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# Health literacy policies: National examples from the United States

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## Introduction

Health literacy as a concept, a research topic and a field of practice has steadily grown since the beginning of the 21st century in the US. There is also a growing acknowledgement that health literacy is a key tool to promote better health among entire populations, *perhaps even the most important tool*. The evolution of health literacy has responded to different influences and taken different paths in multiple countries, as we see in the other chapters of this book. Since health literacy is such a multifaceted concept, involving a wide range of types of organisations, levels of leadership, community populations and strategies for improvement, it is intriguing to see the paths taken by different countries to build awareness and incorporate health literacy into their healthcare systems and support activities.

There is often a question of whether an initiative should be top-down or bottom-up. Top-down is when policies and guidance are given from the top levels of leadership, then interventions are implemented by the layers of hierarchy until they reach down to the individual community members. The policies are the catalyst that starts the change. A bottom-up approach is also referred to as a *grass-roots* process where individuals identify a need and create solutions to implement in their own area of influence. Over time the isolated solutions gradually become a larger movement.

How has it worked for health literacy? In the US, health literacy started as a bottom-up, grass-roots movement. However, top-down support for health literacy initiatives was also a need, and this support has grown over the years to strengthen the movement. While there are few federal mandates for specific health literacy interventions, there are some government policies that provide very useful guidance to support training, education and overall attention to health literacy.

We often hear from other professionals working on health literacy interventions that they are 'working in silos'. In many cases, one or two dedicated people will shoulder the burden of incorporating basic health literacy practices into their organisation's activities. For example, one patient education coordinator at a large hospital will pull together a review team to ensure that written materials are in plain language. One nurse manager will create and teach a *Health Literacy 101* training module for newly hired providers. One adult literacy teacher will integrate

health literacy skills into the curriculum and take students on a field trip to the local health centre. We are aware of many innovative and successful projects to improve health literacy skills and lower barriers to healthcare.

We highlight the important federal policies that either directly or indirectly mandate and support grass-roots health literacy initiatives. In general, there are only a few federal policies that *mandate* specific health literacy solutions, but there are some others that directly address health literacy. Moreover, some policies have indirectly created such an acute need for solutions that they effectively spurred the health literacy movement into action. Guidance, rather than policy, is perhaps the most important support from federal government agencies. This includes resources, information and tools to help health professionals learn about health literacy and implement health-literate solutions. We first focus on federal policy, but also discuss federal initiatives and institutional guidance in other sectors. Most federal policy and guidance focus on the general population across the lifespan, although we highlight those aimed at specific age groups. While we highlight the important federal policies and resources, we are unable to include an exhaustive analysis of every initiative that exists in the US.

## 2010: A landmark year for health literacy

In 2010, there were four major initiatives from the US government that supported health literacy efforts throughout the country:

- Patient Protection and Affordable Care Act (ACA)
- *National action plan to improve health literacy*
- Plain Writing Act 2010
- *Healthy people 2020*

The release of each initiative in the same year provides some weight that the government sees health literacy as a critical factor to improve Americans' health and the system of healthcare in the US. It was at this point that the federal support rose up to try to meet the needs of the grass-roots efforts.

## Patient Protection and Affordable Care Act (ACA)

The ACA is one of the most significant federal laws to promote health literacy since the creation of Medicare in 1968 (Quadagno, 2005). Also known as 'Obamacare', the ACA is a complicated law, which was passed in 2010 after much debate and revision (Quadagno, 2010). Its main purpose is to provide more Americans with health insurance, but in the process the law continues to have an impact on many other areas of healthcare delivery, such as patient-centred care and the payment structure for healthcare services. In effect, the ACA had positive effects on health literacy promotion as newly insured people, many of whom had poor health literacy, flooded into the healthcare system (Somers and

Mahadevan, 2010). Healthcare providers and hospitals quickly realised that they were unprepared to effectively serve this newly insured population (Angel et al, 2011; Blumberg, 2012; Clemans-Cope et al, 2012). In turn, increasing attention focused on health literacy barriers and the need to improve policies and training in the healthcare sector (Koh et al, 2012, 2013a, b).

While the ACA explicitly mentions health literacy in a few places, the majority of legislation indirectly points to the rationale for promoting health-literate practices (Koh et al, 2013b). By including policies for health insurance enrolment, improved patient care, patient-friendly written materials and improved communication, the ACA indirectly required health literacy practices in many areas of outreach and service (Somers and Mahadevan, 2010).

### *Health insurance and the US healthcare system*

The US healthcare system does not include universal care, and is thus intricately tied to health insurance coverage (Quadagno, 2005). Although there are options for free or low-cost care for people with a low income, people with health insurance are healthier and receive better healthcare services (Rikard, 2013). There are many reasons for this disparity. Those without insurance are more likely to be elderly, poor, unemployed and foreign-born, all of which are groups likely to have poor health literacy skills and poorer health outcomes (Fiscella et al, 2002; Hadley, 2003; Kutner et al, 2006; Angel et al, 2011; Blumberg, 2012; Clemans-Cope et al, 2012; Lavelle and Smock, 2012; Sentell, 2012).

But the most significant reason may be that people with health insurance are much more likely to receive primary care and have a medical home, which is a regular doctor and a place where they go for coordinated care. People with health insurance are more likely to get regular health screenings and manage chronic conditions that could lead to worse health outcomes down the road (Clemans-Cope et al, 2012; Sentell, 2012). By comparison, many people who are uninsured tend to avoid seeing a doctor unless it is an emergency and chronic health conditions, like high blood pressure or pre-diabetes, go unnoticed until there is a significant health event (Hadley, 2003).

There exist 'safety net' services for people who are uninsured or underinsured. 'Underinsured' means that a person has health insurance for catastrophic events, but not a good enough plan to cover primary care and other important services to keep them healthy (Dickman et al, 2017). Federally qualified health centres and public hospitals serve people who cannot pay for services and who do not have health insurance. Yet not everyone who needs healthcare knows about or uses the services, especially primary care.

### *Basics of the ACA*

While the main goal of the ACA is to provide health insurance for more Americans, there are parts of the law that specifically address health literacy

in the context of improving patient-centred care and communication (Koh et al, 2012, 2013a, b). The ACA essentially made health insurance coverage mandatory for all Americans. This meant that employers were required to offer health insurance plans to employees, and each state was required to offer subsidised health insurance plans, offered through a 'marketplace' where people could compare plans and sign up. The enrolment process alone was immensely complicated and revealed a huge need for clear communication and health literacy (Koh et al, 2012, 2013a, b).

### *Health literacy components of the ACA*

There are four subsections in the ACA that mention health literacy (Somers and Mahadevan, 2010):

- *Accessibility of quality and improvement and patient safety research:* The law states that this research must be made 'available to the public through multiple media and appropriate formats to reflect the varying needs of healthcare providers and consumers and diverse levels of health literacy.'
- *Shared decision-making:* The law provides grants to develop decision-making aids to help providers educate patients, and states that 'decision aids must reflect varying needs of consumers and diverse levels of health literacy.'
- *Prescription drug benefit and risk information:* The law calls for consulting with 'experts in health literacy' when making decisions about standardised drug labelling and advertising.
- *Training of healthcare providers:* Preference is given to award grants for provider trainings that 'provide training in enhanced communication with patients … and in cultural competence and health literacy.'

These call-outs to health literacy may have helped to create an awareness of health literacy for the healthcare systems and provide some incentive to address it in their activities. But the reasons why the ACA had the most effect on health literacy programmes may have been more related to the need to serve a new population of patients in a more effective and accountable way.

### *Medicaid expansion*

As part of the ACA, most states could also opt to expand Medicaid and increase their portion of federal Medicaid funding. Medicaid is a government-administered healthcare programme for families with low income and people with disabilities. The expansion allowed millions more people to take advantage of Medicaid and obtain basic primary care along with many other health benefits. The population of new Medicaid members share many of the demographic characteristics as those with low health literacy, such as low income, immigrants and people with disabilities (Kutner et al, 2006).

### *Patient-centred care*

Perhaps anticipating the influx of new patients with health literacy challenges, the ACA also includes policies to support patient-centred care and communication practices of healthcare providers (Koh et al, 2012). In addition to the explicit support for training providers in cultural competence and health literacy, the law created other incentives to create patient-centred medical homes. These are hospitals or health centres where a person has doctors who know them and a coordinated set of primary care and specialty services. Standards must be met in order to be certified as a patient-centred medical home. The standards include providing services and care that patients can understand, which requires a level of communication that is impossible without addressing health literacy (Koh et al, 2013a).

This element of the ACA incentivised healthcare systems across the country to improve their communication practices, and many used health literacy interventions as key tools in this process. In fact, the Agency for Healthcare Research and Quality (AHRQ) created a health literacy universal precautions toolkit and specifically mapped out which health literacy tools could be used to achieve each element required to become a patient-centred medical home (Brega et al, 2015). This toolkit has been widely used by healthcare organisations to help assess their practices, train providers and work towards a standard of clear communication in order to meet the needs of all patients.

### *Results of implementing the ACA*

Before the ACA, 16-18 per cent of Americans were uninsured or underinsured (Kaiser Family Foundation, 2017). This meant that there was a huge pool of people who were not routinely connected to the healthcare system, were less healthy than others and had poor health literacy skills. During the first few years of the ACA, 15.8 million people enrolled in health insurance or Medicaid, many of them for the first time. During the enrolment process, health literacy principles were adopted out of necessity. Health insurance companies started to create plain language materials, and special navigators were trained to help people through the enrolment process, which meant explaining complicated information in a way that was easy to understand. Workshops and curricula were created to help people through this process of learning about health insurance and making informed decisions. One example is the Smart Choice Health Insurance programme from the University of Maryland Extension Program (Bartholomae et al, 2016). The programme includes a series of workshops and educational materials that were designed with health literacy principles and created to help people with low literacy skills learn about and use their insurance options. To date, over 2,000 people have benefited from the Smart Choice Health Insurance programme (Bartholomae et al, 2016).

To date, we are unaware of any efforts to quantitatively track the health literacy-related benefits resulting from the ACA (Gurley-Calvez et al, 2017).

Yet, anecdotal evidence suggests that many key stakeholders across the country responded with specific programmes aimed at reducing health literacy barriers in order to increase health insurance access and patient-centred healthcare. These programmes include training and support to improve the communication practices of healthcare providers; the development of easy-to-understand written materials about health insurance and Medicaid; and the provision of trained navigators to help people face-to-face as they enrol in health insurance and navigate the complicated healthcare system.

A recent study tracked the amount of professional discourse about the ACA as it relates to health literacy activities (Kurtz-Rossi et al, 2017). The 'Health Literacy Discussion List' is a longstanding community of practice with over 1,500 members from many different fields of practice, including healthcare, education, public health, research and others. A recent analysis of common topics of interest showed that one of the most popular discussion topics was the ACA and health literacy interventions, with about 30 per cent of over 2,000 posts between 2012 and 2014 focused on this (Kurtz-Rossi et al, 2017). This level of activity reveals that health literacy advocates were actively addressing ACA components.

### *Limitations of the ACA*

However, many stakeholders agree that there is still much work to be done and that the ACA did not go far enough in requiring more health literacy training of professionals and education for communities. In one US state, Colorado, a state-wide *Health literacy environmental scan* (JSI, 2017) assessed the status of health literacy activities and progress. Since Colorado was particularly successful in enrolling new members in health insurance plans under the ACA, much of the discussion centred around those efforts and other health literacy activities that stemmed from the ACA. Interviews were conducted with community groups, patient navigators, providers, educators, public health officials and health literacy advocates to find out what health literacy practices were in place, and how well they were filling the needs of diverse communities. The interviews revealed that while there were many great ACA-related policies around practice transformation, payment reform and data tracking systems, there was not enough effort to educate the public. People who were newly enrolled in health insurance still did not understand the 'culture' of relating to healthcare in the way that people with insurance are used to. Not enough new enrollees were taught how best to access care or how to use their insurance benefits effectively. To make it worse, the insurance information was so complex and varied that even healthcare providers and staff did not understand it well enough to explain to patients how much their care may cost or what benefits were covered.

One public health professional described it this way: "There is a disconnect between those creating the policies and the people in the communities. Policy folks and administrators put in these great systems, then wonder why people still show up in the ER" (JSI, 2017).

## *National action plan to improve health literacy*

The *National action plan to improve health literacy* was released in May 2010 by the US Department of Health and Human Services (USDHHS) (Office of Disease Prevention and Health Promotion, 2010). While the ACA was focused on the healthcare and insurance sectors, the Action Plan involved a much broader group of organisations. The Action Plan 'seeks to engage organisations, professionals, policymakers, communities, individuals, and families in a linked, multisector effort to improve health literacy' (USDHHS Office of Disease Prevention and Health Promotion, 2010, p 1).

The Action Plan contains seven goals, each with identified strategies that will enable a variety of organisations and fields to improve health literacy from their particular angle (see Box 32.1).

**Box 32.1: Goals of the *National action plan to improve health literacy***

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable
2. Promote changes in the healthcare system that improve health information, communication, informed decision-making and access to health services
3. Incorporate accurate, standards-based and developmentally appropriate health and science information and curricula in childcare and education through the university level
4. Support and expand local efforts to provide adult education, English language instruction and culturally and linguistically appropriate health information services in the community
5. Build partnerships, develop guidance and change policies
6. Increase basic research and the development, implementation and evaluation of practices and interventions to improve health literacy
7. Increase the dissemination and use of evidence-based health literacy practices and interventions

This inclusive approach encouraged other sectors outside healthcare to address health literacy. Notably, the Action Plan described *how education across the lifespan can contribute to a more health-literate population* by including objectives for early childhood through university-level education, and even adult literacy education and English language instruction. It also focused on creating partnerships between sectors, which has been a successful overall strategy for addressing health literacy.

While the Action Plan did not dictate any specific policy or mandate any activities, it contained two important components. First, by addressing health literacy from many angles with multiple stakeholders, it shows that health literacy is an important national priority. Advocates from diverse organisations from healthcare to education to research could use the Action Plan to leverage support and buy-in from leadership and funders. Second, it provides a framework and

instruction for organisations to create health literacy policies and interventions. In addition to detailed guidance to implement each of the seven goals, the Action Plan offered a template that organisations could use to create their own internal action plans.

The 'Health Literacy Discussion List' hosted three nationwide discussions about the Action Plan between 2010 and 2012. All discussions revealed extensive and varied activity spurred on by the Action Plan. We heard from many different organisations about what exactly they were doing to implement the goals, including state-wide health literacy coalitions, adult education programmes, community health centres, advocacy agencies, primary care providers, researchers and others (LINCS, 2010, 2011, 2012). The activities were just as varied and geared toward educating audiences throughout the lifespan and improving health system capacity to serve diverse communities. Here are some examples: maternal and child health organisations created pregnancy and baby care books written in easy-to-read language; programmes for children in day care centres addressed early health literacy skills through nutrition education units; universities created health literacy courses for health professionals; adult education programmes created health literacy curricula to integrate into adult education and English language instruction; hospitals implemented techniques such as brown bag medication checks to help patients – especially older adults – to manage their medication regimes; and government agencies put out more requests for research proposals related to health literacy.

As mentioned, there were several grass-roots state-wide health literacy coalitions and initiatives forming at this time. Their goals were to bring together a variety of state and local stakeholders to increase health literacy awareness of and use it to improve health in their state. The Action Plan became a common framework for the goals and activities of these coalitions, and many new ones were formed since its release. Now, about half of the 50 US states have formal health literacy coalitions, which continue to support health literacy efforts in their respective regions. So, while the Action Plan was neither a law nor a policy, it lent both government support and specific guidance that catalysed a huge number and range of health literacy interventions.

## Plain Writing Act of 2010

The Plain Writing Act of 2010 requires all federal agencies to follow plain language guidelines in their communications. The goal is to 'improve the effectiveness and accountability of Federal agencies to the public by promoting clear Government communication that the public can understand and use.' This Act includes provisions for training staff in plain language writing and overseeing the process of creating or revising all communication to meet the standards. While the Act sent a strong message about the importance of plain language and clear communication, and it was in fact a mandate, it does not seem to have had as big an impact as other programmes on lowering health literacy-related barriers for

most citizens. While many government websites and documents improved a great deal, there are still many federal websites that are difficult for most Americans to understand (Politi et al, 2016).

## *Healthy people 2020*

Since 2000, *Healthy people* has provided science-based objectives for improving the health of all Americans (USDHHS Office of Disease Prevention and Health Promotion, 2014). It establishes national benchmarks for each decade and monitors progress over time to encourage community collaborations, empowers people to make informed health decisions, and measures the impact of prevention activities. *Healthy people 2020* includes an objective for improving health literacy for the second decade in a row, to be measured by how many healthcare providers give instructions to patients in an easy-to-understand format. Other health literacy related objectives in *Healthy people 2020* measure increases in:

- providers who have good communication skills
- shared decision-making
- personalised health information resources
- easy-to-use health websites.

The *Healthy people 2020* objectives lend public health policy support to the ACA, the Action Plan and the Plain Writing Act 2010. Specifically, *Healthy people 2020* objectives on health communication and health information technology (IT) offer measures and targets for tracking progress on population-level health outcomes and hold healthcare systems accountable to improve patient health literacy.

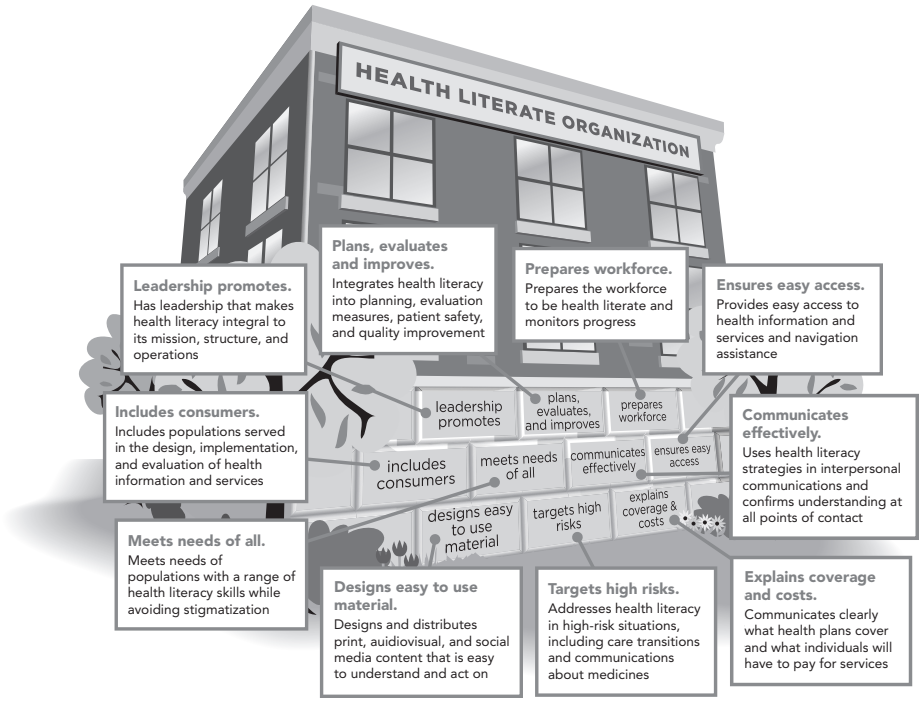
### *Health literacy: a prescription to end confusion, and the Ten attributes of health literate health care organizations*

The National Academy of Science Engineering and Medicine (formerly the Institute of Medicine, IOM) has been a key player in health literacy advocacy for many years. In 2004 they created the Roundtable on Health Literacy, and commissioned the seminal report, *Health literacy: A prescription to end confusion* (Nielsen-Bohlman et al, 2004). The report was one of the first big wake-up calls for healthcare systems and providers to address health literacy, and catalysed significant progress in the following decade. The most commonly cited definition of health literacy came from this report, which called on providers to take ownership of their role in lowering barriers to care for people with literacy challenges. The report described the role of healthcare providers in communicating clearly with patients, and providing written information that is easy to understand (Nielsen-Bohlman et al, 2004). Up until this point, health literacy was mostly framed as a deficit of knowledge and skills of individuals (a 'blame the patient' model) rather than a lack of providers' capacity to present

information in a way that people could understand and act on. This report opened up many new avenues of improvement by framing health literacy as more of a *two-way street*. Ironically, the definition of health literacy from the report did not reflect this dual ownership, only the skills of the individual. Since then, other definitions have included the skills of providers and systems as well as those of individuals (Coleman et al, 2009).

The Roundtable on Health Literacy has convened a diverse group of health literacy researchers and advocates for annual meetings and quarterly workshops for over a decade. They have written and commissioned several white papers on topics such as informed consent, numeracy, communicating with immigrants and refugees, and health literacy's role in public health. Perhaps the Roundtable's largest achievement and source of impact is the *Ten attributes of health literate health care organizations* (Brach et al, 2012; see also Chapters 31 and 35, this volume). This report identified 10 standards that a healthcare organisation must meet to provide effective, understandable care to all people, regardless of their health literacy level (see Figure 32.1).

**Figure 32.1:** Elaborations on the foundations of a health-literate organisation




*Source:* Reprinted with permission from Nielsen Bohlman et al (2004) by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC

Like the Action Plan, the Ten Attributes provides not just proof of federal support for health literacy standards, but also a framework to help organisations know where and how to instil new policies and interventions. This document has supported many healthcare organisations in their efforts to promote health-literate practices and better serve patients and communities. In fact, a companion guide was written to help organisations implement the standards described in the Ten Attributes – *Building health literate health care organizations* (Abrams et al, 2014).

## Other federal agencies

Some of the most effective support for health literacy efforts has come not from specific federal policies, but from government agencies that adopted health literacy as an important area of focus. These agencies created workgroups, wrote white papers and developed practical guidance, tools and courses to help organisations lower health literacy barriers and better serve people with low health literacy skills (Pleasant, 2013a, 2013b). While we cannot describe all the useful and effective work done by these agencies, we will highlight a few key projects here.

The following federal agencies have all played important roles in championing health literacy efforts in the US: the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the National Academy of Science Engineering and Medicine (formerly called the Institute of Medicine, or IOM), the Health Resources and Services Administration (HRSA), the Office of Minority Health (OMH) and the National Library of Medicine (NLM). Many departments have well-developed and informative health literacy sections of their websites that have been useful for educating professionals and consumers and building awareness. Notably, the CDC has an extensive health literacy section that includes information and guidance about improving organisational health literacy capacity, a listing of state-wide health literacy coalitions, research summaries and a series of free online courses that they developed for healthcare providers and public health professionals. The CDC also developed a Clear Communication Index that helps organizations, governmental departments, and developers of health materials to assess public health messaging to ensure that it is easy to understand and actionable.

The National Network of Libraries of Medicine (NNLM) has also had a big impact. They created a variety of health literacy training programmes for and by librarians, who then implement training for health professionals and communities. NNLM also created a widely used consumer health information website, MedlinePlus, that provides easy-to-understand health information for the public.

The Office of Minority Health (OML) recognised its role in advocating for health literacy as a tool to ensure that access to health information and services be improved for minorities. This is important because minorities of all kinds have been found to have greater health literacy challenges, especially those with limited English proficiency (Nielsen-Bohlman et al, 2004; Kutner et al, 2006; Rikard et al, 2016). This agency developed the *National standards for culturally and*

*linguistically appropriate services (CLAS)*, which was modelled after the *Ten attributes for health literate health care organizations*. The CLAS standards provide similar guidelines for healthcare organisations to adopt practices to better serve patients from diverse cultures. The overarching standard is: 'Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs' (USDHHS, 2012). These have also been used widely, especially in the growing numbers of communities with large populations of new immigrants.

## Conclusion

In general, the field of health literacy in the US began as a grass-roots movement. This was an important way to begin, as it grew from real needs identified by a wide variety of social service and health professionals struggling to serve vulnerable populations. These needs, and the solutions that were created, were the driving force to guide the federal policies that later stepped in to provide the top-down support. This support has grown significantly over the past decade and has served in several ways to strengthen the efforts that improve health literacy throughout the US. While the laws, mandates and strict policies, like those stemming from the ACA, have pressed organisations to adopt health-literate practices, it has largely been the practical guidance that has helped them to create the programmes and interventions that put these practices into action. The support for health literacy from so many diverse agencies and sectors has helped the US to address this issue from the many different angles that are needed to have widespread impact. Furthermore, the fact that several of these agencies stepped up with guidance around the same time, in 2010, helped to create a 'splash' of awareness that put health literacy firmly in our national consciousness.

Our hope is that localised programmes continue to respond to the needs of their communities, and that federal agencies and departments continue to play the supportive role that we have described here. We have seen that by combining top-down support with grass-roots efforts, we can make better progress towards improving the nation's health through health literacy.

### References

Abrams, M.A., Kurtz-Rossi, S., Riffenburgh, A. and Savage, B. (2014) *Building health literate organizations: A guidebook to achieving organizational change*, Wes Des Moines, IA: UnityPoint Health.

Angel, J.L., Montez, J.K. and Angel, R.J. (2011) 'A window of vulnerability: Health insurance coverage among women 55 to 64 years of age', *Women's Health Issues*, 21, 6-11.

Bartholomae, S., Russell, M.B., Braun, B. and McCoy, T. (2016) 'Building health insurance literacy: Evidence from the Smart Choice Health Insurance™ Program', *Journal of Family and Economic Issues* 37, 140-55.

Blumberg, L. (2012) *The Affordable Care Act: What does it do for low-income families?*, FastFocus, Madison, WI: University of Wisconsin-Madison.

Brach, C., Keller, D., Hernandez, L.M., Baur, C., Dreyer, B., Schyve, P., et al (2012) *Ten attributes of health literate health care organizations*, Washington, DC: Institute of Medicine of the National Academies.

Brega, A.G., Barnard, J., Mabachi, N.M., Weiss, B.D., DeWalt, D.A., Brach, C., et al (2015) *AHRQ health literacy universal precautions toolkit* (2nd edn), Rockville, MD: Agency for Healthcare Research and Quality.

Clemans-Cope, L., Kenney, G.M., Buettgens, M., Carroll, C. and Blavin, F. (2012) 'The Affordable Care Act's coverage expansions will reduce differences in uninsurance rates by race and ethnicity', *Health Affairs*, 31, 5, 920-30.

Coleman, C., Kurtz-Rossi, S., McKinney, J., Pleasant, A., Rootman, I. and Shohet, L. (2008) *Calgary Charter on health literacy: Rationale and core principles for the development of health literacy curricula*, The Center for Literacy of Quebec (www.centreforliteracy.qc.ca/sites/default/files/CFL_Calgary_Charter_2011.pdf).

Dickman, S.L., Himmelstein, D.U. and Woolhandler, S. (2017) 'Inequality and the health-care system in the USA', *The Lancet*, 389, 10077, 1431-41.

Fiscella, K., Franks, P., Doescher, M.P. and Saver, B.G. (2002) 'Disparities in health care by race, ethnicity, and language among the insured: findings from a national sample', *Medical Care*, 40, 1, 52-9.

Gurley-Calvez, T., Hembree, J., Mosley, J., LaPierre, T., Aslam, M., Jones, E.V. and Zimmerman, M. (2017) 'Lessons from a broad-based ACA outreach effort: Promises and pitfalls', *Journal of Health Care for the Poor and Underserved*, 28, 1, 46-57.

Hadley, J. (2003) 'Sicker and poorer – The consequences of being uninsured: A review of the research on the relationship between health insurance, medical care use, health, work, and income', *Medical Care Research and Review*, 60, 3S-75S.

JSI (JSI Research & Training Institute, Inc.) (2016) *Health literacy environmental scan*, with support from the Rose Community Foundation and the Colorado Health Foundation.

KFF (Henry J. Kaiser Family Foundation) (2017) 'Key facts about the uninsured population', in KFF (ed) *Kaiser Commission on Medicaid and the uninsured* (www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/).

Koh, H.K., Brach, C., Harris, L.M. and Parchman, M.L. (2013a) 'A proposed "health literate care model" would constitute a systems approach to improving patients' engagement in care', *Health Affairs*, 32, 2, 357-67.

Koh, H.K., Baur, C., Brach, C., Harris, L.M. and Rowden, J.N. (2013b) 'Toward a systems approach to health literacy research', *Journal of Health Communication*, 18, 1, 1-5.

Koh, H.K., Berwick, D.M., Clancy, C.M., Baur, C., Brach, C., Harris, L.M. and Zerhusen, E.G. (2012) 'New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly "crisis care"', *Health Affairs*, 31, 2, 434-43.

Kurtz-Rossi, S., Rikard, R.V. and McKinney, J. (2017) 'Learning from the field and its listserv: Issues that concern health literacy practitioners', *Information Services & Use*, 37, 219-34.

Kutner, M., Greenburg, E., Jin, Y. and Paulsen, C. (2006) *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy* (No NCES 2006-483), Washington, DC: National Center for Education Statistics: US Department of Education.

Lavelle, B. and Smock, P.J. (2012) 'Divorce and women's risk of health insurance loss', *Journal of Health and Social Behavior*, 53, 413-31.

LINCS (2010) 'Using the National Action Plan to improve health literacy – Health literacy discussion list (https://lincs.ed.gov/lincs/discussions/healthliteracy/10action).

LINCS (2011) 'Sharing our Health Literacy Action Plan stories – Guest discussion – Health literacy' (https://lincs.ed.gov/lincs/discussions/healthliteracy/11actionplan_transcript).

LINCS (2012) 'Sharing our Health Literacy Action Plan stories: Year 2 – Guest discussion – Health literacy' (https://lincs.ed.gov/lincs/discussions/healthliteracy/12action).

Nielsen-Bohlman, L., Panzer, A.M. and Kindig, D.A. (2004) *Health literacy: A prescription to end confusion*, National Institutes of Medicine, Washington, DC: National Academies Press.

Pleasant, A. (2013a) *Commissioned paper: Health literacy around the world: Part 1: Health literacy efforts outside of the United States*, Washington, DC: The National Academies Press (www.ncbi.nlm.nih.gov/books/NBK202445/).

Pleasant, A. (2013b) *Commissioned background report: Health literacy around the world: Part 2: Health literacy efforts within the United States and a global overview*, Washington, DC: The National Academies Press (http://nationalacademies.org/hmd/~/media/Files/Activity%20Files/PublicHealth/HealthLiteracy/Commissioned%20Papers%20-Updated%202017/Pleasant%20A%202013%20Health%20Literacy%20Around%20the%20World%20Part%202.pdf).

Politi, M.C., Kuzemchak, M.D., Liu, J., Barker, A.R., Peters, E., Ubel, P.A., et al (2016) 'Show me my health plans: Using a decision aid to improve decisions in the federal health insurance marketplace', *MDM Policy & Practice*, 1, 1.

Quadagno, J. (2005) *One nation, uninsured: Why the US has no national health insurance*, New York: Oxford University Press.

Quadagno, J. (2010) 'Institutions, interest groups, and ideology', *Journal of Health and Social Behavior*, 51, 125-36.

Rikard, R.V. (2013) *Looking upstream, downstream, and between: Examining health literacy in the stream of health disparities research*, Raleigh, NC: North Carolina State University.

Rikard, R.V., Thompson, M.S., McKinney, J. and Beauchamp, A. (2016) 'Examining health literacy disparities in the United States: A third look at the National Assessment of Adult Literacy (NAAL)', *BMC Public Health*, 16, 1, 975.

Sentell, T. (2012) 'Implications for reform: Survey of California adults suggests low health literacy predicts likelihood of being uninsured', *Health Affairs*, 31, 1039-48.

Somers, S.A. and Mahadevan R. (2010) *Health literacy implications of the Affordable Care Act*, Trenton, NJ: Center for Health Care Strategies, Inc.

USDHHS (United States Department of Health and Human Services) (2012) *National standards for culturally and linguistically appropriate services (CLAS) in health and health care* (www.thinkculturalhealth.hhs.gov/pdfs/EnhancedNationalCLASStandards.pdf).

USDHHS Office of Disease Prevention and Health Promotion (2010) *National action plan to improve health literacy*, Washington, DC.

USDHHS Office of Disease Prevention and Health Promotion (2014) *Healthy people 2020* (www.healthypeople.gov/).