Amplifying the Voice of the Underserved in the Implementation of the Affordable Care Act

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*Participants in the activities of the IOM Roundtable on Health Literacy and/or the IOM Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities

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In April 2013, in collaboration with the Connecticut Health Foundation, the Institute of Medicine’s (IOM’s) Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities convened a public workshop with community leaders and health policy makers on the implications of the Patient Protection and Affordable Care Act (ACA) for health equity. Among the most powerful presenters were two community organizers based in Connecticut who described both the appetite of the underserved for information about opportunities for health insurance coverage and the prevailing confusion among these families and communities regarding the ACA. Even among the law’s strongest supporters and the architects of ACA implementation, there was concern—if not dread—that the goal of expanding health coverage for the underserved would be sidetracked by misinformation, a lack of community trust, and a lack of coordinated and consistent messaging around the potential benefits of the new law.

Earlier in the spring of 2013, the IOM Roundtable on Health Literacy convened a meeting in Washington, DC, and invited speakers to describe their organizations’ efforts to assimilate the “attributes” of a health literacy–sensitive organization. Although the focus of this convening was not the ACA per se, a prevailing theme was the importance of the patient voice in the health care delivery system and the need for organizations to adopt programs that consistently incorporate this voice.

These two important messages, one about the importance of amplifying the patient voice, and the other about the importance of communicating in ways meaningful to a community about new opportunities to invest in its health, converge at a critical time in our country’s great test in expanding health care access to all Americans. For those invested in the successful implementation of the ACA, particularly in the expansion of health care coverage through the establishment of state insurance marketplaces and the expansion of Medicaid eligibility, work must begin swiftly not only to communicate about coverage options, but also to empower and engage grassroots organizers and communities in the process.

Although the ACA does provide funding for “patient navigators,” namely, a cadre of trained individuals to facilitate the process of applying for health insurance either through the marketplaces or through Medicaid, navigators alone cannot ensure that messaging about opportunities to access health care coverage are understood by those who are newly eligible for coverage.

For most Americans, the process of understanding and accessing health insurance is a complex ordeal. One can imagine how difficult this process will be for Americans who have

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never been insured, or who have been uninsured for some length of time. For individuals with low health literacy, limited English proficiency, and/or little familiarity with the American health care system, these challenges will be further compounded. Although the prospect of bringing an additional 37 million Americans under health insurance coverage is tantalizing, making it a reality requires a commitment to engaging communities in creative ways.

One of the invited speakers at the health equity workshop, a grassroots organizer, said that outreach to underserved populations “should be like H&R Block®”—to wit, their offices are everywhere, everyone knows what they do, and they present their services in a way that is easily understood. This is a model, she said, that should be considered as new health care coverage options are rolled out for newly eligible consumers.

Ironically, given that the health insurance exchanges have been renamed “marketplaces,” these new marketplaces do not necessarily embody the characteristics of an H&R Block. For example, unlike an H&R Block office, marketplaces will reside principally in the Internet universe. Although in-person assisters and telephone service will be available to assist newly eligible consumers in applying for health care coverage, creating brick-and-mortar marketplaces across communities would be costly as well as difficult to manage, organize, coordinate, and sustain.

The ACA provides some funding for community-based organizations to play a role in outreach to newly eligible consumers of health insurance under the ACA. This seems to be a worthy enterprise. However, the commitment to “get real” with Americans who have been chronically uninsured should not end there. The initial process of enrollment for insurance coverage through the marketplace or via Medicaid is but one step in empowering those individuals to become informed consumers.

Second, an appraisal of the new health care consumer’s needs and expectations must be considered. For some, this leads to trepidation about the pent-up demand of uneducated consumers entering the health care system. Notwithstanding the prejudice this concern reveals about the underserved, there is little evidence that actually supports it. For example, contrary to popular belief, health care is not “free” when one factors in copayments, deductibles, transportation costs, and time allotted to accessing care. Low-income populations are more likely to be concerned about these costs than those with greater financial resources, and may just as judiciously consider when and how to utilize their newly acquired health care coverage.

Amplifying the voice of consumers while at the same time simplifying paths to obtain and use health insurance is about empowering underserved communities to take their health care needs into their own hands. This should not be feared; rather, it should be embraced and advocated by those seeking a more equitable and accessible health care system.

More concretely, we propose that in the ensuing months (or, perhaps, years),

1) aggressive, creative, and widespread dissemination of community-created messages should be used to accurately capture opportunities under the ACA;
2) messaging to communities should not only address how to obtain health care coverage, but also should educate the public about being responsible, informed, and empowered health care consumers;
3) community-based organizations that are awarded contracts to conduct community outreach efforts should be grassroots-oriented and provided with adequate training and resources to engage the broadest constituencies possible;
4) the needs of limited-English-speaking communities in being informed about the opportunities of the ACA should be engineered into the core of outreach and dissemination work, as opposed to being an “add-on;” and

5) levels of trust and confidence among new consumers of health care coverage should be evaluated in the process of enrollment through the marketplaces and Medicaid, and should be incorporated as a measure of performance at the state and federal levels.

These are small, but important, considerations during this historic embarkation of the implementation of the ACA. These considerations are also essential to our nation’s commitment to health care for all Americans. Finally, these are investments that maintain a promise to our national values of equality and fairness for every American.