personal and family health. Results for young children are demonstrable reductions in behavioral, cognitive, social and emotional functioning (Kinzer, Theberge & Johnson, 2008). Weiss, Francis, Senf, et al. (2006) found that people with limited literacy skills and those who are depressed share characteristics of low self-esteem, poor self-efficacy, an external locus of control, and shame over their limitations, all of which relate to negative health behaviors. Weiss and colleagues (2006) also found that depression severity was lower among participants assigned to receive literacy training plus depression treatment than it
was among participants assigned to receive only depression treatment. Confirmation of this finding by analysis of correlations between depression scores on the LSP and FHLM scores would support prioritizing efforts to hone and disseminate the intervention’s protocol for referring parents to literacy enhancing services and supporting their sustained participation.

**Health Literacy & Social Support.** Lee, Arozullah & Young (2004) theorized that social support mitigates or buffers the negative impacts of low literacy and specifically low health literacy. Jackson (2006) found that high levels of social support contribute independently to specific health practices for women, including adherence to routine medical attention. Home visitors directly provide various types of social support, and help parents expand and improve their social support networks. Confirmation of Lee’s theory by analyses of correlations between social support scores on the LSP and FHLM scores would guide future research on the role of social support in health literacy, and may suggest strategies to promote health literacy indirectly through social support.

**Health Literacy & Child Development.** Low maternal health literacy is associated poor child development (Robinson & Wharrad 2000). Examples of how a mothers’ functional health literacy may positively or negatively affect child development include her ability to establish a medical and dental home (regular sources of care) for herself and her child, her ability to arrange well-child checkups and immunizations, her ability to recognize the child’s illness and injury, provide appropriate home-care, trigger timely intervention, administer medications and follow treatment regimens, her ability to recognize her own depression and access timely treatment. The LSP data includes information on all these factors, plus eight aspects of child development. One would reasonably expect strong correlation between parents’ functional health literacy scores, particularly item scores for “Support of child development”, and child development scores. Analyses of correlations between FHLM scores and child development scores on the LSP could confirm or question the findings of this study and the validity of the FHLM.
While the scope of this study is limited to the FHLM scales, the LSP data is richly informative. Ongoing action research using the LSP/FHLM can guide not only health literacy promotion, but also guide continuous quality improvement of home visitation services across national models.

Implications for Home Visitation Practice

The Role of Curriculum

The differentiating factor of the Beginnings Guides Life Skills Development Curriculum approach to home visiting and health literacy promotion is the integration of collaborative reflective practices and teaching strategies into the usual activities of home visitation to develop parents’ reflective skills and reflective functioning. This curriculum was the basis for the intervention and a common element in all the participating programs. All the participating programs used the *Beginnings Guides* content and materials to some degree.

Researchers have established that effective home visitation programs develop a clear set of goals and then match curriculum to the goals and ensure veracity to the curriculum through rigorous quality assurance and supervision (Family Strengthening Policy Center, 2007). Future studies should consider the how well the curriculum matches the goals of national program models. The programs that primarily intend to prevent child maltreatment produced only insignificant improvement on functional healthcare literacy, meaning use of health information and services. (All programs produced statistically significant improvement on selfcare literacy, meaning self-management of personal and child health.) This finding suggests the curriculum may be less well matched to the goal of preventing child maltreatment. However, those programs do report success in preventing child maltreatment, and they believe that literacy and health literacy are factors in their success, suggesting alternatively, that the goal, rather than the curriculum, may be less compatible with health literacy promotion. Programs focused on violence prevention (e.g. Healthy Families America model) may be less potentially effective channels for
promoting health literacy. If this is confirmed, future health literacy promotion efforts should target program models that focus on health and literacy (e.g. Early Head Start, Parents as Teachers).

In my study, the California site, an Early Head Start program, used the *Beginnings Guides* content and materials exclusively and produced the highest ending scores. Other programs used a combination of content and materials with mixed results. Future studies should compare LSP/FHLM scores in caseloads using the *Beginnings Guides* content and materials exclusively according to protocols versus caseloads integrating the materials, content, and strategies as visitors choose, versus caseloads using only other curricula.

Among the home visitation program models represented in this study, only one (the California Early Head Start site) includes literacy promotion in program goals and standards. Still, the results of this study confirm the observation of the participating programs that parents need adequate functional health literacy to achieve their goals for their families (health, safety, child development, school readiness) and the goals of home visitation (maternal & child health, school readiness, strong families). Lack of specific attention to literacy and health literacy may explain why home visitation overall has been able to demonstrate only moderate outcome effects (Gomby, 2005). Findings suggest further that making health and literacy explicit program priorities increases effectiveness in those areas. This confirms home visitation research that suggests programs produce outcomes in those areas that are explicit priorities included in goals, standards, training and evaluation (Gomby 2005).

Fidelity to the curriculum emerged as a potentially significant issue. In this initial cycle of action research, home visitors were free to use and adapt the curriculum to individual families according to their own judgment and comfort level. This hands-off approach served to verify that the curriculum can be integrated into various models of home visitation and effectiveness is not limited to a particular model or population. It also highlighted the positive impact of the curriculum’s differentiating factor, emphasis on reflection. The participating programs and
collaborators agreed that future cycles of research should focus on more deliberate practices and veracity to specific protocols in order to tease out the most effective strategies, integration processes, and training methods. Further analyses by visitor/caseload would aid this inquiry.

Investigate Disparities in Outcomes

African American parents achieved less improvement in functional health literacy than did Hispanic/Latino or Caucasian parents. As a group, they did not achieve the improvement in first six months of service that marked overall results. Formative research with African American parents should investigate whether the Beginnings Guides and the reflective teaching strategies are less culturally and linguistically appropriate for African American families. Other possible explanations to explore include that the difference relates to variations in implementation; that the difference reflects variation in available community services; or that it relates to greater accumulated disadvantage (poverty, racism).

Focus on Identifying “Clinically Feasible” Health Literacy Promoting Practices

An important lesson learned from the clinical model and confirmed by the home visitors is that acceptable and sustainable health literacy promotion strategies are those that are “clinically feasible”, meaning they can be integrated into practitioners’ usual activities with no more than minimal time and documentation burdens. Such strategies also may be applicable in clinical settings. This suggests a research focus on identification of best practices for health literacy promotion, and intervention focus on adaptation of those practices across disciplines and settings for a comprehensive coordinated response. Future action research should aim to define and test protocols for specific strategies to promote aspects of functional health literacy with the focus on interventions that can be embedded in practitioners’ usual activities and practices. For example, efforts could be directed to scripting and testing Reflective Questions designed to promote progress on specific items in the FHLM scales. Content for Reflective Questions and additional
strategies can be learned from parents in home visitation. Future studies should investigate and build on the coping strategies of parents with low literacy skills.

*Test reading aloud as a strategy.* Reading aloud is a teaching and learning strategy included in the intervention to promote literacy in adults and emergent literacy in children (Mendelsahn, 2002). It received mixed reviews from visitors. Many reported resistance due to concern about potential damage to the visitor/parent relationship, insulting parents who read well or embarrassing those who read poorly. Others reported embracing the strategy with good results. Further investigation of the theoretical foundation for this strategy, and development and testing of a specific protocol is warranted.

*Address the tension between reflection and rescue.* While the reflective approach meets the criteria for feasibility, it does represent a significant change for many in the helping professions who often are inclined and sometimes mandated to quickly "rescue" or "fix" low functioning families. The rescue approach is antithetical to health promotion and the reflection approach. If this tendency toward rescuing is established in programs or staff, especially supervisors, it presents a significant challenge to implementation of the reflective model of health literacy promotion. The intervention’s implementation training addressed this issue, and the reflective approach is an effective antidote to rescuing. However, more attention to this issue is required in training and support, especially for supervisors. Future research should pilot a formal protocol for implementing TED*, The Empowerment Dynamic (Emerald, 2009) as an antidote to rescuing.

*The Role of Reflective Supervision*

More attention is needed to reflective supervision. Qualitative data from interviews with participating staff and program directors indicate this part of the Curriculum was most unevenly implemented. I observed, and program directors noted resistance on the part of some supervisors, and not all supervisors participated in training. Home visitor/researchers who
experienced reflective supervision reported that consistent, regular, frequent use of the LSP in reflective supervision enhanced their practice and may explain in part greater improvement in FHLM scores at some sites. Supervisors provide the essential initiative and sustainability in an important parallel process in which supervisors’ model and support reflection and reflective functioning for visitors to aid them in modeling and supporting reflection and reflective functioning in parents who in turn model and support reflection and reflective functioning in their children. The stakeholders observed that the top health literacy promoting programs were those that obtained additional training and consultation on reflective supervision and most fully embraced reflective practices. More research is needed with supervisors to identify effective supervisor-training methods, support mechanisms, and efficient acceptable ways to incorporate regular, frequent reflective supervision into busy programs. Future studies should compare results in caseloads of home visitors who obtain and do not obtain reflective supervision according to a protocol.

Profile Effective Functional Health Literacy Promoters

It is impossible to separate supervision from staffing issues. Staffing remains a central question for home visitation generally and health literacy promotion in particular. Additional analyses of the existing database should guide future experiments to profile the personal, educational, training and experience characteristics of effective individual health literacy promoters and teams.

The FHLM scores and all the LSP data are analyzable by visitor and supervisor. A standardized process for reporting and comparing individual visitor’s and supervisor’s education, training, use of materials and tools, supervision, and adherence to protocols will increase potential for experimentation and ability to identify what works for whom under what circumstances.
**Consider Collaboration an Outcome of Interest**

In alignment with health promotion practice, home visitation practice dictates developing a network of community partnerships to increase effectiveness through synergy and collaboration. Partners may include parent advisory boards, healthcare providers, adult education programs, libraries, school systems, faith-based organizations, transportation authorities, child care providers, Child Protective Services, and the justice system. In future health literacy promotion studies, collaboration, which is embedded in the intervention, should be considered an outcome variable (Koelen, Vaandrager & Colomer, 2001). Increased understanding of the roles and contributions of community collaborators, and of facilitators and barriers to cooperation, will elucidate the elements of effective intersectoral collaboration for health literacy promotion.

**Increase Understanding and Support of Fathers’ Role**

The original question for this study was: Does home visitation promote *maternal* health literacy? Due to the surprising (at least to me) number of fathers in the cohort, with unanimous agreement of stakeholders, I changed “maternal” to “parental”. Stakeholders reached strong consensus on the need to increase and support fathers’ involvement in family health and literacy promotion. More research is needed to clarify strategies to support fathers’ involvement in maintaining and promoting family health.

**Implications for Home Visitation Policy**

**Integrate and Standardize Health Literacy Promotion Practice**

Organized reflective inquiry among the collaborators in this project with their invited experts and funders produced the following recommendations for home visitation policy:
• Integrate health literacy promotion into home visitation. This would involve mapping health literacy promotion into the goals, policies, procedures, curricula, training and evaluation of home visiting programs. It would require building awareness, coordinating messaging, and activating the collaborative efforts of current and new community partners. Health literacy promotion needs to be achieved with no more than minimal added burden on visitors or families.

• Establish practice standards for home visitation, including standards for health literacy promotion. Standards could be modeled on HEDIS (Healthcare Effectiveness Data and Information Set), a tool used by more than 90 percent of America's health plans to measure performance on important dimensions of care and service. Home visitation standards could be administered by the National Commission for Quality Assurance, which administers HEDIS.

Expand Home Visitors Research Network

Another facilitated reflective inquiry specifically considered whether the Home Visitors Research Network should continue/expand? And if it should continue/expand, what should be its role? There was unanimous agreement that the Network should continue with action research and should expand to include more home visitation programs and more collaborators. The role of the Home Visitors Research Network should be to champion health literacy promotion and cross-fertilize home visitation programs by translating research into practice. This should include disseminating results to other home visitation programs and groups, national network leaders, policymakers, state legislators, federal agencies, certification bodies, and schools of public health through publications, presentations and a website; and mentoring other sites preparing to implement health literacy promotion.

Forging a National Public Health Response to Health Literacy

Focus on Disadvantaged Families in the Prenatal to Preschool Period
This project demonstrated that home visitation can be an effective channel for promoting functional health literacy in growing disadvantaged families. An effective national response to health literacy will focus first on disadvantaged parents in the prenatal to preschool period when efforts and investments are highly leveraged since pregnancy and early parenting trigger readiness to learn, change behaviors, and promote personal health as well as initiation of health insurance and utilization of significant health services. Because the scaffolding for physical, cognitive and socio-emotional health is built in the early years of life, early investments in health promotion and effective parenting can greatly improve long-term health, behavior, economic and civic outcomes for entire families over their lifetimes (National Academy of Science, NRC, 2000 [Shonkoff, ed.]). Health literacy intervention integrated into the usual activities of home visitation could be implemented through these existing systems with short and long term benefits extending to the healthcare system and the schools. A program of action research through an expanded Home Visitors Research Network could identify and rapidly disseminate best practices across systems and disciplines.

Simultaneously Promote Health Literacy and Improve the Quality and Reach of Home Visitation

Historically, the national home visitation program models have been proprietary and in competition for funding. Programs models operate in silos; independent programs (privately funded and not part of a national network) often operate in isolation. Evaluation has been limited to major programs when funding is available and has focused primarily on outputs (e.g. number of visits completed) which are the basis for funding. For most programs, especially independent programs, evaluation is unaffordable and at best sporadic, limited and focused on funding requirements. Prior to introduction of the Life Skills Progression (LSP) instrument in 2006, no instrument existed to collect comparable data across program models. These conditions have led to a fragmented and under-funded system of home visitation.
This project demonstrated that home visitors, national program executives and program funders are eager to collaborate, hungry for data that can guide practice, and willing to share data to learn together from experience in order to improve their effectiveness. The action research approach, availability of the Life Skills Progression and the Functional Health Literacy Measure, and the combined database established in this project form the foundation for feasible ongoing evaluation of home visitation across program models. Such regular and ongoing collaborative evaluation would make possible identification and efficient dissemination of promising and best practices for promoting functional health literacy while improving the overall quality of home visitation. This presents an extraordinary opportunity to mount a national response to health literacy and simultaneously increase the reach and effectiveness of home visitation.

Scale up with Quality

Forging a national response to health literacy through existing national networks of home visitation will require integrating evidence-based health literacy promotion practices into effective home visitation program models. It will require moving home visitation from the margins of public health practice to the mainstream of health services. Scaling up existing models entails starting new and upgrading existing programs to achieve consistent service quality. This will require efforts by policymakers at all levels, program funders, research funders, program staff and national leadership and other stakeholders to assure conditions exit for home visiting programs to achieve real results (Schorr, 1997). Efforts to promote health literacy to the exclusion of other home visitation goals are unlikely to succeed.

According to the Harvard Family Research Project (2006), the foremost challenge is “scaling up with quality”. Continued research into best practices must leverage investments that national models have made in program evaluation, quality assurance, training and technical assistance. Lack of standardization in research design, especially lack of comparable data across programs, has impeded identification of effective program features (Sweet & Applebaum
2004), and resulted in the fragmentation of childhood policies and programs. The LSP/FHLM and the database developed in this project provide a foundation for overcoming this challenge.

Scaling up also will require significant financial resources since early childhood interventions that work are rarely simple, inexpensive or easy to implement (Institute of Medicine/National Research Council, 2004. Federal government should enact the Education Begins at Home Act (S. 667 and H.R. 2343) which would authorize dedicated funds for home visitation service delivery and research.

Federal research agencies should hold programs accountable for parent and child outcomes, particularly health literacy improvement. This cannot be an unfunded mandate. The National Institutes of Health, Health Resources and Services Administration, and the Centers for Disease Control and Prevention should support development of consistent program evaluation standards (Thompson, Kropenske, Heinicke, et al., 2001) and ongoing evaluation of home visitation programs, using a variety of methods including action research by home visitors. Development of a national LSP database would enable comparative and aggregate studies to discover which home visiting models, curricula, and staff combinations are appropriate to promote health literacy and other home visiting goals, and to rapidly identify and disseminate best practices.

Conclusion

Functional health literacy means using health information and services in ways that maintain and promote health. It is a personal asset important in both clinical and community settings. Parental functional health literacy can be promoted through health education and health promotion efforts implemented by existing national networks of home visitation programs. Functional health literacy can be measured as progressive levels of health functioning corresponding to progressive levels of health literacy using the LSP/FHLM.
This project demonstrated that home visitation promotes functional health literacy in disadvantaged parents of young children regardless of reading level, age or ethnicity in periods as short as six months. Poor readers and lower functioning parents made the greatest gains. Efforts to improve health literacy in this population are highly leveraged and promise short and long term benefits for entire families over their lifetimes with benefits extending to the healthcare system and the schools.

While the data are insufficient to assign causality to the Beginnings Guides Life Skills Development Curriculum or any particular element of home visitation, the intervention’s reflective approach appears to be an underlying construct in the promotion and attainment of health literacy and warrants further research and development.

This project was groundbreaking for health literacy research in several ways. It demonstrated that the public health concept of health literacy promotion is practical for implementation. In addition, it proposed a theoretical framework for measuring functional health literacy and demonstrated the utility of the Functional Health Literacy Measure (FHLM). Thus, this project opened a new direction for health literacy intervention and research. Further, the project initiated health literacy intervention outside the healthcare delivery system, and initiated action research methods in health literacy studies.

The project was groundbreaking for home visitation in that it introduced health literacy into home visitation. In doing so, it demonstrated that a reflective model of home visitation promotes parental functional health literacy. The project showed home visitors are capable collaborative researchers who can employ action research methods to increase understanding of health literacy, bridge research and practice in health literacy promotion, and improve the effectiveness of home visitation services.

I envisioned this project as the initial cycle in a program of action research on health literacy promotion through home visitation. In this first effort, the Home Visitors Research
Network already has made significant contributions to both health literacy research and home visitation and has shown itself worthy of funder support to continue and expand its work. The data collected using the LSP and the FHLM is rich. Further analyses of the existing data will further elucidate the research questions addressed in this project and many other pressing questions related to health literacy, health disparities, the social determinants of health, and the potential of home visitation. With continued data collection to grow the database and ongoing action research, the Home Visitors Research Network could lead a national response to home visitation through the existing national networks of home visitation programs.

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32 Does home visitation promote health literacy? Who progresses? Can the LSP/FHLM be used as a meaningful measure of functional health literacy?


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