

Opening the Door:

**The Importance of Language and Literacy Access
under Health Reform**



July 2010

Health Rights Organizing Project
Northwest Federation of Community Organizations

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We would like to thank Julius Chaidez, Jill Mangaliman, Fatima Morales, Theo Oshiro, Robyn Shultz and Mara Youdelman for their contributions and assistance with this report.

Introduction

On March 23, 2010, President Obama signed historic health reform legislation, the Patient Protection and Affordable Care Act (PPACA). The bill aims to reduce uninsured rates and thereby ensure access to quality health care for the approximately 46.3 million¹ currently uninsured. This population consists disproportionately of people of color, immigrants, and low-income people, and successful implementation of PPACA depends on careful attention to their needs.

One of the primary mechanisms for expanding coverage under PPACA is the creation of state insurance “exchanges,” entities that will facilitate the purchase of insurance by individuals and small employers.² The federal Department of Health and Human Services (the Department) will develop rules for the implementation of these exchanges, which will begin making insurance available in 2014.

In setting the basic guidelines for the exchanges, the federal government should make coverage and services through the exchanges as accessible as possible to their intended beneficiaries. In particular, the Department should take into account the needs of people of limited literacy and people with limited English proficiency (LEP). This report discusses some major areas of concern with regard to language and literacy access.

Zoila

My husband suffers from throat cancer. One day, his cancer was causing great pain, and he needed immediate assistance. We went to the emergency room for help, but there was nobody there whose duty it was to interpret for us. While we were waiting, a security guard spoke to the director on our behalf, explaining that we needed an interpreter quickly because my husband needed medical attention urgently.

Eventually, my husband fell to the ground with immense pain and coughing. When the hospital did locate someone to translate, it was a woman employed for housekeeping duties, who was not prepared to translate medical terminology. After further wait, another woman came to interpret, but she was upset because her job also was not as an interpreter. Both of these women said they didn't have time to interpret because their official duties needed to be performed. Then, a nurse came to us and said, “You are in America. You need to speak English.” That day we never did meet an official interpreter.

What I saw my husband endure caused me great emotional sadness because I had no control and I could not help him.

Story provided by Make the Road New York.

Addressing language and literacy barriers to state insurance exchanges

The success of PPACA depends on whether those seeking coverage understand the exchanges and the insurance plans the exchanges provide. This will require clear information, enrollment support, and interpreting and translation³ at all levels of engagement – with particular attention to people of limited literacy and people with limited English proficiency.

Barriers related to language and literacy

People with limited English proficiency face language barriers across a range of agencies and programs. This occurs despite the civil rights obligation of agencies and health care providers administering federal programs or receiving federal funds to provide access to people with limited English proficiency.⁴ Generally, these agencies are required to provide competent oral interpretation and translation of written materials at no cost and notify LEP clients of the availability of such services.⁵

Language barriers can prevent people from receiving basic or essential public services. A 2002 study of children's Medicaid participation found that "English language proficiency has a significant effect on patterns of enrollment and perceived barriers to Medicaid enrollment."⁶ However, this effect is not limited to Medicaid. Lack of interpretation and translation has also hampered parental involvement in schools⁷ and blocked access to driver's licenses and other key services.⁸

Similarly, people with limited literacy often find it particularly difficult to navigate the paperwork associated with public programs and services. (As of 2003, there were an estimated 93 million adults in the U.S. with basic or below basic prose literacy.⁹) One recent study found an association between the reading level of Medicaid applications and children's disenrollment from the program. The study found that "[w]ith each grade level increase in the literacy level of the application, there is a significant increase in a child's risk of disenrollment from Medicaid."¹⁰ On top of application form challenges, requirements to submit documents not readily available or easily obtained can also prove onerous.¹¹

Over time, policymakers and researchers have developed a range of recommendations and best practices to increase and maintain enrollment in programs such as Medicaid and the Children's Health Insurance Program

(CHIP). Examples include: simplification and streamlining of application and renewal forms; minimization of documentation requirements; coordination of information collected from other programs, and paperless renewal; outreach and public education, including one-on-one assistance; and, designating multiple "points of entry" to the program.¹²

As described below, PPACA creates a number of responsibilities for the state exchanges with regard to information, enrollment support, and communications. The Department should draw on the experience with Medicaid and CHIP when developing the rules concerning these responsibilities.

Joselita

My mom was diagnosed by her doctor with hypertension and a heart condition. After receiving two notes from two doctors saying that she needed immediate attention, we went to fill out a Medicaid application at the DSHS clinic.

When I marked on the application that we needed an interpreter the social worker demanded to know if my mom spoke English. I told her "Yes, but she's very shy." Especially with the tone of voice that the social worker was using, it was very intimidating.

She began to get angry when I started to answer the questions for my mom. "What's wrong with you?" she said to my mom. "Why can't you speak English? If you don't speak English, then you don't qualify here." I tried to show her the doctors' notes, but the social worker wouldn't look at them. I continued to ask for an interpreter, since I can't interpret medical terms, like the terms in the medical notes. But we never got one.

The social worker asked for identification, but my mother had left her immigration documents at home. So the social worker accused her of being "illegal" and yelled, saying she was going to call immigration.

By then, I was flustered and intimidated. I can't believe we faced such discrimination and rudeness when we needed help the most.

Story provided by the Washington Community Action Network.

Consumer information and assistance obligations Under PPACA

Responsibilities of the state exchanges

Under PPACA, the state exchanges will have an obligation to assist individuals looking for coverage and streamline the enrollment process. This assistance will include functions such as¹³ :

- Operating a toll-free telephone hotline;
- Maintaining an internet website with standardized information comparing each plan;
- Using a standard enrollment form;
- Presenting health plan information in a standardized format;
- Informing people about potential eligibility for Medicaid, the Children's Health Insurance Program, and other public coverage programs;
- Coordinating enrollment with state and federal public coverage programs;
- Creating a "navigator" program that awards grants for public education about and enrollment in the exchanges; and,
- Certifying exemptions from the individual responsibility penalty established under PPACA.

These provisions and others create a framework for the role state exchanges will play in educating the public about their health insurance options and assisting applicants. In developing rules for the operation of the exchanges, the Department should elaborate upon on this framework by drawing on accessibility best practices in Medicaid and CHIP. Moreover, the Department also should clarify the responsibility of state exchanges to protect the civil rights of LEP people and provide interpretation and translation at all levels.

Responsibilities of insurers

It is not only the exchanges that must provide information and assistance. Under the new law, health insurers participating in the exchange must also disclose certain pieces of information. These disclosures relate to, among other things, the insurer's claims payment policies, rating practices, and cost-sharing for out-of-network care. Insurers must provide this information in "plain language," taking into account readers of limited English proficiency.¹⁴ Additionally, insurers are required to provide information about their appeals processes in a linguistically and culturally appropriate manner.¹⁵

In light of these requirements – and the important role that insurers play in the reformed health care system – private insurance companies as well as state exchanges should be required to meet the highest standards related to language and literacy access. The Department should set out clear and meaningful requirements through its rulemaking.

Diana Corcoran

I have a learning disability and read at a first-grade level. So, when I had to fill out paperwork related to my family's Medicaid eligibility, I needed help. Somebody had to read the forms and fill them out for me.

Nobody at the Department of Health and Welfare was ever willing to help me, though. They're very intimidating there. Thankfully, I had friends and families that gave me a hand, but without them I don't know what I'd have done. My whole family could have wound up uninsured.

Story provided by the Idaho Community Action Network.

Health care language services are health care

The importance of health care language services

Health care language services are a crucial component of health care. Nearly 20 percent of people in the U.S. speak a language other than English at home,¹⁶ and many of them have limited proficiency in English. Competent language services are necessary to effectively communicate symptoms and treatment instructions across this language barrier.

Accordingly, in the 1990's the Office of Minority Health (within the Department of Health and Human Services) initiated the development of standards for culturally and linguistically appropriate services (CLAS).¹⁷ These standards mandate the availability of competent interpreter services, among other forms of language assistance.¹⁸ The Department's Office of Civil Rights has also issued guidance for compliance with language access obligations.¹⁹

Yet failure to address the needs of non-English speaking patients remains a common occurrence. In a 16-city study of uninsured patients, more than half of LEP patients did not receive interpretation services – either the wait for someone who spoke their language was too long, or a friend or family member had to interpret for them.²⁰ Another study at a university-affiliated children's hospital found that medical residents rarely used professional interpreters, despite awareness that they were not communicating adequately with their patients.²¹

When hospitals and clinics fail to provide competent language services they are effectively shutting the door to quality care for patients with limited English proficiency. This failure can have severe consequences, increasing the possibility of misdiagnosis and treatment that falls short of professional standards. For instance, one study of hospital data found that patients who did not speak English as their primary language were more likely to experience adverse health outcomes not related to their underlying medical condition.²²

Failure to provide competent language services also has civil rights implications. Title VI of the 1964 Civil Rights Act requires all recipients of federal funding to make their services accessible to people with limited English proficiency. This includes hospitals and other health care providers that receive funding through Medicare and Medicaid.²³ The development of the CLAS standards and LEP guidance were intended to promote compliance with these obligations. However, as the studies cited above indicate, additional measures are needed to ensure the proper provision of health care interpretation. PPACA provides opportunities to adopt such measures and protect the health and civil rights of LEP patients.

Ms. Kim

Once I had to go to the hospital for a tumor in my uterus. It hurt me just to move, and I couldn't eat right, either. I wound up losing 15 pounds because of it. Finally, my husband took me to the emergency room, where the intake workers gave me painkillers and I waited and waited. At midnight my husband went home to take care of our children. Meanwhile, I continued to wait – and eventually I fell asleep.

Then the hospital staff woke me up and told me I had to leave. I asked for a Korean interpreter, because I couldn't communicate very well with the staff there. They told me I just had to leave. So, I left, barefoot and with no money, and called my husband collect to come pick me up. And still the hospital billed me \$4,000 for the time I spent in the emergency room.

Story provided by the Korean Resource Center.

Health care language services are an essential health benefit

All health insurance plans available through the state exchanges will be required to cover a uniform set of “essential benefits.” Under PPACA, the Department is required to define the set of services to be included among the essential benefits. The law identifies certain services that must be so designated, such as emergency services and hospitalization, but this list represents a floor for the benefit package rather than a ceiling. Additionally, PPACA states that the Department must consider the needs of diverse populations when defining the essential health benefits.²⁴

Accordingly, the Department should include competent language services among the essential benefits that must be covered in exchange-certified health insurance plans. Recognition of competent language services as an essential benefit would be consistent with the research linking interpretation to health outcomes. It also would provide an important mechanism for increasing access to language services and improving the quality of care received by LEP patients.

Health care language services and the medical loss ratio

In addition to creating the state exchanges, PPACA requires that private health insurers spend at least a certain percentage of each premium dollar on health care, as opposed to administrative expenses or profit.²⁵ The process is now underway to determine which services and functions will qualify as health care for the purposes of this calculation. Because language services are an important component of health care, the Department should classify them as a health care cost in medical loss ratio calculations.

Lucila

My mother, Maria, went to the hospital for an operation on her knee. After the surgery, there were no interpreters available. She needed help going to the bathroom, but she fell because the nurse couldn't understand her requests, and she re-injured her knee because she wasn't supposed to be walking alone.

It's been more than six months, and she still can't walk well. When she did have an "interpreter," one was a student, and the other was always using a dictionary because they didn't know the words.

Story provided by the Idaho Community Action Network.

Conclusion

The United States took a major step toward addressing the country's vast health care inequities when Congress passed the Patient Protection and Affordable Care Act in March 2010. The success of the legislation will depend on implementation that promotes full access for its intended beneficiaries, in particular people of color, low-income people, and immigrants.

The Department of Health and Human Services must now clarify the responsibilities of state exchanges and private insurers under PPACA. Through its rulemaking, the Department should set the highest standards for ensuring language and literacy access and thereby advance the goals of this historic legislation.

Recommendations

The Patient Protection and Affordable Care Act has the potential to ensure access to quality health care for millions of people currently shut out of the health care system. To take advantage of this opportunity, the Department of Health and Human Services should adopt rules that accomplish the following:

- ♦ **Include competent language services in the essential benefits package.** Competent language services can be a matter of life or death in the clinical setting. For LEP patients, language services are an essential benefit and should be so recognized as the Department defines the essential benefits package for the exchanges.
- ♦ **Ensure competent interpretation and translation at all levels of the state exchanges.** Regardless of the language they speak, people seeking and maintaining health insurance through state exchanges should have access to full oral and written information about insurance options, cost, enrollment, subsidies, appeals, and other issues. Websites should include translated materials and tag lines in multiple languages.
- ♦ **Ensure that people of limited prose literacy have full access to the state exchanges.** The Department should set clear guidelines regarding the accessibility of written and electronic materials distributed by the state exchanges and the insurers offering plans through the exchanges.
- ♦ **Streamline and simplify the enrollment process.** When developing rules for the exchanges, the Department should draw on best practices from Medicaid and CHIP to maximize enrollment and retention. Additionally, eligibility determination for Medicaid and CHIP should be integrated seamlessly into the exchange enrollment processes.
- ♦ **Require health insurers to provide and pay for interpretation, translation, and literacy-appropriate information.** Private health insurers play an important role in the health coverage mechanisms established under PPACA. Consequently, insurers as well as state exchanges should be expected to meet standards related to language and literacy access.
- ♦ **Classify health care language services as a health care cost in medical loss ratio calculations.** Health care language services are a vital part of health care and the Department should classify them as such in rules related to medical loss ratios.
- ♦ **Require health insurers and state exchanges to collect primary language data of applicants and enrollees and of the usage of language services.** Periodically, insurers and exchanges should be required to analyze their data, stratified by language needs, to ensure that all applicants and enrollees are receiving meaningful access. Moreover, exchanges and state insurers should be required to develop and periodically update LEP access plans.

Notes

- 1 U.S. Census, "Income, Poverty and Health Insurance Coverage in the United States: 2008," Press Release, September 10, 2009.
- 2 Under PPACA, states have the option of operating their own exchanges or allowing the federal government to operate an exchange in that state. As of 2017, states will also have the option of allowing large employers to purchase insurance through the exchange. Kaiser Family Foundation, "Explaining Health Care Reform: Questions About Health Insurance Exchanges," April 2010, p. 1
- 3 Interpretation refers to conversion of oral communications. Translation refers to written conversion. National Council on Interpreting in Health Care, "FAQs for Health Professionals," viewed at: <http://www.ncihc.org/mc/page.do?sitePageId=101286&orgId=ncihc>.
- 4 See Department of Justice, Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, June 18, 2002, viewed at: <http://www.justice.gov/crt/cor/lep/DOJFinLEPFRJun182002.php>
- 5 National Immigration Law Center, "Increasing Access to Services for Limited English Proficient Persons," Issue Brief, August 7, 2003, pp. 1-2.
- 6 Emily Feinberg, et al, "Language Proficiency and the Enrollment of Medicaid-Eligible Children in Publicly Funded Health Insurance Programs," *Maternal and Child Health Journal*, March 2002, p.14.
- 7 Advocates for Children of New York & New York Immigration Coalition, Denied At the Door: Language Barriers Block Immigrant Parents from School Involvement," February 19, 2004, p. 5
- 8 Southern Poverty Law Center, *Under Siege: Life for Low-Income Latinos in the South*, April 2009, pp. 38-41.
- 9 National Assessment of Adult Literacy, "Demographics, Overall," viewed at: http://nces.ed.gov/naal/kf_demographics.asp#3.
- 10 Sumitra Pati, et. al, "Literacy Level of Medicaid Applications and Child Medicaid Retention Rates : Comparison across 50 States," Abstract for research presented at the Pediatric Academic Societies annual meeting, May 1, 2010, see, <http://www.aap.org/advocacy/releases/PAS2010/Medicaid.htm>.
- 11 Center for Children and Families, Georgetown University Health Policy Institute, "Maintaining Coverage for Children: Retention Strategies," March 2009, pp. 2 & 4.
- 12 Center for Children and Families, Georgetown University Health Policy Institute, "Reaching Eligible but Uninsured Children in Medicaid and CHIP," March 2009, pp. 4-7; Catherine Hess & Maureen Hensley-Quinn, "Building on Success to Effectively Integrate Current Children's Coverage with National Health Reform: Ideas from State CHIP Programs," Briefing, National Academy of State Health Policy, August 2009, pp. 2-7.
- 13 Kaiser Family Foundation, "Explaining Health Care Reform: Questions About Health Insurance Exchanges," April 2010, p. 2.
- 14 National Health Law Program, "Analysis of the Health Care Reform Law: PPACA and the Reconciliation Act," p. 32.
- 15 Ibid, p. 8.
- 16 Agency for Healthcare Research and Quality, "National Healthcare Disparities Report, 2008," 2008, p. 214; see also, Office of Management and Budget, "Report to Congress. Assessment of the Total Benefits and Costs of Implementing Executive Order No. 13166: Improving Access to Services for Persons with Limited English Proficiency," March 14, 2002, p. 4, viewed at: <http://www.omhrc.gov/assets/pdf/checked/cultural12.pdf>.
- 17 Robert Putsch, et al, "Reflections on the CLAS Standards: Best Practices, Innovations and Horizons," Cross Cultural Health Program, October 2003, pp. 8-9.
- 18 Ibid, p. 10.
- 19 U.S. Department of Health and Human Services, Office of Civil Rights, Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons.
- 20 Dennis Andrulis, Nanette Goodman, & Carol Pryor, "What a Difference an Interpreter Can Make," Access Project, April 2002, p. 7.
- 21 Sonja C. Burbano O'Leary, et. al, "The Truth About Language Barriers: One Residency Program's Experience," *Pediatrics*, May 2003, pp. e571-e572.
- 22 Chandrika Divi et al, "Language proficiency and adverse events in US hospital: a pilot study," *International Journal for Quality in Health Care Advance Access*, February, 2007.
- 23 National Immigration Law Center, "Increasing Access to Services for Limited English Proficient Persons," Issue Brief, August 7, 2003, p. 2.
- 24 National Health Law Program, "Analysis of the Health Care Reform Law: PPACA and the Reconciliation Act," pp. 25-26.
- 25 Elizabeth Abbott, et al, "PPACA Implementation: Consumer Recommendations for Regulators and Lawmakers," May 2010, p. 22.

The Health Rights Organizing Project (HROP)

The Health Rights Organizing Project (HROP) is a collaboration of grassroots community organizations around the country. Each of the member organizations is committed to securing quality, affordable health care for all, reflecting our commitment to promoting the wellbeing of all members of our communities. We believe the call for health care for all should arise from the grassroots, with diverse leaders from across the country at the forefront. HROP is coordinated by the Northwest Federation of Community Organizations.

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California Immigrant Policy Center
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