APPENDIX D:







Background Information on Health Literacy

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Functional Literacy in the U.S.

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Findings from Key Health Literacy Studies

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Findings from Research Linking Literacy and Health Outcomes

FUNCTIONAL LITERACY IN THE UNITED STATES

he National Adult Literacy Survey (NALS) was conducted in 1992 and was the first national assessment of adults in the United States. The survey involved home-based interviews with 26,000 adults. The survey examined adults' functional literacy skills – their ability to use the written word to accomplish tasks. The NALS did not measure reading skills as such. The NALS focused on adults' ability to use the written word to perform tasks with accuracy and consistency.

The NALS and related surveys conducted in other industrialized nations assessed adults' functional literacy skills by focusing on people's ability to use the written word to accomplish everyday tasks. The materials used in these assessments were drawn from everyday life and were examined for levels of complexity. The tasks that adults were asked to perform ranged from fairly simple (locate a piece of information in a text) to sophisticated (determine the amount of medicine to be given to a child of a specified age and weight based on a medicine label). The scores were reported for three different literacy scales:

Prose literacy – the knowledge and skills needed to understand and use information from texts that include editorials, news stories, poems, and fiction. Two examples are: finding a piece of information in a newspaper article; identifying the contrasting views expressed in an editorial.

Document literacy – the knowledge and skills required to locate and use information contained in materials that include job applications, payroll forms, transportation schedules, maps, tables, and graphs. Two examples are: using a schedule to choose the appropriate bus; entering information on an application form.

Quantitative literacy – the knowledge and skills required to apply arithmetic operations, either alone or sequentially, using numbers embedded in printed materials. Two examples are: balancing a checkbook; determining the amount of interest from a loan advertisement.

NALS Scores

The NALS functional literacy tests are scored on a 500-point scale and are divided into five skill levels. The scores are related to the complexity of the materials and to the difficulty of the tasks. Scores on each of the three literacy scales were reported both by number and by quintiles. Level 1 represents the lowest level of proficiency and Level 5 the highest.

- Tasks at NALS Level 1 (0 225 points) require participants to locate a requested piece of information, such as a winning score in a sports article.
 - Participants scoring at the lowest level, Level 1, generally can, with accuracy and consistency, locate a piece of information in a newspaper story or on a form; however, they have difficulty locating and matching two such pieces of information or locating one piece of information in a complex text. Most are able to complete a simple mathematical operation.
- NALS Level 2(226-275) tasks require a participant to match two pieces of information.
 - Adults scoring at Level 2 can, with accuracy and consistency, locate and match two pieces of information in familiar and easy text; however, they have difficulty integrating this information or finding needed information in complex text. Most are able to complete a simple sequence of basic arithmetic.
- NALS Level 3 (276-325) tasks require a participant to integrate several pieces of information to answer a question.
 - Participants scoring at Level 3 can generally locate, match, and integrate information, with accuracy and consistency. Participants at Level 3 may have some difficulty solving problems that require them to find and integrate needed information available in materials but not identified in the question. This is also the case for needed mathematical operations.
- NALS Level 4 (326-375) tasks require a participant to find information in text that is not specified in a question and to bring this information together to accomplish a task.
 - Adults with Level 4 scores can respond to questions that require them to use information present in the text to solve problems and can find and integrate needed information even in complex text.
- NALS Level 5 (376-500) tasks require participants to analyze information, such as identifying the point of view expressed in an editorial.
 - Participants scoring at Level 5 are able to analyze materials and can, for example, identify the point of view in an editorial or a poem.

The findings from the 1992 NALS indicate that fully 47% to 51% of U.S. adults have limited or low functional literacy skills. *This does not mean that they cannot read.*Most of these adults can and do read.

The average score for U.S. adults is in the upper level of NALS 2 functional literacy skills. The mean score for U.S. adults is between 267 and 273, which is at the upper level of NALS Level 2. A number of national and state organizations in the U.S., including the National Governors Association, have identified Level 3 proficiency as a minimum standard for success in today's labor markets. Skills needed to fully function in today's health systems have not been thoroughly assessed as yet. However, researchers in health and in education speculate that very high skills are often assumed and surely needed.

In Summary

Findings indicate that about half of U.S. adults do not quite have the literacy skills required for many of the tasks needed in the twenty-first century workplace and for full participation in the activities of everyday civic life. Studies by education scholars and economists have documented the consequences.

FINDINGS FROM KEY HEALTH LITERACY STUDIES

Over the past several decades, public health, nursing, and medical researchers have documented the mismatch between the reading levels of health-related print materials and the reading ability of the intended audience. Most of the health-related print materials assessed score at reading grade levels that far exceed the reading ability of the average adult.

Research studies in education and adult literacy indicate that literacy influences the ability to access information and navigate in literate environments, has an impact on cognitive and linguistic abilities, and affects self-efficacy. Self-efficacy refers to people's sense of what they are able to do. Albert Bandura, the social psychologist who examined what helps people learn and take action, noted that self-efficacy can be built over time. Research indicates that self-efficacy is critical for learning and for action.

Literacy and Access to Information:

Patients' literacy directly influences their access to crucial information about their rights and their health care. Studies in medicine and public health indicate that reading skills influence people's ability to:

- Follow instructions for care
- Take medicine
- Comprehend disease-related information
- Learn about disease prevention and health promotion

In addition, studies indicate that patients with limited reading skills who need to manage a chronic disease such as diabetes, asthma, or HIV/AIDS may be less well-informed about the basic elements of their care plan. Several studies indicate some measurable health consequences.

Literacy and Rights:

Because consent procedures contain complex legal and medical jargon, a patient's literacy may influence his or her opportunities for inclusion in research and exposure to a variety of procedures. Studies of informed consent documents indicate that these documents are very likely not accessible for adults with average literacy skills.

Literacy and Access:

Furthermore, literacy levels may directly affect access to care. For example, difficulties in completing registration forms or applications for insurance coverage may delay the procurement of needed medical services.

Literacy and the Social Environment:

Finally, limited or low literacy-related skills are often accompanied by feelings of embarrassment or shame. This sense of shame may diminish a person's capacity to express his or her concerns in our highly demanding and literate health care environment.

Literacy and Disparities:

NALS findings indicate that people who live in poverty are more likely to have limited literacy skills than are people who do not. In addition, people who belong to minority population groups have lower literacy skills than do European-Americans. Poverty, bias, access to resources including well-funded schools may well limit the development of literacy skills. Established epidemiological data indicate that death rates from chronic and communicable diseases are related to education level.

Plain Language Initiatives:

Plain language initiatives in the United States, Canada, and Sweden are encouraging writers in a variety of professional organizations to adopt plain language principles.

These organizations include:

- U.S. Securities and Exchange Commission
- American Bar Association
- Canadian Bankers Association
- Canadian Public Health Association
- Ministry of Justice in Sweden

Plain language principles vary but generally include attention to the difficulty of words, sentence length, complexity of concepts, organization of text, as well as to the layout and design of print materials.

Multiple guidebooks for plain writing, available as texts and on Web sites, support these same principles. In addition, studies of participatory design work offer insight into the value of incorporating the voice and perspective of members of the intended audience. Such work engages members of the intended audience in the development of learning materials. This process yields materials that are more appropriately matched to the reading ability of proposed readers than are materials developed by experts.

FINDINGS FROM RESEARCH LINKING LITERACY AND HEALTH OUTCOMES

Education, occupation, and income are commonly used markers of socioeconomic status and are strongly correlated with health. *Healthy People 2010*, the U.S. Department of Health and Human Services (DHHS) report of national health promotion and disease prevention objectives for the nation, notes that people living in poverty have:

- Limited access to health promotion and disease prevention programs
- Limited access to curative services
- Greater need for preventive programs and curative services
- Greater exposure to environmental and occupational hazards
- Limited options in education, housing, and employment (all of which are often substandard among those with limited incomes)

Consequently, *Healthy People 2010* highlighted the need to reduce the disparities in health between the more advantaged segments of the population and those groups that are disadvantaged economically, educationally, and politically.

Links between Education and Health:

A report of national trends in health statistics, *Socioeconomic Status and Health Chartbook: Health United States, 1998*, highlights a substantial body of research findings relating life expectancy as well as lung cancer and heart disease rates to family income. Similarly cited are numerous studies clearly demonstrating that death rates for chronic diseases, communicable diseases, and injuries are all inversely related to education for men and for women. Educational attainment and/or income are the most convenient and commonly used indicators of socioeconomic status, and the association between years of schooling and health or income and health is well established.

Some researchers suggest that education is the best socioeconomic measure for use in epidemiological studies. They hypothesize that education may protect against disease by influencing lifestyle behaviors, problem-solving abilities, and values. Other researchers have demonstrated a strong association between education and health by exploring three explanations for this association:

- 1. Education influences work and economic conditions.
- 2. Education influences social psychological resources.
- 3. Education supports a healthy lifestyle.

Although the demonstrated evidence of the association between health and education is strong, the explanations for this association and the underlying mechanisms have not been extensively studied. Literacy may be an important pathway.

Health researchers began to look more closely at literacy issues since the publication of findings from the National Adult Literacy Survey in 1993.

A good deal of the research linking health and literacy skills has focused on activities within health care settings. However, adults are engaged in health-related activities on a daily basis – in the home, at work, in the community. They are intimately involved, of course, in the occasional visits to health centers, doctors' and dentists' offices, emergency departments, and hospitals. Rudd and colleagues Irwin Kirsch and Kentaro Yamamoto of the Educational Testing Services (ETS) have provided an expanded schema for examining a broad range of health related activities. Their report, *Literacy and Health in America*, examines adults' ability to use printed materials to accomplish tasks related to health promotion, health protection, disease prevention, health care, and navigation.