



Special Senate Commission to  
Study the Topic of Health Literacy

**Findings and Recommendations**

Report Submitted to the  
Rhode Island State Senate  
November 2017

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*2016 Senate Resolution 2594*

*Agenda & Meeting Summaries*

# **SPECIAL SENATE COMMISSION TO STUDY THE TOPIC OF HEALTH LITERACY**

## **Members**

Senator Louis P. DiPalma, Chair

Senator Gayle L. Goldin

Senator Nicholas D. Kettle

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Ruth Feder, Mental Health Association of RI

Walter Burke, Town of Bristol, Parks and Recreation

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The Honorable Dominick J. Ruggiero  
President of the Rhode Island Senate  
State House  
Providence, RI 02903

Dear President Ruggiero:

On behalf of the Special Senate Commission to Study the Topic of Health Literacy, we hereby submit this Final Report. Our focus was to develop a strategic plan on the topic of health literacy that would maximize opportunities for collaboration and programs that would assist Rhode Islanders in navigating the healthcare system and help to improve health outcomes. Our Report represents the combined input of our Commission members and those who presented before the Commission to share their expertise and perspective on improving health outcomes in Rhode Island. We owe all who participated our sincere gratitude for giving so much of their time.

Rhode Island has made great progress in increasing access to affordable health insurance, but must be aware that access alone does not automatically translate to improved health outcomes. It is important for individuals to possess the capability to understand health information, and health care providers must also ensure that information is available and easy to comprehend. The Commission members worked to formulate recommendations that will have a real impact on improving the overall quality of healthcare in Rhode Island. We believe these recommendations will help to ensure that every Rhode Islander has the capacity to obtain, process, and understand basic health information and services that will help them make the best health decisions and therefore improve their overall health.

We hope this Report serves as a starting point for improving Rhode Islanders' health through improved health literacy, particularly among our most vulnerable communities. We thank you for the opportunity to serve on this Commission and look forward to continuing our work together.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Louis P. DiPalma".

Senator Louis P. DiPalma, Chairman

## EXECUTIVE SUMMARY

On May 17, 2016, Senate Bill 2594 Substitute A as amended was read and passed by the Rhode Island Senate creating a Special Legislative Commission to Study the Topic of Health Literacy. The Commission, chaired by Senator Louis P. DiPalma, was authorized to make a comprehensive study on the topic of health literacy in order to develop a strategic plan that would maximize opportunities for collaboration and programs that would assist Rhode Islanders' ability to navigate the healthcare system and improve health outcomes. This Special Legislative Commission consists of the following seventeen (17) members:

- Three (3) members of the Rhode Island Senate
- Three (3) consumer advocates
- One (1) representative of higher education
- One (1) representative of the Executive Office of Health and Human Services
- One (1) representative of the Rhode Island Community Action Association
- One (1) representative of the Rhode Island Department of Health
- One (1) representative of the Rhode Island Office of the Health Insurance Commissioner
- One (1) representative of the Rhode Island Division of Elderly Affairs
- One (1) representative of the Rhode Department of Education
- One (1) representative of the Hospital Association of Rhode Island
- One (1) representative of HealthSource Rhode Island
- Two (2) representatives who are culturally and linguistically competent professionals

The Commission met four times over the course of several months (October 25, 2016, November 11, 2016, January 10, 2017, and February 14, 2017) and was charged with presenting its findings and recommendations to the Senate President. This document represents the final report of the Special Senate Commission.

The Commission process was collaborative, with input and support from all members and presenters. The major findings were:

- A lack of health literacy among the American population negatively impacts individual health and drives up healthcare costs; the problem is particularly acute for certain sub-demographics
- Improving health literacy at an early age has a direct impact on health literacy later in life and a specific health literacy curriculum is required to achieve proficiency
- Healthcare providers must have a strong education in health literacy and understand the consequences of illiteracy to reduce its negative impact on health outcomes
- Cultural and linguistic competence are essential in engaging and educating patients about their healthcare
- Patient engagement is necessary when discussing policy initiatives related to healthcare, health reform, and health literacy
- A significant proportion of adults in Rhode Island and nationwide have difficulty understanding their health insurance plans

- A failure to understand health insurance plans negatively impacts an individual's health and their decision making abilities
- Rhode Island's readability requirement does not solve the issue of health insurance illiteracy

In response to these findings, the Commission recommends the following:

- Develop a statewide toolkit aimed at assisting public and private schools, community groups, and healthcare providers to support the current level of health literacy among Rhode Islanders
- Incorporate health literacy into elementary and secondary education health standards developed through a collaboration between community health organizations, healthcare providers, health insurance providers, the RI Department of Health (RIDOH), the RI Department of Education (RIDE), and other stakeholders
- Integrate health literacy training into the curriculum for medical students and encourage licensed professionals to utilize various training resources available at the state and national level
- Create specific programs and strategies to educate our most vulnerable populations, such as the elderly, individuals with disabilities, and individuals suffering from mental illness. This includes incorporating health literacy into adult education programs, supports for the homeless, and community organizations
- Ensure consumer advocates are included in health reform efforts by establishing a Consumer Advisory Board that is person-centered, culturally and linguistically competent, disability-sensitive, and addresses the care and delivery of services through informed decision making and advocacy
- Promote the provision of health services to deaf and hard of hearing individuals by simplifying the process of finding interpreters or other effective communication methods, and informing healthcare providers of their obligations
- Incorporate health literacy into all aspects of the State Innovation Model (SIM).
- Move beyond an exclusive reliance on grade-level readability requirements and promote plain language usage across the healthcare landscape

# INTRODUCTION

Rhode Island has made great progress in ensuring access to affordable health insurance for all residents. HealthSource RI provides Rhode Islanders with the tools, resources, and information that allow health insurance customers to choose what best works for them. HealthSource RI enrolled 34,888 individuals or 99.5% of its targeted enrollment for coverage in 2016.<sup>1</sup> A survey estimated that the state's uninsured rate had dropped to an estimated 5% at the end of open enrollment 2015, leaving just under 50,000 Rhode Islanders without insurance coverage.<sup>2</sup>

Although access to health insurance improves overall individual health, it does not ensure that individuals are receiving high-quality healthcare or that they understand which services to seek out. The Affordable Care Act (ACA) defines health literacy as the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions.<sup>3</sup> This literacy is essential to promote a healthy population. Despite this pressing need, a 2014 survey of 1,000 U.S. adults found that only 18% had “proficient” health literacy.<sup>4</sup> Even people with strong general literacy skills can face challenges when participating in the healthcare system. This lack of proficiency has severe consequences: millions of adults have difficulty with common health tasks, such as following directions on a prescription drug label or adhering to a childhood immunization schedule using a standard chart.<sup>5</sup> Consequently, low health literacy levels drive up costs and result in poorer outcomes across the healthcare system. Therefore, it is essential to promote targeted health literacy initiatives aimed at all communities and age levels.

In 2016, the Rhode Island Senate created the Special Legislative Commission to Study the Topic of Health Literacy in order to develop a strategic plan that would maximize opportunities for collaborations and programs that would assist Rhode Islanders' ability to navigate the healthcare system and improve health outcomes. Throughout the Commission meetings, members were informed about what Rhode Island has done on the topic thus far and discussed a number of priorities that aim to increase health literacy.

This report seeks to reach a better understanding of how to increase health literacy rates within our state, particularly among our most vulnerable populations. Generally, health literacy must be promoted throughout an individual's lifespan by a variety of stakeholders. Younger populations should begin to develop their health literacy skills as part of their general health curricula, while older populations must receive significant health literacy training to compensate for lower health literacy levels now seen in elderly populations. Adult education programs should strive to promote health literacy outside of the healthcare environment, as providers often do not have the time or resources to address low literacy levels during appointments. Still, providers should also seek to improve their understanding of health literacy and how best to serve patients at all literacy levels. The findings and recommendations within this report strive to improve health literacy across the state to better promote individual health and save money on a personal and statewide level.

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<sup>1</sup> “Open Enrollment 2016 Report,” *HealthSource RI* (2016).

<sup>2</sup> *Ibid*

<sup>3</sup> The Patient Protection and Affordable Care Act – Title V. Health Care Workforce (2010).

<sup>4</sup> “Survey Finds Americans' Health Literacy Lacking,” *AETNA* (2015).

<sup>5</sup> “America's Health Literacy: Why We Need Accessible Health Information,” *U.S. Department of Health and Human Services* (2008).

## FINDINGS

- **A lack of health literacy among the American population negatively impacts individual health and drives up healthcare costs—the problem is particularly acute for certain sub-demographics**

A 2014 survey of 1,000 U.S. adults found that only 18% had “proficient” health literacy.<sup>6</sup> Nearly the same number (17%) had below basic health literacy levels, while the rest rated as either basic or intermediate.<sup>7</sup> This lack of proficiency in health literacy has concerning implications for both patients and healthcare providers. The impact of low levels of literacy on health behavior is manifold: adult patients with low levels of literacy struggle to complete medical forms, understand prescription medication instructions, comprehend provider instructions, and provide accurate medical histories.<sup>8</sup> Additionally, literacy problems affect the success of health education programs and limit productive communication between patients and providers.<sup>9</sup> The tangible impact of these difficulties—on both patients and the healthcare system as a whole—is significant.

According to a study from the U.S. Department of Health and Human Services, individuals with below basic health literacy are more likely to report their health as poor and to lack health insurance than individuals with proficient health literacy.<sup>10</sup> Furthermore, low health literacy has been linked to higher rates of hospitalization and less frequent use of preventative services.<sup>11</sup> The economic impact of these behaviors on the healthcare system is immense: experts predict that the potential savings stemming from improved health literacy is between \$106 and \$238 billion.<sup>12</sup>

While insufficient health literacy is a problem across demographics, certain groups are more acutely impacted. For example, a 2003 study showed that while 28% of white adults had basic or below basic health literacy, that number increased to 65% of Hispanic adults.<sup>13</sup> While these specific proportions might have shifted over the past decade and a half, it is reasonable to assume that large disparities continue to exist. This gap is relevant in Rhode Island where 14% of the population is Hispanic<sup>14</sup> and approximately 7% of

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<sup>6</sup> “Survey Finds Americans’ Health Literacy Lacking.”

<sup>7</sup> *Ibid.*

<sup>8</sup> Manganello, Jennifer A. “Health Literacy and Adolescents: A Framework and Agenda for Future Research,” *Health Education Research* 23, No. 5 (2008): 840-847; <https://academic.oup.com/her/article/23/5/840/627799/Health-literacy-and-adolescents-a-framework-and>.

<sup>9</sup> *Ibid.*

<sup>10</sup> “Quick Guide to Health Literacy: Fact Sheet,” *U.S. Department of Health and Human Services*; <https://health.gov/communication/literacy/quickguide/factsbasic.htm>.

<sup>11</sup> *Ibid.*

<sup>12</sup> Vernon John. A., Antonio Trujillo, Sara Rosenbaum, Barbara DeBuono. “Low Health Literacy: Implications for National Healthcare Policy,” *George Washington University School of Public Health and Health Services* (2007); [http://publichealth.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10\\_4\\_07.pdf](http://publichealth.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf).

<sup>13</sup> “America’s Health Literacy: Why We Need Accessible Health Information.”

<sup>14</sup> “Demographic Profile of Hispanics in Rhode Island, 2014.” *Pew Research Center* (2014); <http://www.pewhispanic.org/states/state/ri/#note-2>.

Rhode Island students are English Language Learners.<sup>15</sup> Proficient health literacy is also significantly less common in elderly individuals, demonstrating a need for health literacy promotion both in youth to develop skills early on, and in adult populations to rectify an existing gap in health literacy.<sup>16</sup>

- **Improving health literacy at an early age has a direct impact on health literacy later in life and in specific health literacy curriculum is required to achieve proficiency**

Education directly promotes health literacy, even in the absence of a specific health literacy curricula, because it improves an individual's general literacy. Most health materials are written at a 10th grade level or above; thus, a high level of general literacy is required to successfully engage with the healthcare system, even apart from a knowledge of medical terminology and practices.<sup>17</sup> Health literacy corresponds directly with an individual's level of education. In a 2003 study, over three-quarters of adults with less than a high school degree had a basic or below basic level of health literacy, but this number decreased dramatically as education levels rose.<sup>18</sup>

However, simply attaining a higher level of education is not enough to produce proficient health literacy. In the same 2003 study, 44% of high school graduates and 12% of college graduates had only a basic or below basic level of health literacy.<sup>19</sup> This demonstrates that a general high school or college education is not enough to achieve proficient health literacy and indicates a need for specific, targeted programs to increase health literacy among younger populations.

The benefits to establishing health literacy at an early age are clear. A 2008 study on health literacy found that adolescence is an appropriate time to develop health literacy interventions.<sup>20</sup> Some argue that health literacy interventions and programs should focus on adults due to their more frequent contact with healthcare providers. There are many reasons, however, to promote health literacy at an earlier age. Specifically, while adolescents might not be directly engaging with healthcare providers at the time of their education, it is likely that they will do so in future years. Improving health literacy at an early age has a direct impact on health literacy later in life as adolescents are acquiring knowledge and setting behavior patterns they will carry with them as they transition into adulthood."<sup>21</sup>

Additionally, waiting to intervene until an individual makes contact with a healthcare provider can be unwise. Due to the rapid nature of many interactions in clinical settings, healthcare providers may not have the time or resources to independently identify a patient's level of health literacy and address this knowledge

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<sup>15</sup> "2015 Rhode Island KIDS COUNT Factbook," *Rhode Island KIDS COUNT* (2015); <http://www.ri.kidscount.org/Portals/0/Uploads/Documents/Factbook%202015/Education/Ind59-EnglishLanguageLearners-2015.pdf>.

<sup>16</sup> "Quick Guide to Health Literacy: Fact Sheet."

<sup>17</sup> "Pfizer Principles for Clear Health Communication," ed. Leonard G. Doak and Cecilia Conrath Doak (2004); <http://aspiruslibrary.org/literacy/PfizerPrinciples.pdf>.

<sup>18</sup> "America's Health Literacy: Why We Need Accessible Health Information."

<sup>19</sup> *Ibid.*

<sup>20</sup> Manganello, Jennifer A. "Health Literacy and Adolescents."

<sup>21</sup> *Ibid.*

gap. Additionally, many patients are often in denial about their own limitations and might try to hide their lack of understanding, further complicating a provider's ability to address a lack of health literacy. Building health literacy before a patient first makes contact with a provider can improve the patient-provider relationship from the very beginning of the interaction. Additionally, it is more feasible to incorporate specific health literacy topics into existing health curricula than it is to educate adults outside of a formal education setting.

Finally, adolescents are interested in understanding health information. A recent survey from the Nemours Foundation found that around 80% of respondents were "very" or "sort of" interested in learning more about health but 22% said health information was "very" or "sort of" hard to understand.<sup>22</sup> Dedicated health literacy education can bridge the gap between the students' desire to understand healthcare and their current lack of knowledge.

- **Healthcare providers must have a strong education in health literacy and its consequences to reduce its negative impact on health outcomes**

While efforts to bolster health literacy education among children and adolescents will have immense benefits in the long-term, health literacy remains low in many adult and elderly populations. Adult education initiatives can attempt to build literacy in older populations, but healthcare providers will continue to regularly interact with individuals with basic or below basic literacy. These providers must have a strong understanding of health literacy and how they can provide adequate health services to those with a low level of understanding. Various studies have indicated a need to raise awareness of the issues and to incorporate health literacy content into nursing and medical school programs.<sup>23</sup> Specifically, providers should know:

- Ways to determine or estimate a patient's health literacy levels;
- Effective health communication principles (such as plain-language and read-friendly print materials) for individuals with low health literacy; and
- Particular communication strategies, such as teach-back, that improve health outcomes in individuals with low health literacy<sup>24</sup>

While this is not an exhaustive list of what effective health literacy education for practitioners should cover, the combination of understanding what health literacy is and how to provide quality care in its absence ensures that providers can interact with their patients in a meaningful, useful way, regardless of the patient's health literacy and general literacy levels.

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<sup>22</sup> Manganello, Jennifer A. "Health Literacy and Adolescents."

<sup>23</sup> Egbert, Nicole and Kevin M. Nanna. "Health Literacy: Challenges and Strategies," *The Online Journal of Issues in Nursing* 14, No. 3 (30 September 2009); [http://www.nursingworld.org/MainMenuCategories/ANA\\_Marketplace/ANAPeriodicals/OJIN/TableofContents/Vol142009/No3Sept09/Health-Literacy-Challenges.aspx](http://www.nursingworld.org/MainMenuCategories/ANA_Marketplace/ANAPeriodicals/OJIN/TableofContents/Vol142009/No3Sept09/Health-Literacy-Challenges.aspx).

<sup>24</sup> Abrams, Mary Ann, Peri Klass, and Benard P. Dreyer. "Health Literacy and Children: Recommendations for Action," *Pediatrics* 124, No. 3 (November 2009); [http://pediatrics.aappublications.org/content/124/Supplement\\_3/S327](http://pediatrics.aappublications.org/content/124/Supplement_3/S327).

- **Cultural and linguistic competence are essential in engaging and educating patients about their healthcare**

Cultural and linguistic competence refers to the ability of healthcare providers and healthcare organizations to understand and respond effectively to cultural and linguistic needs of a patient in a healthcare encounter.<sup>25</sup> Culture and language influences the behaviors of individuals who are seeking healthcare and their attitudes toward speech, language, and hearing services and providers.<sup>26</sup> Culture may include a number of factors including but not limited to race, ethnicity, religion, national origin, gender, age, socioeconomic levels, disabilities, gender identity, and sexual orientation.<sup>27</sup> Linguistic diversity can accompany cultural diversity.<sup>28</sup>

According to the Pew Research Center, Americans are more racially and ethnically diverse than ever before, and the country's increasing diversity is expected to continue.<sup>29</sup> Furthermore, in 2010 about 19% of the U.S. population, or 56.7 million people, had a disability.<sup>30</sup> As the demographics within the U.S. change, the specific needs of certain communities or populations vary. Many of these changes affect service delivery, research, and professional or supervisory relationships.<sup>31</sup> Cultural competence is widely seen as a foundational pillar for reducing disparities through culturally sensitive and unbiased quality care.<sup>32</sup> The Office of Minority Health, in the U.S. Department of Health and Human Services, has established national standards for culturally and linguistically appropriate services in health and healthcare; however, a lack of clarity remains due to confusion about what cultural competence means and the different ways it is operationalized.<sup>33</sup> Future efforts must identify what cultural competence looks like in practice and how it can augment health literacy efforts for all individuals, regardless of their cultural or linguistic needs.

- **Patient engagement is necessary when discussing policy initiatives related to healthcare, health reform, and health literacy**

Engaging patients in policy discussions pertaining to healthcare, health reform, and health literacy provides keen insight for policy makers. Federal guidance from the Centers for Medicare and Medicaid Services

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<sup>25</sup> "Assuring Cultural Competence in Healthcare: Recommendations for National Standards and an Outcomes-Focused Research Agenda," *U.S. Department of Health and Human Services, Office of Minority Health* (2000); [https://minorityhealth.hhs.gov/Assets/pdf/checked/Assuring\\_Cultural\\_Competence\\_in\\_Health\\_Care-1999.pdf](https://minorityhealth.hhs.gov/Assets/pdf/checked/Assuring_Cultural_Competence_in_Health_Care-1999.pdf).

<sup>26</sup> "Issues in Ethics: Cultural and Linguistic Competence," *American Speech-Language-Hearing Association* (2013); <http://www.asha.org/Practice/ethics/Cultural-and-Linguistic-Competence/>.

<sup>27</sup> "Issues in Ethics: Cultural and Linguistic Competence."

<sup>28</sup> *Ibid.*

<sup>29</sup> "10 Demographic Trends that are Shaping the U.S. and the World," *Pew Research Center* (2016); <http://www.pewresearch.org/fact-tank/2016/03/31/10-demographic-trends-that-are-shaping-the-u-s-and-the-world/>.

<sup>30</sup> Newsroom Archive. *U.S. Census Bureau* (2012); <https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html>.

<sup>31</sup> "Issues in Ethics: Cultural and Linguistic Competence" *American Speech-Language-Hearing Association* (2013); <http://www.asha.org/Practice/ethics/Cultural-and-Linguistic-Competence/>.

<sup>32</sup> "Improving Cultural Competence to Reduce Health Disparities for Priority Populations," *Agency for Healthcare Research and Quality* (2014); <http://effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?productid=1934&pageaction=displayproduct>.

<sup>33</sup> *Ibid.*

calls upon states to ensure all voices are heard in the design, implementation, and oversight of health programming. The key to successful integrated care – especially for older adults and people with disabilities – is active and meaningful consumer engagement since consumers and their caregivers are at the heart of it all.<sup>34</sup> Many national organizations are looking at ways to engage patients in individual and policy discussions regarding their healthcare.<sup>35</sup> Meaningful feedback from consumers can help improve care delivery by rethinking organizational priorities, addressing current problems, and spearheading new initiatives.<sup>36</sup>

- **A significant portion of adults, both in Rhode Island and nationwide, have difficulty understanding their health insurance plans**

Studies have shown that healthcare-related information can be uniquely difficult to comprehend, due to its use of highly technical terminology and generally complex language.<sup>37</sup> Over 30% of English-speaking Americans struggle to understand their healthcare plans.<sup>38</sup> This problem is present nationwide, but is particularly acute in Rhode Island which had the lowest adult literacy rate in New England in 2009.<sup>39</sup> In 2005, the *Providence Journal* reported that nearly half of Rhode Island’s adult population reads at or below a sixth-grade level.<sup>40</sup> Additionally, a study conducted in the state found that 19% of those over the age of 16 “ha[ve] literacy skills insufficient to confidently perform the basic literacy and numerical tasks necessary to continue their education or achieve advancement in the workplace.”<sup>41</sup>

This problem is even more significant for uninsured Americans. In 2011, nearly 50 million Americans lacked health insurance. More than half of uninsured Americans are at either basic or below-basic health literacy, meaning they could only understand health information written at or below a fifth-grade level.<sup>42</sup> While Americans of all demographics struggle to understand their healthcare plans, it is even more difficult for uninsured Americans and minority groups. Five percent of Rhode Island is uninsured,<sup>43</sup> and over 15% of the population identifies as Hispanic or Latino.<sup>44</sup> Lawmakers must pay special attention to these

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<sup>34</sup> “Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups and Communities,” *Community Catalyst*; <http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement>

<sup>35</sup> “U.S. and Rhode Island Health Care System: A Brief Overview,” *HealthRight*; [http://static1.1.sqspcdn.com/static/f/1521910/26727350/1449768729320/HRIPB\\_Overview.pdf?token=C8A%2BhmrCcbuVI8eNyxgUT%2B%2FUY0Q%3D](http://static1.1.sqspcdn.com/static/f/1521910/26727350/1449768729320/HRIPB_Overview.pdf?token=C8A%2BhmrCcbuVI8eNyxgUT%2B%2FUY0Q%3D).

<sup>36</sup> “Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups and Communities.”

<sup>37</sup> “Regulation 5 Standard for Readability of Health Insurance Forms,” *Office of the Health Insurance Commissioner* (2009); <http://www.ohic.ri.gov/documents/Regulation-5-Readability-of-Health-Forms.pdf>.

<sup>38</sup> *Ibid.*

<sup>39</sup> *Ibid.*

<sup>40</sup> *Ibid.*

<sup>41</sup> “Five-Year State Plan for the Fiscal Years 2008 to 2012,” *Rhode Island Office of Library and Information Services*; <http://www.olis.ri.gov/aboutus/5yplan/2008/5yrplan2008-12.pdf>.

<sup>42</sup> Donnelly, Nicole, Penny Lane, Joan Winchester, and Christina Powell. “An Introduction to Health Literacy and Enrollment,” *Enroll America*. December 2011. <https://www.enrollamerica.org/an-introduction-to-health-literacy-and-enrollment/>.

<sup>43</sup> Stabile, Lori. “CDC: R.I. Uninsured Rate Falls to 4.5%,” *Providence Business News* (18 May 2016); <http://pbn.com/CDC-RI-uninsured-rate-falls-to-45,114328>.

<sup>44</sup> “QuickFacts: Rhode Island.” *United States Census Bureau* (last modified 1 July 2015); <https://www.census.gov>.

populations and communities when considering how to make health insurance more accessible to Rhode Island as a whole.

Rhode Island has taken important steps to address this problem. Most significantly, a 2010 regulation mandates that all health insurance plans must have a readability standard no higher than the eighth-grade level. This is in line with recommendations that the readability of health-related legal documents should be between fourth and eighth grade levels.<sup>45</sup> Still, given the large percentage of the Rhode Island population that cannot read above a sixth-grade level, further consideration of the issue is needed. Even with the current readability standards, a significant portion of the population still struggles to understand their plans.

- **A failure to understand health insurance plans negatively impacts an individual's health and their decision making abilities**

The consequences stemming from this lack of comprehension are significant. A person's inability to accurately comprehend their health insurance documents greatly minimizes their understanding of the healthcare system as a whole. More than half of Americans do not understand basic health insurance terms like premium, deductible, and copay.<sup>46</sup> Over 20% of all Americans do not know that health insurance premiums must be paid every month, and that number jumps to 36% of all uninsured adults.<sup>47</sup> Furthermore, in an October 2014 Kaiser Family Foundation survey, 37% of marketplace enrollees did not know what their deductible was, and 47% of those receiving subsidies did not know the amount of federal assistance they were getting.<sup>48</sup> While there are a variety of causes for these knowledge gaps, a major factor is a person's inability to glean this information from their own health insurance plans.

An inability to understand insurance plans has been linked to poor overall health, a failure to use preventative care, and higher healthcare costs.<sup>49</sup> Generally, the lack of health insurance literacy changes how effectively people use healthcare services and their insurance.<sup>50</sup> For example, those who do not know what a provider network is, or how cost-sharing differs between in-network and out-of-network institutions, might unwittingly choose a more expensive out-of-network physician or hospital.<sup>51</sup> Similarly, only 41% of the general public and 29% of uninsured individuals know that surgeons and anesthesiologists might not be in their plan's network, even when having surgery at an in-network hospital.<sup>52</sup> A lack of health insurance literacy can also affect how people shop for their health insurance and whether they make the best decision for their needs.<sup>53</sup> Generally, not fully comprehending health insurance plans affects the services that

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gov/quickfacts/table/PST045215/44.

<sup>45</sup> "Regulation 5 Standard for Readability of Health Insurance Forms."

<sup>46</sup> Parragh, Zsofia A., and Deanna Okrent. "Health Literacy and Health Insurance Literacy: Do Consumers Know What They Are Buying?," *Alliance for Health Reform* (6 January 2015); [http://www.allhealth.org/wp-content/uploads/2017/01/Health-Literacy-Toolkit\\_163.pdf](http://www.allhealth.org/wp-content/uploads/2017/01/Health-Literacy-Toolkit_163.pdf)

<sup>47</sup> *Ibid.*

<sup>48</sup> *Ibid.*

<sup>49</sup> "Regulation 5 Standard for Readability of Health Insurance Forms."

<sup>50</sup> Parragh, Zsofia A., and Deanna Okrent. "Health Literacy and Health Insurance Literacy."

<sup>51</sup> *Ibid.*

<sup>52</sup> *Ibid.*

<sup>53</sup> *Ibid.*

individuals seek out, the price they pay for these services, and their fundamental capacity to take control of their own health.

- **Rhode Island’s readability requirement does not solve the issue of health insurance illiteracy**

Rhode Island has taken good initiative to address the issue of health insurance language and established itself as a national leader. A 2009 *Harvard Business Review* article identified Rhode Island, and its 2010 readability regulation, as a model for other states wishing to simplify health insurance plans offered to their residents.<sup>54</sup> Still, as mentioned previously, many within the state cannot read at an eighth-grade level and still face enormous difficulties when trying to understand their health insurance. The solution, however, is not as easy as lowering the grade-level requirement. First of all, as acknowledged in the 2010 regulation, certain terminology used in policies is difficult or impossible to restate in simplified language.<sup>55</sup> Even when restating such terminology is possible, it puts a large burden on health insurance providers to reword their materials. Thus, in the initial regulation, Rhode Island chose to set the requirement at an eighth-grade level to balance “the high level of adult illiteracy in Rhode Island and the burden of implementing a readability standard.”<sup>56</sup>

Furthermore, research has shown that grade level requirements have the potential to do harm when attempting to promote readability.<sup>57</sup> Editing text to score at a lower grade level involves shortening words and sentences, which often reduces the clarity of the text.<sup>58</sup> Editors might remove familiar words just because they are long, ultimately producing text that is more confusing or choppy than the original.<sup>59</sup> Thus, Rhode Island must move beyond a dependence on grade-level requirements to ensure that all residents understand their insurance plans.

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<sup>54</sup> Ashkenas, Ron. “Let’s Simplify the Language of Healthcare,” *Harvard Business Review*. 2 October 2009. <https://hbr.org/2009/10/lets-simplify-the-language-of>

<sup>55</sup> “Regulation 5 Standard for Readability of Health Insurance Forms.”

<sup>56</sup> *Ibid.*

<sup>57</sup> *Ibid.*

<sup>58</sup> “Toolkit for Making Written Material Clear and Effective,” *U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services* (last modified 16 March 2012); <https://www.cms.gov/outreach-and-education/outreach/writtenmaterialstoolkit/downloads/toolkitpart07.pdf>.

<sup>59</sup> *Ibid.*

# RECOMMENDATIONS

- **Develop a statewide toolkit aimed at assisting public and private schools, community groups, and healthcare providers**

There is a wealth of publicly-available health literacy material, aimed at a variety of populations. A state-wide toolkit would be useful in identifying and organizing the most relevant health literacy materials for specific purposes and audiences. The toolkit could provide a list of standards that schools, community groups, and healthcare providers should strive for, as well as recommendations for how to achieve these standards. While various toolkits for a national audience are already available online, a Rhode Island toolkit could focus on the healthcare landscape within the state and the specific needs that arise based on local demographics and existing programs.

- **Incorporate health literacy into elementary and secondary education health standards developed through a collaboration between community health organizations, healthcare providers, health insurance providers, the RI Department of Health (RIDOH), the RI Department of Education (RIDE), and other stakeholders**

Building health literacy at a young age is both possible and desirable. By incorporating health literacy into health standards and curricula for students of all ages, students can progressively improve their health literacy skills. This was a better approach as opposed to learning a significant amount of information when they first enter into a healthcare setting. In order to build health literacy, an explicit focus on literacy within health standards and curricula is necessary. Teaching health information without an emphasis on literacy is not enough, as many students graduate from secondary school still having below-average health literacy. Thus, various stakeholders must work together to set appropriate health literacy standards for different ages and develop a plan for how to meet these standards. Emphasizing collaboration during this process ensures that the curricula will be comprehensive and have real world value.

- **Integrate health literacy training into the curriculum for medical students and encourage licensed professionals to utilize various training resources available at a state and national level**

Many definitions of health literacy, such as the “ability to obtain, process, and understand basic health information and services to make appropriate health decisions,” place the full burden of health literacy on the patient. Healthcare providers, however, play a crucial role in facilitating literacy based on how they interact with their patients and how they present information to them. Health literacy curricula for students of medicine, nursing, and allied health professions should emphasize how to effectively interact with patients with low health literacy levels, as well as how to identify patients’ literacy levels. Studies have shown that health literacy education efforts should be longitudinal or integrated—rather than one-time

lectures—in order to make an impact.<sup>60</sup>

For health professionals who have already received their licenses, health literacy training can be integrated into continuing education programs or encouraged as an additional certification. Many universities offer certification courses in health literacy or communication. Additionally, there are a variety of resources available online, such as a six-part course from the Center for Disease Control, along with trainings and certifications from a wide array of organizations across the country. Finally, several states have established local initiatives. Many have created health literacy boards or coalitions to promote health literacy education at all levels, including for health professionals. In Rhode Island, community health workers are frontline public health professionals who often have ties to the community that they serve. Encouraging community health workers to receive certification and integrating these workers into state health initiatives can further the dialogue on health literacy and help educate medical professionals about the topic.

- **Create specific programs and strategies to educate our most vulnerable populations, such as the elderly, individuals with disabilities, and individuals suffering from mental illness; this includes incorporating health literacy into adult education programs, homeless service supports, and community organizations**

Many communities outside of the education system also need health literacy education. In fact, inadequate health literacy is more common in older populations; thus, education cannot solely be focused on young students. Rhode Island should begin educating these vulnerable populations before they make contact with healthcare providers, along with training providers on how to best serve individuals with low health literacy levels. When educating vulnerable populations, cultural competence must be a priority. Educators and healthcare providers should understand the specific health challenges that individuals in these communities face.

Incorporating health literacy into programs not exclusively focused on health helps build literacy throughout an individual's lifespan, instead of only when they need to make contact with a healthcare provider. Providers often do not have sufficient time or resources to adequately serve individuals with low health literacy levels. By incorporating literacy into programs outside of the healthcare community, individuals can enter interactions with their provider at a higher level of understanding. Also, by encouraging adult education programs in RI, which serve thousands of students annually in English language acquisition and GED classes, to incorporate health literacy into their programs, we can improve health literacy among adult populations. This would have a wide range of benefits, including achieving better health outcomes and spending less money on healthcare.

- **Ensure consumer advocates are included in health reform efforts by establishing a Consumer Advisory Board that is person-centered, culturally and linguistically competent, disability-sensitive, and addresses the care and delivery of services through informed decision making and advocacy**

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<sup>60</sup> Coleman, C.A., S. Peterson-Perry, and T. Bumsted. "Long-Term Effects of a Health Literacy Curriculum for Medical Students," *Family Medicine* 48, No. 1 (January 2016); <https://www.ncbi.nlm.nih.gov/pubmed/26950666>.

In Rhode Island, there are several bodies aimed at shaping the future of healthcare within the state. Many include consumer advocate representation, but most are not consumer focused and led. Although there are several organizations and individuals engaged in ensuring consumers are heard, it can become difficult to participate when there are several bodies meetings at different times. Creating a Consumer Advisory Board would reserve space for strong public and consumer input in all healthcare reforms, including those related to health literacy.

- **Promote the provision of health services to deaf and hard of hearing individuals by simplifying the process of finding interpreters or other effective communication methods, and informing healthcare providers of their obligations**

Under the Americans with Disabilities Act (ADA), healthcare providers are required to provide deaf and hard of hearing individuals with full and equal access to their services. This often involves contracting an interpreter or providing another effective method of delivering information to the individual. Under the ADA, healthcare providers are also responsible for covering the full cost of these services. Despite this obligation, many healthcare providers do not fulfill these requirements sufficiently or at all, forcing patients to seek out other providers or using inferior interpreting methods, such as having a family member assist them. This directly impacts health literacy, because the lack of a qualified interpreter prevents individuals from fully understanding their healthcare provider and the actions they might need to take.

First and foremost, providers should understand their federal obligation to provide services to and accommodate individuals with disabilities. Rhode Island should also facilitate the process of finding interpreters. Massachusetts allows organizations to complete an interpreter request form online. Rhode Island should seek to establish a similar model in order to remove some of the burden of finding an interpreter. Additionally, providers should be made aware of the Disability Access Credit, which covers up to 50% of eligible access expenditures that are between \$250 and \$10,250 for a taxable year. This tax credit can ease the financial burden that eligible access expenditures place on businesses, making them more likely to comply with their federal obligations.

- **Incorporate health literacy into all aspects of the State Innovation Model (SIM)**

In 2015, Rhode Island was one of 24 states to receive a State Innovation Model (SIM) Test Grant from the federal Centers for Medicare and Medicaid Services (CMS). The state received \$20 million with the expectation that the funds would be used to transform the way healthcare is delivered and paid for.<sup>61</sup> SIM funds are supporting activities in three categories: improving primary care and behavioral health infrastructure; engaging patients in positive health behaviors and self-advocacy; and expanding the ability of providers and policy makers to use and share data. Incorporating health literacy into all aspects of SIM would strongly support the engagement of patients in positive health behaviors and strengthen their self-advocacy.

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<sup>61</sup> “State Innovation Model (SIM).” RI Executive Office of Health and Human Services (EOHHS); <http://www.eohhs.ri.gov/ReferenceCenter/StateInnovationModelSIM.aspx>.

- **Move beyond an exclusive reliance on grade-level readability requirements and promote plain language usage across the healthcare landscape**

Relying exclusively on grade-level readability requirements can often further complicate texts by shortening words and sentences, instead of focusing on comprehensibility. Readability formulas are just one of many resources available to simplify texts. The U.S. Department of Health and Human Services provides a “Toolkit for Making Written Material Clear and Effective.” The Toolkit offers insight into organization, writing styles, content, design, and more, all with the intention of making written materials about health easier to understand by readers at all levels. Health insurance providers should familiarize themselves with various strategies, instead of only shortening sentences and substituting short words for long ones in order to pass a readability formula. As the Toolkit explains, “use the formulas as a screen for complexity of words and sentences, but use the other guidelines ... to help simplify the material.”<sup>62</sup> Finally, healthcare providers should strive to use plain and common language in all health materials, not just health insurance policies. By focusing on using clear and cohesive language in all health materials, readers of any proficiency can gain knowledge and improve their health literacy.

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<sup>62</sup> “Toolkit for Making Written Material Clear and Effective.”

# **Addendum**

**2016 -- S 2594 SUBSTITUTE A AS AMENDED**

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LC005075/SUB A  
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**STATE OF RHODE ISLAND**

**IN GENERAL ASSEMBLY**

**JANUARY SESSION, A.D. 2016**

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**SENATE RESOLUTION**

**CREATING A SPECIAL LEGISLATIVE COMMISSION TO STUDY THE TOPIC OF  
HEALTH LITERACY**

Introduced By: Senators DiPalma, Miller, Goldin, Gallo, and Satchell

Date Introduced: February 25, 2016

Referred To: Senate Health & Human Services

1           WHEREAS, Health literacy is the degree to which individuals have the capacity to  
2 obtain, process, and understand basic health information and services needed to make appropriate  
3 health decisions; and

4           WHEREAS, Health literacy affects people's ability to:

- 5           • Navigate the health care system, including filling out complex forms and locating  
6 providers and services;
- 7           • Share personal information, such as health history, with providers; and
- 8           • Engage in self-care and chronic-disease management; and

9           WHEREAS, According to research studies, persons with limited health literacy skills are  
10 more likely to skip important preventive measures and are more likely to have chronic conditions  
11 and are less able to manage these conditions effectively; and

12           WHEREAS, Persons with limited health literacy skills are also significantly more likely  
13 to report their health as poor and will more often make greater use of services designed to treat  
14 complications of disease as opposed to using services designed to prevent complications; and

15           WHEREAS, In addition, persons with limited health literacy skills have demonstrated a  
16 higher rate of hospitalization and use of emergency services, resulting in higher health care costs;  
17 now, therefore be it

18           RESOLVED, That a special legislative commission be and the same is hereby created  
19 consisting of ~~fifteen (15)~~ seventeen (17) members: three (3) of whom shall be members of the

1 Rhode Island Senate, not more than two (2) from the same political party, to be appointed by the  
2 President of the Senate; three (3) of whom shall be consumer advocates, to be appointed by the  
3 President of the Senate; one of whom shall be a representative of higher education, to be  
4 appointed by the President of the Senate; one of whom shall be the Secretary of the Executive  
5 Office of Health and Human Services, or designee; one of whom shall be the Director of the  
6 Rhode Island Community Action Association, or designee; one of whom shall be the Director of  
7 the Rhode Island Department of Health, or designee; one of whom shall be the Director of the  
8 Rhode Island Office of the Health Insurance Commissioner, or designee; one of whom shall be  
9 the Director of the Rhode Island Division of Elderly Affairs, or designee; one of whom shall be  
10 the Commissioner of the Rhode Island Department of Education, or designee; one of whom shall  
11 be the President of the Hospital Association of Rhode Island, or designee; ~~and~~ one of whom shall  
12 be the Executive Director of Health Source Rhode Island, or designee; and two (2) culturally and  
13 linguistically competent professionals to be appointed by the senate president.

14 In lieu of any appointment of a member of the legislature to a permanent advisory  
15 commission, a legislative study commission, or any commission created by a General Assembly  
16 resolution, the appointing authority may appoint a member of the general public to serve in lieu  
17 of a legislator, provided that the Majority Leader or the Minority Leader of the political party  
18 which is entitled to the appointment, consents to the member of the general public.

19 The purpose of said commission shall be to make a comprehensive study on the topic of  
20 health literacy in order to develop a strategic plan that would maximize opportunities for  
21 collaboration and programs that would assist Rhode Islanders' ability to navigate the health care  
22 system and improve health outcomes.

23 Forthwith upon passage of this resolution, the members of the commission shall meet at  
24 the call of the President of the Senate and organize and shall select a chairperson.

25 Vacancies in said commission shall be filled in like manner as the original appointment.

26 The membership of said commission shall receive no compensation for their services.

27 All departments and agencies of the state shall furnish such advice and information,  
28 documentary and otherwise, to said commission and its agents as is deemed necessary or  
29 desirable by the commission to facilitate the purposes of this resolution.

30 The Joint Committee on Legislative Services is hereby authorized and directed to provide  
31 suitable quarters for said commission; and be it further

1           RESOLVED, That the commission shall report its findings and recommendations to the  
2 Governor and the President of the Senate no later than February 1, 2017, and said commission  
3 shall expire on July 1, 2017.

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LC005075/SUB A  
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EXPLANATION  
BY THE LEGISLATIVE COUNCIL  
OF  
SENATE RESOLUTION  
CREATING A SPECIAL LEGISLATIVE COMMISSION TO STUDY THE TOPIC OF  
HEALTH LITERACY

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1           This resolution would create a ~~fifteen (15)~~ seventeen (17) member special legislative  
2 study commission whose purpose it would be to study the topic of health literacy, and who would  
3 report back to the Governor and the President of the Senate no later than February 1, 2017, and  
4 whose life would expire on July 1, 2017.

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LC005075/SUB A  
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# SPECIAL LEGISLATIVE COMMISSION TO STUDY THE TOPIC OF HEALTH LITERACY

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## NOTICE OF MEETING

**DATE:** Tuesday, October 25, 2016

**TIME:** 3:30 P.M. – 5:00 P.M.

**PLACE:** Room 313 – State House

- I. Senator Lou DiPalma, Commission Chair  
*Welcome and Introductions*
- II. Michael Barton Laws, Brown University, Assistant Professor of Health Services, Policy and Practice  
*Overview of Health Literacy Issues*
- III. Roundtable Discussion  
*Commission's priorities*
- IV. Next meeting date(s)

Please contact Marea B. Tumber at 528-1718 with any questions or concerns.

**POSTED: TUESDAY, OCTOBER 18, 2016, 3:05 P.M**

# Special Commission to Study the Topic of Health Literacy

First Meeting Summary (not intended as official minutes) – October 25, 2016

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**Chairman Louis P. DiPalma** welcomed all Commission members and guests and asked that the members introduce themselves. The chairman read the legislation to articulate the purpose of the Commission. The chairman welcomed Dr. Michael Barton Laws, the Assistant Professor of Health Services, Policy and Practice at Brown University to present on the Overview of Health Literacy Issues.

**Dr. Michael Barton Laws, Brown University**, presented on Health Literacy Issues. Dr. Laws defined health literacy as it is stated in the resolution. He explained the First Order Model of Health Literacy and the two most common forms of measures of health literacy: Test of Functional Health Literacy in Adults (TOFHLA) and Rapid Estimate of Adult Literacy in Medicine (REALM). The measures consisted of fill in the blanks and pronouncing words from small to large. Dr. Laws explained what these results mean in relation to high and low scoring, what the scores correlate with, and how they affected health outcomes. Dr. Laws summarized the issues, explaining how people with a limited education and basic skills, and/or less cognitive capacity, may have more difficulty understanding information, instructions, and navigating the healthcare system.

**Chairman DiPalma** commented that there was a lot of room for growth for the average health literacy scores of adults by race/ethnicity. One of the desired outcomes of the Affordable Care Act (ACA) was health insurance for all which puts cognitive demands on people to make many healthcare decisions.

**Dr. Laws** explained that there are navigation services available through HealthSource RI and commented that people do not use the emergency department (ED) any less, even if they have health insurance.

**Mary Parella, RIDE**, asked Dr. Laws if certain cultural backgrounds are associated with ED use.

**Dr. Laws** explained that the individuals who consistently use the ED are usually people with substance abuse and/or mental health disorders.

**Meghan Connelly, RI Division of Elderly Affairs (RIDEA)**, asked if Dr. Laws had done any analyses of age groups.

**Dr. Laws** answered that there was information regarding age group analysis in the report and that health literacy falls off in the elderly group.

**Chairman DiPalma** asked how often this analysis has been done and if we are moving in the right direction.

**Dr. Laws** responded that interventions need to be evaluated; however, an operational study cannot answer the question about causality.

**Meghan Connelly** inquired if a health insurance customer would be considered health illiterate if they understood information but did not have computer skills or accessibility of all information.

**Dr. Laws** answered that he did not believe that access and technical skills are considered part of the operationalization of health literacy.

**Chairman DiPalma** read the purpose of the Commission before he moved to the roundtable discussion.

The roundtable discussion consisted of the Commission members stating their priorities:

***Stephen Brunero, RIPIN***

- Establish a Consumer Advisory Body that is person-centered, culturally and linguistically appropriate, disability-sensitive, and addresses the care and delivery of services through informed decision making and advocacy
- Current consumer bodies should be better supported by providing adequate funding and representative recruitment from all consumers having difficulty navigating systems of care and addressing logistical challenges. Training and accessibility are important, and tools must be set to monitor and evaluate the success of the programs
- Establish a loop for reliable feedback so that consumers, caregivers, and health delivery systems are all speaking to each other
- Improve integration of peer navigators

***Walter Burke, Bristol Parks & Recreation***

- Provide health literacy curriculum in schools and for healthcare workers. Communication with academia needs to change and include reflective listening. Doctors should understand cultures, communities, and be person-focused
- RIDOH should engage differently in their health outreach, and find unique, integrated people in the community who can educate others and share information

***Amanda Barney, HARI***

- Purchasing of health plans must become easier. Consumers need more information and a better understanding of the financial liabilities
- There must be greater education around advanced directives and living wills, as well as medication management

***Mary Parella, RIDE***

- Integrate adult programs with health literacy
- Community schools can serve as a model; peer navigators and people can help with

- healthcare access
- Coordinate care
- Incorporate adolescent healthcare into school settings

***Meghan Connelly, RIDEA***

- Medical providers, RIDOH, and insurers must address cognitive and hearing challenges faced by older populations.
- Address the challenges that older adults face with technology
- Include caregivers in health information

***Ruth Feder, Mental Health Association of Rhode Island***

- Behavioral health (priority)
- Choice of plans – mental health side:
  - Individuals do not know how to access the system; systems are complicated, especially for individuals with mental illness. Solution: Perhaps addressing issue before illness

***John Garrett, OHIC***

- Produce common definitions across the board such as benefits, charges, reasonable and customary, etc.
- With the increase of consumer driven plans there is the need for consumers to understand their financial responsibilities to access care. Questions that people should be able to answer include: how does my deductible apply, what is my coinsurance and out of pocket maximum, what does my explanation of benefits mean, how do I access the provider I want in a restricted network and what are the consequences, etc.
- Incorporate healthcare literacy into educational curricula with education requirements for providers related to health literacy
- Create standard practices that incorporate healthcare literacy into all disseminated information and services delivered
- Make healthcare literacy a part of employer health and wellness programs

***Gail Mance-Rios, Office of Postsecondary Commissioner***

- Higher education perspective:
  - Community health worker certificate – will provide training to individuals in the community
  - Nursing education center – information obtained in this Commission could help with best practices
  - Workforce development

***Meg Ivatts, Health Source RI***

- Assistance with purchasing of insurance is important; support people and make the decision simpler for consumers
- Teach people how to use their plans more effectively and efficiently
- Assist individuals through the call center, in person channels, and website

*Angela Lemire, RIDOH*

- Use the RIDOH strategic plan to improve health literacy
- Use the 10 health equity zones to help identify champions within communities
- Integrate health literacy into all aspects of the State Innovation Model (SIM)
- Focus on patient empowerment
- Increase data capacity and expertise
- Align health literacy work with all aspects of the SIM project looking at areas of prevention

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# **SPECIAL LEGISLATIVE COMMISSION TO STUDY THE TOPIC OF HEALTH LITERACY**

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## **NOTICE OF MEETING**

**DATE:** Tuesday, November 15, 2016

**TIME:** 3:30 – 5:00 P.M.

**PLACE:** Room 313 – State House

**Agenda:**

- I. Opening remarks – Senator Lou DiPalma, Commission Chair
- II. Health Literacy and Patient Engagement
  - Marti Rosenberg, Project Director, Rhode Island’s State Innovation Model Test Grant (SIM)
  - Courtney Smith, Assistant Director, United Way 2-1-1 in Rhode Island & The Point
- III. Roundtable Discussion
- IV. Next meeting date(s)
- V. Public comment

Please contact Marea Tumber at [mtumber@rilegislature.gov](mailto:mtumber@rilegislature.gov) with any questions.

**POSTED: THURSDAY, NOVEMBER 10, 2016, 12:02 PM**

# Special Commission to Study the Topic of Health Literacy

Second Meeting Summary (not intended as official minutes) – November 15, 2016

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**Chairman Louis P. DiPalma** welcomed all Commission members and guests and explained that the hearing initially had two presenters; however, Courtney Smith from the United Way will be presenting at a future date. Chairman DiPalma introduced Marti Rosenberg, Project Director, Rhode Island's State Innovation Model (SIM) Test Grant.

**Marti Rosenberg, Project Director, RI State Innovation Model (SIM) Test Grant**, presented on SIM. She explained that SIM was a \$20 Million grant from the Centers for Medicare and Medicaid Services (CMS) to transform the way care is delivered and paid for and to enhance the way individuals are engaged in their health. SIM is an interagency team that creates the strategy for the project that includes a steering committee with a variety of community members as the decision making body. Their goal is healthier people, better care, and smarter spending.

**Mary Parella, RIDE**, inquired about linking payments to outcomes and wanted to know what is being done to prevent patients from being dropped by physician groups for noncompliance.

**Marti Rosenberg** responded that it bears a close look and when Medicaid and CHIP Reauthorization Act (MACRA) comes into being, it will change how Medicare is paying for things. She also explained that in 2020-2022 there will be penalties for doctors who are not moving towards value-based care. There is an awareness that there is not a place that regulates accountable entities right now. They will be a part of the team that addresses it.

**Mary Parella** asked about medical homes for kids and where school-based clinics or school-based medical homes come into that discussion.

**Marti Rosenberg** responded that the Primary Care Medical Home (PCMH) kid's model is based on the PCMH adult model. They would like RIDE on the steering committee and on the interagency team. They would also like to make that connection between RIDE and SIM, it is their next top priority for new agencies.

**Ruth Feder, Mental Health Association of RI**, asked what she meant by "Community Health Teams".

**Marti Rosenberg** explained that they are folks who are certified and may be housed at a primary care entity to be utilized when needed (i.e. a diabetes team, a lactation counselor, etc.). The entity makes up a team based on the needs that they have, and is a link between the doctor's office and the community. SIM is hoping to prove their worth and sustain them.

**Dennis Roy, President, East Bay Community Action**, remarked that there is a real possibility that Medicaid expansion may be eliminated in the not so distant future.

**Marti Rosenberg** stated that it is a very deep concern and could be a crisis. RI needs to be thinking about it as a state and what our priorities are. The state will need to look to see if it needs to go back up to 185% of poverty, at least for parents.

**Maria Barros, President, Home Health & Hospice Care of Nursing Placement**, expressed her concern as a home health nurse about Medicare recipients who receive in-home care especially those with chronic diseases. The concern is that once they are no longer homebound they will not receive these services that work.

**Marti Rosenberg** stated that this issue has not come before them but now that it has been brought up, they can put it in their discussions with CMS.

**Walter Burke, Bristol Parks and Recreation**, detailed the prescriptive parks program that is appearing all over the country; they lessen the cost of hospital and emergency room visits. Walter asked Marty if she had looked into this program.

**Marty Rosenberg** responded favorably regarding the prescriptive parks program and told Walter that in the next couple of weeks they are going to have an RFP out for patient engagement that she will send him.

**Stephen Brunero, RIPIN**, referred to data sharing and data collection with the SIM investments. Specifically, data sharing agreements or business associate agreements that exist currently so that effectiveness can be measured and demonstrated for any of these initiatives, including the RFP coming out.

**Marti Rosenberg** responded that Health Facts RI is going to be a way to help show these changes. URI will be doing their evaluation and they will be going deep into the child psychiatry program, patient engagement, provider coaching etc. She explained how they file quarterly reports on those achievements to the steering committee.

**Chairman DiPalma** directed Marti to look at her chart on what determines population health and asked how the percentages were determined.

**James Rajotte** answered that they are all slightly adaptive, but the range is always 10-20% healthcare, genetics consistent at 20-30%, and 80-90% outside of the healthcare system.

**Chairman DiPalma** asked to refer to the SIM Investments chart regarding facts, data, and evidence. The Chairman asked if the outcomes have been identified to know if this was a good investment and why.

**James Rajotte** responded that in order to get approval from CMS to move from the planning stage to the true implementation and test within the grant, they had to submit an

operational plan. They had to select a variety of measures used to see the effectiveness of the SIM implementation overall, the individual components, and population health outcomes.

***Marti Rosenberg*** added that she can get the Chairman the link to the operational plan to see all the metrics. The measure alignment that James spoke about is another part of the project and falls in the regulatory levers portion of SIM. They have come up with a core set and a menu set. Office of the Health Insurance Commissioner (OHIC) is calling on its carriers to use those metrics with the providers so they can all look at the same metrics.

***Chairman DiPalma*** thanked Marti and reminded everyone that Marti will provide operational metrics, as well as a list of investments and quarterly reports, that can be put on the Commission web site along with the Commission's priorities discussed at the last hearing.

The chairman discussed and scheduled the next hearing of the Commission.

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# **SPECIAL LEGISLATIVE COMMISSION TO STUDY THE TOPIC OF HEALTH LITERACY**

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## **NOTICE OF MEETING**

**DATE:** Tuesday, January 10, 2017

**TIME:** 2:30 – 4:00 P.M.

**PLACE:** Room 313 – State House

### **Agenda:**

- I. Opening remarks – Senator Lou DiPalma, Commission Chair
- II. Health Literacy and Patient Engagement
  - Jay Burdick, Program Outreach Coordinator, United Way  
2-1-1 in Rhode Island
- III. Roundtable Discussion
- IV. Next meeting date(s)
- V. Public comment

Please contact Katuska Perez at [kperez@rilegislature.gov](mailto:kperez@rilegislature.gov) with any questions.

**POSTED: THURSDAY, JANUARY 5, 2017, 2:37 PM**

# Special Commission to Study the Topic of Health Literacy

Third Meeting Summary (not intended as official minutes) – January 10, 2017

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**Chairman Louis P. DiPalma** welcomed Commission members and guests and mentioned the last meeting in November with Marti Rosenberg presenting on (SIM) System Innovation Model. He elaborated on three categories supported by the SIM fund:

1. Practice and workforce transformation
2. Patient empowerment
3. Data capacity and expertise expansion

Marti Rosenberg invited all present to join the mailing list to receive notices and updates at the last hearing. The Chairman explained that the hearing had two key items on the agenda: Health Literacy & Patient Engagement and the Commission’s priorities outlined in the hearing on October 25, 2016. The Chairman welcomed Jay Burdick, Program Outreach Coordinator for the United Way 2-1-1 in Rhode Island, to present.

**Jay Burdick, Program Outreach Coordinator, United Way 2-1-1 in Rhode Island**, presented on Health Literacy and Patient Engagement. The United Way is part of a system across the country that is active 24-7, is multilingual, and has access to a translator line with 153 languages and 4,000 services listed in the database of Rhode Island that they work off of. To reach United Way in Rhode Island, you can dial 2-1-1 or utilize online chat or text options. Additionally, Jay explained that walk-ins are welcome in Olneyville for any questions or appointments. Jay explained that most phone conversations are about basic needs – food, shelter, and housing – but can vary from services for non-profits, governmental, or the faith-based world. In 2015, there were 203,500 calls in Rhode Island with 79,185 for health-related issues. There is a basic tenet of self-empowerment for the client—giving them the most information possible to handle the problem themselves. The 2-1-1 system in Rhode Island also has a number of contracts that service residents. The largest of these contracts is “The Point,” or a point of contact that seniors, adults on disability, or caregivers can go to get information on available programs or services. One of United Way’s objectives is improving positive health outcomes. The United Way works with outreach on HealthSource RI assisting people with their health insurance needs. They also have eight staff members on the State Health Insurance Program (SHIP) to help residents get into Medicare health-related programs. The United Way has a new van that was donated to them that they use to provide services for the community, from blood pressure to addiction services.

**Ruth Feder, Mental Health Association**, asked Mr. Burdick about the backgrounds of the employees who either answer phones or assist the clients that come in.

**Jay Burdick** stated that 2-1-1 has both college graduates with social service backgrounds and community-based individuals who are trained to find services using their database. Jay expressed that what they find most important at 2-1-1 is the personalities of their workers. Regarding the phone, from 12PM to 6PM, the 2-1-1 service answers the phone, unless there is a state of emergency when all employees work full time to assist with disaster work.

**Mary Parella, RIDE**, asked Mr. Burdick how up-to-date their database information is and how they are updated about a shelter's capacity.

**Jay Burdick** explained that because the database is so extensive, they ask the different organizations to go onto the United Way website to update their information. Regarding the shelters, it is a multi-part system. First, someone with a domestic violence issue will come to The United Way. They will then send their information to the local domestic violence organizations. For single individuals, they give them a list and background of shelters available. For families, they first perform an intake because they may be able to divert them based on their circumstances. They then go into the housing management information system and create a list of families "ranked" by necessity. When rooms open, the shelter contacts families based on their availability. He expressed his concern that there is great need in the community and very few social workers out in the field to help.

**Nancy Maguire Heath, Director, RI School for the Deaf**, asked Jay what has been their approach to communicate with deaf clients.

**Jay Burdick** explained that they work very closely with Ocean State Center for Independent Living (OSCIL) and use interpreters. On the phones they have TTY and other systems that help with telephone communication for those with hearing or language disabilities.

**Maria Barros, President Home Health & Hospice Care of Nursing Placement**, asked when 2-1-1 makes a referral to community case management agencies—who have a shortage of social workers—whether there is a mechanism to follow up.

**Jay Burdick** responded that they have the client call them back if they run into a problem. Jay explained that they do that with The Point and 2-1-1. If it is not working out for the client they will reach out to that organization for them.

**James Rajotte, RIDOH**, asked about the 79,000 health-related calls the United Way receives. Do they have an estimate of how many of those is due to folks not understanding their health insurance, health in general, or the caller having a specific issue or illness and

needing educational resources. He noted that this could be a data source for what the Commission is looking into regarding health literacy and if there is a way 2-1-1 could flag this.

**Jay Burdick** disclosed that he did not have statistics but speculates that about 10% of the calls are illness specific and 80% are for health insurance-related questions.

**Chairman DiPalma**, inquired about gathering information from 2-1-1 calls regarding how often a specific question is being asked. This could help the Commission with facts, data, and evidence.

**Chairman DiPalma** shifted to the roundtable discussion and the Commission priorities, asking the members for comments.

**Mary Parella, RIDE**, conveyed that the groups that need to be getting out the information on health literacy to community groups are schools, adult education programs, health equity zones, and key community partners. She added that a common theme and concern is healthcare language, understanding your financial responsibility around insurance, as well as mental health issues.

**Steve Brunero, RIPIN Director**, inquired about where the patients are in the policy conversations; patient engagement is necessary at the policy level. However, there are many obstacles to patient participation. They are trying to coordinate patient involvement and patient engagement in a consumer advisory body that is person-centered.

**Tara Provencal, EOHHS**, emphasized establishing healthcare language using common terms and definitions. She noted that a place to start is in the providers' offices and that SIM could be an asset to this group to carry out this priority.

**John Garrett, OHIC**, discussed that his main focus was on health insurance. He felt that the concept of common definitions is a challenge with federal and state statutes that define health insurance terms differently. A common depository of terms is needed. From the perspective of OHIC, people need to understand their complex health insurance documents, benefit coverage, exclusions, responsibilities and how to access their care. He shared OHIC's concern regarding the literacy rate for RI adults. According to the Providence Journal in 2005, 47% of the adult population reads at a 6<sup>th</sup> grade reading level. Currently, OHIC reviews documents to assure they do not exceed an 8<sup>th</sup> grade reading level. They are considering lowering this requirement for some of these documents to a 6<sup>th</sup> grade reading level.

**Amanda Barney, Hospital Association of R.I.**, focused on patient financial liability because the burden is growing as co-pays and deductibles increase. She noted that stakes are getting higher

and it is important that Rhode Islanders are understanding their liabilities.

*Chairman DiPalma* ended the roundtable portion of the agenda and confirmed the next meeting date with the Commission as February 14, 2017 at 2:30. The chairman opened the floor to public comment. With no one choosing to speak, there was a motion to adjourn.

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# **SPECIAL LEGISLATIVE COMMISSION TO STUDY THE TOPIC OF HEALTH LITERACY**

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## **NOTICE OF MEETING**

**DATE:** Tuesday, February 14, 2017

**TIME:** 2:30 – 4:00 P.M.

**PLACE:** Room 313 – State House

### **Agenda:**

- I. Roundtable Discussion
- II. Next meeting date(s)
- III. Public comment

Please contact Katuska Perez at [kperez@rilegislature.gov](mailto:kperez@rilegislature.gov) with any questions.

**POSTED: FRIDAY, FEBRUARY 10, 2017, 2:50 PM**

# Special Commission to Study the Topic of Health Literacy

Fourth Meeting Summary (not intended as official minutes) – February 14, 2017

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**Chairman Louis P. DiPalma** welcomed all Commission members and introduced the agenda items including: a roundtable discussion to address any priorities not addressed during the previous meeting, to set the next and final meeting date, and public comment.

**Chairman DiPalma** opened up the roundtable discussion based on the list of priorities established during the first meeting on October 25, 2016.

The roundtable discussion consisted of the Commission members' priorities:

***Ruth Feder, Mental Health Association of RI***

- Tie mental health to health literacy
- Use health literacy to reduce the stigma surrounding mental illness and inform patients of their rights and options related to mental health treatment
- Address barriers to accessing mental healthcare and understanding various healthcare plans

***James Rajotte, RIDOH***

- Action steps
  - Define and quantify the problem (such as consumer advisory boards to get public input)
  - Establish a common working definition of health literacy
  - Identify the moments of intervention during a life course
- Feedback loop questions:
  - How does one modify existing processes to incorporate health literacy?
  - What type of workforce is needed to maintain these systems?

***Meghan Connelly, RI Division of Elderly Affairs***

- Address reliance on e-health tools
- Have resources accessible to older populations (not online)

***Mary Parella, RIDE***

- Importance of schools in health literacy:
  - Start young, not just in traditional health classes
  - Focus on immigrants/ELL students

***Dennis Roy, RI Community Action Program***

- There was a lack of health literacy discussion in the HHS Accountable Entity roadmap from Dec. 2016; the Commission should make comments to HHS on including health literacy in it

***Stephen Brunero, RIPIN***

- Form Consumer advisory bodies to increase patient engagement
- Promote integration of certified community health workers in any new initiatives

***Chairman DiPalma*** asked how health literacy is measured and how do we know that once initiatives are implemented whether they are effective both from a qualitative and quantitative perspective. He urged Commission Members to think about this moving forward.

***Mary Parella, RIDE***, explained why a definition of health literacy is important for analyzing results—if there is a set of criteria that one must meet to be considered “literate,” you are better able to see the results of certain programs (i.e. through pre- and post-testing)

***James Rajotte, RIDOH***, stated that these benchmarks need to be divided through the life-span. Currently, there is a gap in qualitative measures because we can only observe behavior, and there is a lack of data on knowledge, perceptions, etc.

***Meg Ivatts, HealthSource RI***, noted that her department speaks to customers choosing health plans and that might be helpful in capturing data on what plans they choose and why.

***Chairman DiPalma*** agreed that it comes back to definitions of health literacy and how we track progress based on those definitions. He inquired whether the ultimate marker of success is whether health improves or whether there are other markers (lower cost, etc.).

***Nancy Maguire Heath, RI School for the Deaf***, concurred that schools are an important factor in health literacy, but that ultimately much of the education comes at essential points of a contact between a patient and a doctor. She stated that we must improve that essential point of contact with providers on a direct person-to-person level.

***Chairman DiPalma*** said the next meeting date will be on a Tuesday, around 2-3 weeks after the report is released to give time to review and comment on the report before the final meeting.

***Chairman DiPalma*** asked if anyone had any questions or concerns about the report.

***Ruth Feder, Mental Health Association of RI*** asked whether this report will address the

definition of health literacy and come to a conclusion.

**Chairman DiPalma** suggested collecting thoughts from experts in the field—including **Dr. Michael Barton Laws**, a Brown professor who spoke at the first meeting of the Commission—to develop a definition.

**Maria Barros, Nursing Placement**, said that the Commission should get out into the community and hear patient/provider perspectives on health literacy and potential solutions.

**James Rajotte, RIDOH**, explained that the report needs to distinguish between health literacy and causes of health literacy (e.g. reading ability is a cause of health literacy, not the result).

**Mary Parella, RIDE**, repeated that definitions need to be segmented by age group (e.g. what does health literacy look like for a child vs. an adult)

**Chairman DiPalma** reiterated that Commission members will receive a 2 week notice before the final meeting and asks that they review and comment on the report during that time.

**Chairman DiPalma** opened the floor for public comments. With no one choosing to speak there was a motion to adjourn.