Written Statement On Healthcare Literacy

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AARP is a nonprofit, nonpartisan organization of people age 50 and over with offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. We appreciate the opportunity to discuss health literacy issues with the ERISA Advisory Council and to present the perspective of our members, who, increasingly, find it challenging to navigate our complex and confusing health care system.

In an environment where competition is believed to foster quality improvement, and consumer choice is intended, at least in part, to force consumers to have "more skin in the game," individuals must be able to make decisions in their best interest. In this environment, consumers need to know how to access services; know where to go for assistance; make informed health care choices that best suit their needs, preferences, and values; and use health care resources wisely and effectively. In addition, in a reformed health care system that is patient-centric, integrated, and accountable, all stakeholders must accept certain responsibilities for change. For consumers, this means agreeing to become a new kind of patient—one who is activated, engaged, willing to pursue healthy behaviors, and be a full partner in one's health care.

This kind of “new” consumer will require clear, understandable, and meaningful information to support increased involvement. For employers, insurers, and other information intermediaries, it means getting the right information to the right person at the right time (Seidman, 2008). To support vulnerable sub-population groups, who have inadequate or marginal literacy and health literacy skills (such as older persons, racial and ethnic minorities, and those with less education), it will mean offering materials and support that are especially designed to address their skill levels. Otherwise, the ability of those in vulnerable groups to become more engaged may be hampered by their literacy deficits.

The Patient Protection and Affordable Care Act (ACA) spells out specific requirements for group health plans and health insurance insurers concerning the appearance, language, and contents of materials for prospective or covered individuals. Section 2715(b) requires that such plans present the summary of benefits and coverage using standard definitions; a font size no smaller than 12-point; a uniform format that does not exceed 4 pages; language that is culturally and linguistically appropriate; and terminology that is understandable by the “average plan enrollee.” AARP appreciates that Congress recognized the importance of how information is presented to consumers. However, as these provisions are implemented, it will be important not to treat consumers as a homogenous group, because they vary by demographic and socio-economic factors, as well as personal values and preferences. Targeting information to the “average” consumer could well disadvantage many whose skills are below average.

In the context of making coverage choices (which requires understanding the implications of the choice), decision making and health literacy skills are relevant. Below we review the status of certain populations with respect to health literacy and suggest ways to meet the diverse needs of consumers,

particularly people who have poor health literacy skills. It is this latter group—those with poor or marginal literacy and health literacy skills, who may be at greatest risk of making decisions that could adversely affect their health or financial situation if materials intended to disclose information and guide decisions are not properly designed, and if such individuals do not receive appropriate assistance. Finally, and more specifically, we raise some concerns with ERISA disclosures.

A substantial segment of the U.S. population has marginal or inadequate literacy and health literacy skills.

As measured by the National Adult Literacy Survey (NAALS) that assesses literacy across a continuum of skills — prose, document, and quantitative — about 90 million people — roughly half of the adult U. S. population, lack basic reading skills (National Center for Education Statistics, 2003).

The NAALS also assessed health literacy using items identified by the Institute of Medicine and Health People 2010 and organizing them into three domains of health and health care information: clinical; prevention, and navigation of the health care system (Kutner, 2006). The 2003 NAALS found that about two-thirds of the adult population has intermediate (53 percent) or proficient health literacy skills (12 percent). It is sobering that only 12 percent of adults are well-equipped to navigate the current health care environment. This small group has the ability to read and synthesize complex prose, integrate and synthesize multiple pieces of information in complex documents, and locate abstract quantitative information to solve multi-step problems. About half have “intermediate” health literacy-- they can perform moderately challenging literacy activities. However, over one-third have just basic (22 percent) or below basic (14 percent) health literacy, which means they either can just perform simple literacy or very simple, concrete activities.

In the navigation domain, this means that a substantial proportion of adults may have difficulty understanding how the health care system works (e.g., coverage issues, how to get financial assistance from public programs) or understand their individual rights and responsibilities.

A substantial proportion of older persons, ethnic, and racial minorities potentially faces difficulty in navigating the health system.

Reading requires adequate vision, concentration, word recognition, working memory, ability to process information—competencies that decline with age and that may affect an individual's ability to read. In addition, the diminution of these competencies is exacerbated by literacy challenges that an individual may also have (McGee, forthcoming). Health literacy is situation-specific—the more complex the health care situation or decision, the greater the need to have good health literacy skills (Selden, *et al*., 2000). Numerous studies demonstrate a relationship between low literacy and poor health or poor health outcomes (Committee on Health Literacy - Institute of Medicine, 2004). Since older persons generally rely on the health care system more than any other group, it is of particular concern that poor literacy and health literacy skills among this group may pose a barrier to their obtaining high quality health care. For example, patient involvement through self-management, behavior change, and participation in making decisions are key components of chronic care management. The evidence that poor or marginal health literacy skills may interfere with efforts to educate patients underscores the importance of addressing health literacy issues if initiatives designed to improve chronic care for older persons are to succeed. In addition to older persons, members of racial or ethnic minority groups, those who are Spanish-speaking, or have a lower level of education are also more likely to have poor health literacy skills.

Population projections by the U.S. Census Bureau provide a window into the future demographics of the nation. They make a compelling case for the need to focus on specific sub-populations groups when considering how to help consumers become fully activated partners in their health care. The population is projected to grow older over the next several decades. As this occurs, the racial and ethnic composition of the older population is also expected to change, with an increase in the proportion that is Hispanic and a race other than White. By 2050, 13.2 percent of the population over age 65 will be Hispanic, 18.5 percent Black, 21.9 percent Asian, and 21 percent White (U.S. Department of Commerce, 2010).

Despite the overall increase in educational attainment among older Americans, substantial educational differences exist among racial and ethnic groups (National Center for Education Statistics, 2003). In 2008, 82 percent of non-Hispanic whites age 65 and over had completed high school. Older Asians also had a high proportion with at least a high school education (74 percent). In contrast, 60 percent of older blacks and 46 percent of older Hispanics had completed high school.

Qualitative research among patients who have inadequate or marginal health literacy indicates that they encounter problems with navigation, completing forms, following medication instructions, having productive provider-patient interactions, and mastering coping strategies (Baker, *et al*., 1996). These types of problems can bear directly on the quality of care an individual is likely to receive and can pose barriers to timely access to care, cause inappropriate use of services, and result in mistakes.

Employ communication strategies that address literacy/health literacy concerns.

Even proficient readers prefer clear, straightforward communications. Plain language is easier to read than technical, legal, or complicated writing. Therefore, readers are more likely to read through the information rather than just skim it. A website at http://www.plainlanguage.gov provides checklists to assess whether documents or web-based materials comport with plain English standards (Plain Language Action and Information Network).

Experts have identified processes to help individuals use written information to inform choices. Strategies to help compensate for literacy deficits and build on cognitive strengths are recommended (McGee, forthcoming). These include lowering the amount of cognitive effort required to use information (*e.g.*, reducing the amount of information individuals must process); giving consumers a way of relating the implications of a choice to their own experience; and highlighting the meaning and significance of information through specific presentation approaches. Written materials should use short sentences, the active voice, and large print. Instructions should be provided by grouping segments of information and limiting directions. Visual aids can help to reduce the amount of reading required and clarify written materials (Murphy, *et al*., 1993). The use of narratives and evaluable formatting helps those with moderate skill, but not those in the lowest quartile of skills. Also, consumers are highly influenced by how information is presented and framed. This may be as important as the content itself and failure to focus attention on the manner in which materials are presented could undermine a consumer's ability to consider her own self-interest in the context of making a decision (Hibbard, 2003).

Web-base materials can also be designed to facilitate decision making by: offering step-by-step guidance to navigate a web site; including functionalities

that enable the user to search on key words; defining key terms; allowing the user to easily print a web page; protecting personal information and securing such information. Web-based materials are often very complex and require a unique set of navigation and graphic-reading skills. For Internet-based materials, specific techniques such as graphics, multimedia, and interactive elements may make content more accessible, but they ultimately cannot remove the barriers for individuals with poor health literacy skills (Risk and Peterson, 2002). As a rule, individuals with poor literacy skills rely on their listening skills to learn (Murphy, *et al*., 1993). However, it is not always feasible to provide one-on-one teaching or counseling. For those with low literacy skills, other interventions include offering audio or video instructions and providing visual rather than written cues (Gazmararian, *et al.,* 1999) and suggesting behaviors and actions that the patient/consumer should take.

ERISA Disclosures

As we have shown there are many issues surrounding health literacy, ranging from basic reading skills to health literacy that relates to the complexity and difficulty of the information involved. However, aside from those issues, there is a more basic one that the Department of Labor can address concerning the disclosures provided to health plan participants.

"Congress' purpose in enacting the ERISA disclosure provisions [was to ensure] that 'the individual participant knows exactly where he stands with respect to the plan[.]'" *Firestone Tire & Rubber Co. v. Bruch*, 489 U.S. 101, 118 (1989) (*quoting* H.R. REP. 533, 93d Cong., 2d Sess. (1973), *reprinted in* 1974 U.S.C.C.A.N. 4639). To further this goal, Congress enacted ERISA's disclosure and notice requirements. Indeed, a plan is required to distribute a Summary Plan Description ("SPD") explaining the plan's benefits, its rules for eligibility and its claims and appeals process, among other things. Congress

contemplated that the SPD will be the primary source of information to participants about the plan's benefits, and generally is the only document that the participant ever receives about benefits. An average plan participant must be able to understand the information a plan provides in an SPD. 29 U.S.C. § 1022(b).

Two issues have emerged in jurisprudence surrounding notices and disclosures in SPDs and Summary of Material Modifications. The first issue is the appropriate burden of proof plan participants must carry when there is a conflict between the SPD and master plan document. The circuit courts of appeals have developed different standards, ranging from requiring a material and clear conflict between the SPD and plan terms (the easiest) to requiring detrimental reliance (the hardest). The US Supreme Court granted *certiorari* in the case of *Amara v. Cigna,* 348 Fed. Appx. 627 (2nd Cir. 2009), *cert. granted*, 78 USLW 3762 (June 28, 2010) (No. 09-804), to resolve this conflict. The second issue is whether plans should be permitted to correct "scrivener's errors." *See Young v.* Verizon's *Bell Atlantic Cash Balance Plan,* 2010 U.S. App. LEXIS 16483 (No. 09-3872) (7th Cir. Aug. 10, 2010) (permitting reformation of "scrivener's error" where consistent with participant's reasonable expectations). In this case, AARP believes that if a participant cannot rely on the terms set forth in the SPD, his ability to understand the plan terms becomes irrelevant.

We suggest that the Department of Labor amend its regulations to provide that if the SPDs provides for a greater and/or better benefit than provided for in the plan document, the SPD must govern. The regulation should provide for technical compliance regarding information concerning benefits (eligibility, coverage, restrictions, etc.) and the claims procedure.

Conclusion

We hope these views will be helpful to you as you consider the development of standards for use by group health plans and group health issuers. AARP takes seriously its role as a trusted source of information and devotes considerable resources to helping people understand their health care choices by making available educational materials on a range of health care topics. We offer these materials electronically and in hard copy through a fulfillment service. However, as important as our efforts are to our members, we know they and the public-at-large also seek information from many other sources, including newspaper, magazines, radio, television, and friends and families.

AARP believes it is critically important for the Department of Labor and other federal agencies with jurisdiction to address the need for employers and others to consider the health literacy skills of their employees, retirees, and dependents in the materials they use to communicate on benefits and other related matters. Consumer activation and engagement depend on information that is accessible and understandable that has been developed, tested, and vetted by a reliable source. The Department can play an important role, in collaboration with other federal agencies that are similarly implementing ACA provisions. Such joint activity can assist employers, insurers, and plans to implement innovative and effective communication approaches, including model formats, disclosure statements, and alternative modes for individuals in need of assistance. Federal efforts should inform the development of materials by testing the materials among populations known to have poor or marginal health literacy skills to ensure that the materials are understood by target audiences. Broadly disseminating tested materials would be a major contribution to employers and health insurers.

In addition to research and expanding the evidence base for effective consumer communication, through its rulemaking and enforcement authority, government can ensure that health plans and insurers facilitate consumer understanding of various issues that have a direct impact on their welfare. The newly enacted ACA requirements present an opportunity to address health literacy issues. Consistent formats, uniform terminology, sensitivity to cultural and linguistic preferences are fundamental. But these measures represent just a point of departure. In the final analysis, it will be necessary for all government agencies with jurisdiction to take specific steps to ensure that attention to health literacy is more than a rhetorical exercise. Therefore, we urge strong enforcement of the ACA provisions by factoring into regulatory requirements the findings from the NAALS. This will immeasurably advance the use of materials designed specifically to meet the needs of people with poor or marginal health literacy skills.

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