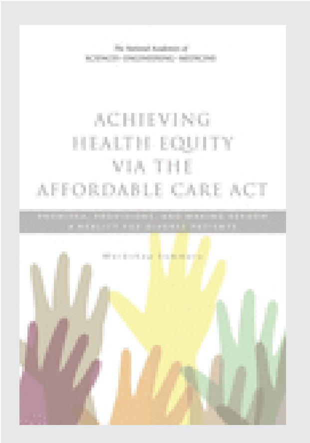

# Achieving Health Equity via the Affordable Care Act: Promises, Provisions, and Making Reform a Reality for Diverse Patients: Workshop Summary

**DETAILS**

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# ACHIEVING HEALTH EQUITY VIA THE AFFORDABLE CARE ACT

## PROMISES, PROVISIONS, AND MAKING REFORM A REALITY FOR DIVERSE PATIENTS

Workshop Summary

Karen M. Anderson and Steve Olson, *Rapporteurs*

Roundtable on the Promotion of Health Equity
and the Elimination of Health Disparities

Board on Population Health and Public Health Practice

Institute of Medicine

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[1] The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the Institute of Medicine, and they should not be construed as reflecting any group consensus.

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[1] Institute of Medicine forums and roundtables do not issue, review, or approve individual documents. The responsibility for the published workshop summary rests with the workshop rapporteurs and the institution.

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# Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

**Elizabeth Krause,** Connecticut Health Foundation
**Menoo Mishra,** Association of State and Territorial Health Officials
**Jewel Mullen,** Connecticut Department of Public Health
**Cheri Wilson,** Hopkins Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Elena Fuentes-Afflick**, University of California, San Francisco. Appointed by the Institute of Medicine, she was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteurs and the institution.

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# Acronyms

| | |
|---|---|
| ACA | Patient Protection and Affordable Care Act |
| ACO | accountable care organization |
| AHRQ | Agency for Healthcare Research and Quality |
| APRN | advanced practice registered nurse |
| CHCS | Center for Health Care Strategies |
| CMS | Centers for Medicare & Medicaid Services |
| EHR | electronic health record |
| FQHC | federally qualified health center |
| HHS | U.S. Department of Health and Human Services |
| IOM | Institute of Medicine |
| IRS | Internal Revenue Service |
| NCQA | National Committee for Quality Assurance |
| NQF | National Quality Forum |
| PCORI | Patient-Centered Outcomes Research Institute |

# 1

# Introduction and Themes of the Workshop

Since its creation by the Institute of Medicine (IOM) in 2007, the Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities has been fostering dialogue on racial and ethnic disparities in health and health care, examining the development of programs and strategies to reduce disparities, and encouraging the emergence of new leadership focused on health equity. For the past several years, a prominent topic of discussion within the roundtable has been the Patient Protection and Affordable Care Act (ACA), which was signed into law by President Barack Obama on March 23, 2010. The ACA has multiple provisions specific to race, ethnicity, and language and other provisions with significant implications for racially and ethnically diverse populations (Andrulis et al., 2010). Many observers view the ACA as the best opportunity in a generation to promote health equity.

On April 22, 2013, the roundtable held a workshop at the Mark Twain House and Museum in Hartford, Connecticut, titled Achieving Health Equity via the Affordable Care Act: Promises, Provisions, and Making Reform a Reality for Diverse Patients. Sponsored and hosted by the Connecticut Health Foundation (see Box 1-1), the workshop addressed many issues surrounding the ACA, including

- Expansion of coverage, delivery systems, and access points;
- Service delivery and payment reform, including the patient-centered medical home model;
- Public–private partnerships; and
- Challenges to the safety net.

## BOX 1-1
## The Connecticut Health Foundation

The Connecticut Health Foundation, which supported and hosted the workshop Achieving Health Equity via the Affordable Care Act: Promises, Provisions, and Making Reform a Reality for Diverse Patients, was created in 1999 to improve the health status of people in Connecticut. As Sanford Cloud, the chair of the foundation's board, said in his opening remarks at the workshop, the foundation uses "strategic communications, leadership cultivation, and public policy to expand health equity."

Shortly before the workshop, the foundation announced a new 5-year strategic plan directed toward an integrated strategy centered on expanding health equity for all Connecticut residents. The plan establishes two broad goals and six underlying objectives.

**Goal 1: Leverage opportunities to advance health equity in reforming health care.**

- Objective 1: Promote health insurance enrollment and navigation support systems that will increase and maintain coverage.
- Objective 2: Foster the inclusion of mental, oral, and physical health in an integrated health care system.
- Objective 3: Increase system accountability by advancing the development and integration of quality standards and measurement protocols into primary care delivery models.
- Objective 4: Maximize the role of the safety net in an integrated health care system.

**Goal 2: Strengthen leadership and network capacity to promote health equity in health care access and delivery.**

- Objective 1: Cultivate diverse, skilled health equity leaders who advocate for and effect change in private, public, and nonprofit sectors.
- Objective 2: Advance public policies that promote health equity by establishing a health advocacy entity.

All of these goals and objectives were discussed at the workshop, which in part used the state of Connecticut as a case study to investigate the implementation of the ACA.

In the course of discussing these issues, it became clear that the detailed implementation of the ACA will be critical in achieving the objective of reducing health disparities. As Patricia Baker, president and chief executive officer of the Connecticut Health Foundation, said in her opening remarks at the workshop, "health equity could get lost in the scope, urgency, and politics of health reform." The many provisions of the ACA bear promise, she said, but "we all know that the devil is in the implementation details." Connecticut was the location of the workshop so that the state's experiences could serve as a "laboratory" for in-depth consideration of the issues associated with implementation of the ACA.

The workshop was widely attended by local policy makers, representatives from philanthropic organizations, journalists, health care professionals, academic researchers, and members of the interested public. The day was structured with four panels following the keynote speaker. As always, statements in this summary are those of the workshop presenters rather than the roundtable or the IOM.

For the purposes of this summary, the definition of health equity used in the planning and implementation of this workshop is from the Connecticut Health Foundation. "We see health equity not just as an aspiration, but as a framework for understanding problems and generating solutions that will help more people, especially populations of color, gain access to better health care."[1]

The definition of health disparities used in this summary is that used in the IOM's 2003 report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*: "racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs" (2003, p. 4).

## THE ACA IN CONNECTICUT

Connecticut has been a leader among the states in implementing the ACA, said Governor Dannel Malloy, who spoke at the workshop's opening session. It has developed a state-based exchange, has supported the expansion of Medicaid, and has taken other steps to expand health equity among Connecticut residents. As a result of these and other initiatives, 170,000 to 200,000 of the 286,000 to 344,000[2] uninsured people in Connecticut will be eligible for credits or Medicaid in gaining health care coverage (Connecticut Health Policy Project, 2012).

> "We cannot afford to provide health care in the same manner in which we have delivered it."
>
> —*Connecticut Governor Dannel Malloy*

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[1] See www.cthealth.org/health-equity/our-approach (accessed July 26, 2013).

[2] Estimates of the number of uninsured in Connecticut vary according to different data sources.

"Preparing the state's health care system to provide much greater access to medical care for that many people raises questions of capacity, timeliness, and expense," said Malloy. In the past, many of these people have relied on emergency rooms. Individuals and institutions alike will therefore need to learn a new set of behaviors on how to access the health care system and how to maneuver through it. "This is going to take a tremendous amount of time and effort on everyone's part." However, the current system imposes expenses on those who are insured, those who are not insured, and the institutions that provide care. "We cannot afford to provide health care in the same manner in which we have delivered it over the past many years," said Malloy.

Connecticut, like other states, has constrained finances, Malloy said, which "gives real urgency to the work that we're undertaking." The state is nearing the limits of its ability to match the services that it wants to give its citizens with the services that it can afford. "Implementation of this law gives us an opportunity to stay on par with where we would like to be," said Malloy.

Implementation of the ACA will require that everyone knows about the act, said Nancy Wyman, the lieutenant governor of Connecticut, in her opening remarks at the workshop. That will require a large-scale outreach effort that encompasses everyone in the state. "We have to get into the churches, we have to get into the streets of Hartford and New Haven and Bridgeport, and make sure that all people know that this[3] is available." At the same time, the state will need to control costs through partnerships and through efficiencies in implementation, she added.

> "We have to get into the churches, we have to get into the streets of Hartford and New Haven and Bridgeport, and make sure that all people know that this is available."
>
> *—Lieutenant Governor Nancy Wyman*

Congressman John Larson, representative from the First District of Connecticut, noted that the ACA continues to face political headwinds. The politics of health care is "not for the faint of heart," said Larson, who was instrumental in the legislation's passage. "It is going to take the Institute of Medicine, concerned citizens, and everyone else to make sure that we understand the difficulty of the task at hand and the necessity to make sure that we get it right."

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[3] Refers to health insurance under the ACA.

> "It is going to take the Institute of Medicine, concerned citizens, and everyone else to make sure that we understand the difficulty of the task at hand and the necessity to make sure that we get it right."
>
> *—Congressman John Larson*

## THEMES OF THE WORKSHOP

Over the course of the workshop, several themes emerged in the presentations of speakers and the ensuing discussions among workshop participants[4]:

- The ACA creates many opportunities to reduce health disparities through expanded coverage, reduced costs, improved quality, and other broadly based health care reforms.
- The ACA contains many provisions aimed specifically at reducing health disparities through measures such as enhanced data collection, greater workforce diversity, increased cultural competency, and health disparities research.
- The numbers of uninsured people in a state can be dramatically reduced, but doing so will require comprehensive and personalized outreach.
- Information technologies can provide powerful tools to increase insurance coverage and keep people covered.
- The concept of a patient-centered medical home offers multiple opportunities to advance health equity.
- Safety net organizations will continue to be critical to the reduction of health disparities under the ACA.
- The commitment of a state's elected leaders is having and will continue to have a major impact on the state-by-state implementation of the ACA.
- Both bottom-up, community-based efforts and top-down policy leadership will be essential if the ACA is to succeed in reducing health disparities.
- Implementation of the ACA will encounter difficulties, but these difficulties can be expected to decline over time.

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[4] These themes are based in part on the concluding remarks of Antonia M. Villarruel, associate dean for research and global affairs at the University of Michigan School of Nursing and chair of the roundtable, and Patricia Baker at the workshop.

- Under the ACA, every part of the health care system has opportunities to promote health equity.
- Achieving health equity is a broader goal than reducing health disparities, but the ACA's focus on health disparities represents a critical step toward equitable coverage and health outcomes for all Americans.

## ORGANIZATION OF THE WORKSHOP SUMMARY

After this introductory chapter, Chapter 2 provides a general overview of the ACA and its potential to reduce health disparities. Chapter 3 summarizes the presentation of the workshop's keynote speaker, Jennifer DeVoe, who delved into several major problems that the ACA addresses and potential ways of solving those problems. Chapter 4 examines the issues associated with patient-centered medical homes, which offer a particularly promising way to achieve greater equity in health care.

Chapter 5 examines the institutions that collectively serve as a safety net for patients and at the roles that they will play under the ACA. Finally, Chapter 6 provides four different perspectives on a critical aspect of the ACA: the need to engage the consumers of health care in the implementation of the act.

# 2

# The Potential of the ACA to Reduce Health Disparities

**Important Points Made by the Speakers**

- All the major goals of the ACA—expanded coverage, reduced costs, and improved health care quality and population health—will have the effect of reducing health disparities. (James)
- Many provisions in the ACA directly affect insurers, who will be expanding the numbers of people and conditions covered. (Rawlins)
- Current experiences in Connecticut and Massachusetts demonstrate that the number of uninsured people could be dramatically reduced, but doing so requires comprehensive and personalized outreach and careful planning. (Counihan)

Provisions of the ACA related to health equity are woven throughout the act. Three speakers at the workshop discussed various aspects of these provisions and their potential to reduce differences in health outcomes among racial, ethnic, and primary language groups. This chapter integrates the presentations and the responses to questions in order to provide an overview of the ACA and a more detailed examination of some of the ways in which it addresses health disparities.

## OVERVIEW OF THE ACA

The ACA has five basic goals, said Cara V. James, director of the Office of Minority Health at the Centers for Medicare & Medicaid Services (CMS):

1. Expand coverage,
2. Reduce health care costs,
3. Improve health care quality,
4. Improve population health, and
5. Reduce health care fraud and abuse.

To expand coverage, the act creates marketplaces, known as exchanges, in which people can purchase health insurance and determine their eligibility for financial assistance. Three types of marketplaces will exist: federally facilitated marketplaces, state-based marketplaces, and state-partnership marketplaces. The responsibilities of the states will vary by type of marketplace. The exchanges will have a single process to determine whether someone is eligible for tax credits to reduce the cost of premiums, in the form of cost sharing, Medicaid, or the Children's Health Insurance Program.

Health plans qualified to be included in the exchanges will be required to cover a range of essential health benefits, including ambulatory patient services, prescription drugs, emergency services, rehabilitative and facilitative services, hospitalization, laboratory services, maternity and newborn care, preventive and wellness services and chronic disease management, mental health and substance use disorder services (including behavioral health treatment), and pediatric services (including oral and vision care). Plans will vary by level depending on how much of the total health care cost the plan will pay versus how much the member will pay. Platinum will be the highest level of coverage, followed by gold, silver, and bronze, but each level will cover the services listed above.[1]

Marketplaces are to be established by October 1, 2013, with the coverage and services becoming available on January 1, 2014. The applications for coverage are somewhat complicated; James observed, to verify incomes, eligibility, and so on. As a result, assistance will be provided to help with applications, including navigators, in-person assistants, certified application counselors, agents, and brokers. This assistance will help, James said, but "we're going to need the churches, we're going to need the schools, and

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[1] In his presentation later in the workshop, Kevin Counihan, chief executive officer for Connecticut's Health Insurance Exchange, described the origins of the metallic levels. When he was involved with health care reform in Massachusetts, he was describing to his wife several possible systems to refer to kinds of coverage in the state. She said that they were all too complicated and that the best system would be to use the colors of metals given in the Olympics, to which platinum was later added.

[we need] a lot of thinking about how to build a very strong ground game to help get the word out, get people covered, and get them the assistance they need to apply for coverage and select a qualified plan."

To improve health care quality, the ACA mandates several initiatives:

- A national quality strategy,
- Increased reliance on value-based purchasing,
- Expansion of meaningful use of electronic health records (EHRs),
- Better care coordination,
- Development of quality measures for Medicaid and Medicare, and
- Measures of quality in the marketplace.

Innovation also will be a way to improve quality, James emphasized. Existing demonstration projects are already boosting innovation. Such projects include Strong Start, which is a program to reduce early deliveries, particularly among Medicaid populations; nurse-managed care organizations; programs supported by Health Care Innovation Awards and the Community-Based Care Transitions Program; accountable care organizations (ACOs); and the Advanced Primary Care Practice demonstrations at federally qualified health centers (FQHCs). In addition, CMS and other organizations are seeking to develop and test models to reduce health care costs, improve health care quality, and evaluate how well models work across different populations.

A number of initiatives will also be used to improve population health, including

- Quality-of-care improvements,
- Employee wellness benefits,
- Preventive services for Medicare beneficiaries,
- Preventive services for women,
- A dental sealant program for children, and
- Community transformation grants.

Strengthening the health care workforce is another major focus of the ACA. The act includes grants to institutions to train physicians in family medicine, general internal medicine, and general pediatrics, as well as to train physician's assistants; increased funding for training in mental and behavioral health; and removal of previous caps on the U.S. Public Health Service Commissioned Corps and the National Health Service Corps. It also has a loan repayment program that encourages providers from diverse backgrounds, including rural backgrounds, to pursue careers in health services, because, said James, "we know that those are providers who are more apt to treat the same population from which they've come."

The ACA includes an increased reliance on nurses because of anticipated difficulties in training the requisite number of doctors. A $50 million grant program for clinics run by advanced practice registered nurses (APRNs), who have post-graduate education in health care, will provide primary care and wellness care to underserved populations. Other provisions include improved access to nurse-midwife services, establishment of Community Health Teams, an independence-at-home demonstration program, a nursing student and faculty loan program, and retention grants and a demonstration project for the education of APRNs. "We're going to have to maximize health services across all levels," said James.

## Reducing Disparities

The ACA includes many provisions specific to the reduction of health disparities, said James. In 2014, almost 50 million people were uninsured, with communities of color overrepresented among that group (see Figure 2-1). Furthermore, disparities in the quality of care among racial and ethnic groups have not changed much over time (AHRQ, 2012).

New data collection standards require monitoring by race, ethnicity, primary language, sex, and disability, and the secretary of the U.S. Department of Health and Human Services (HHS) has the authority to add other categories, such as socioeconomic status and sexual orientation. Monitoring will also look beyond large racial and ethnic groups to more specific groups.

Circumstances vary by state. The southeastern and southwestern states have the highest proportions of people of color (see Figure 2-2). They also have the highest proportions of uninsured individuals (see Figure 2-3). About half of African Americans, American Indians, and Hispanics are eligible to be covered through the expansion of Medicaid, which some states are undertaking and others are not.

Coverage also does not necessarily imply access, James said. For example, people who have been uninsured for long periods need to have the tools to access health care; they cannot just be told to go find a physician. For example, many people need to be educated about health insurance, such as what a copay is, what coinsurance is, and how a navigator program works. And even people who have had insurance coverage can have trouble finding a provider who will accept new patients.

The *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* (HHS, 2011) has five goals:

1. Transform health care.
2. Strengthen the workforce and infrastructure of HHS.
3. Advance the health, safety, and well-being of the American people.

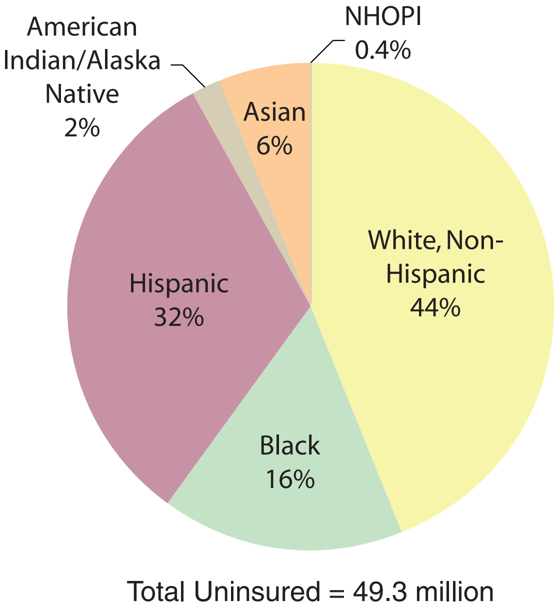

**FIGURE 2-1** Minority groups and uninsured people in the United States.
NOTE: NHOPI = Native Hawaiians and other Pacific Islanders.
SOURCE: James workshop presentation, April 22, 2013.

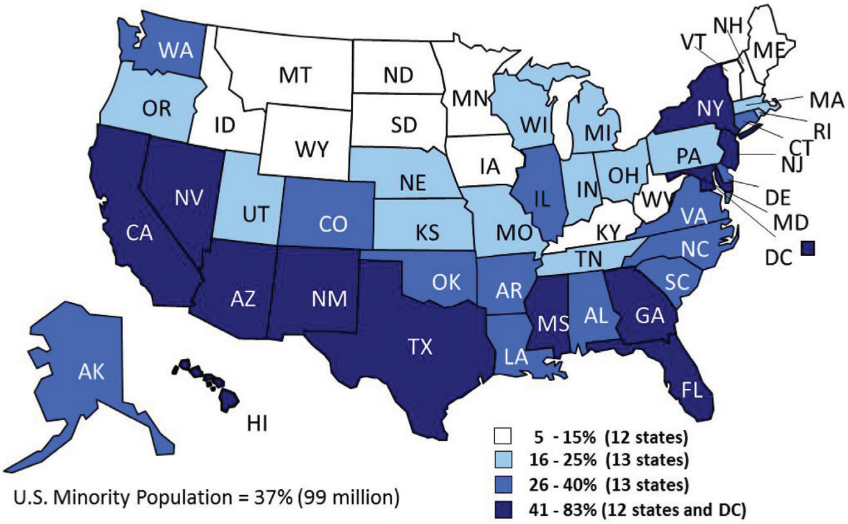

**FIGURE 2-2** Southern states and proportions of non-elderly persons of color.
SOURCE: Kaiser Family Foundation.

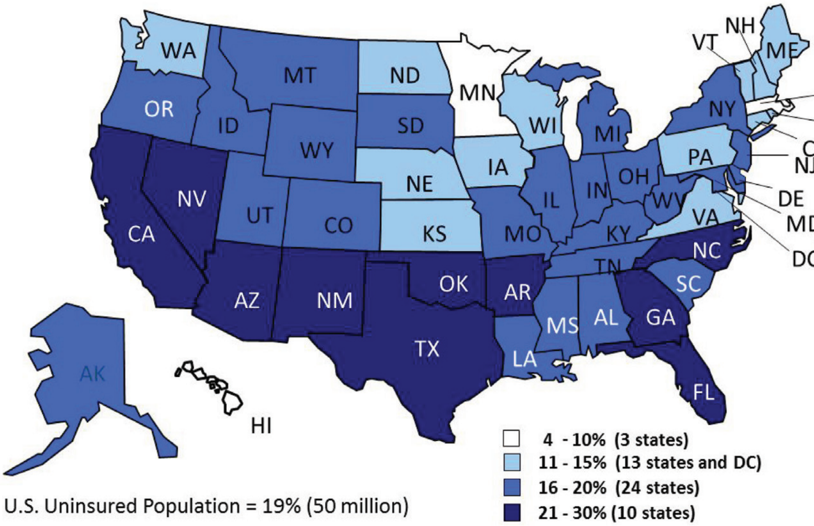

**FIGURE 2-3** Southern states and proportions of non-elderly uninsured persons.
SOURCE: Kaiser Family Foundation.

4. Advance scientific knowledge and innovation.
5. Increase the efficiency, transparency, and accountability of HHS programs.

Each goal has a strategy and a lead agency to ensure that the goal is achieved. In addition, the ACA created offices of minority health in many agencies within HHS that did not have such offices previously, including CMS, the U.S. Food and Drug Administration, the Centers for Disease Control and Prevention, and the Substance Abuse and Mental Health Services Administration.

James cited several programs addressing disparities that have received Health Care Innovation Awards:

- The Delta Dental Plan of South Dakota has focused on oral health improvements for women and children in American Indian and Alaska Native populations.
- The Joslin Diabetes Center is expanding its On the Road program.
- Duke University's program, From Clinic to Community, aims to reduce death and disability from type 2 diabetes in the southeastern United States.

- The Ravenswood Family Health Center in San Mateo, California, is creating a disparities collaborative and training care managers to address chronic diseases.

"Across the board," said James, "demonstration programs offer an opportunity for us to review how these models are working and where we can improve them through tracking and improving data."

James also noted that part of the ACA consists of legislation known as the Indian Health Care Improvement Act, which was reauthorized for the first time since 2001. That act includes a comprehensive set of provisions focused on improving access to care for American Indians. The Indian Health Care Improvement Act:

- Provides authorization for hospice, assisted living, long-term, and home- and community-based care.
- Makes it easier for facilities run by tribes to recover costs from third parties.
- Establishes a Community Health Representative program for urban Indian organizations to train and employ American Indians to provide health care services.
- Directs the Indian Health Service to establish comprehensive behavioral health, prevention, and treatment programs for American Indians.

At the federal level, the secretary of HHS engages in consultation with representatives from American Indian tribes on a regular basis, James said. The Office of Tribal Affairs at CMS also works with tribes on an ongoing basis.

## Benefits Already in Place

Even as regulations are being developed to implement the ACA, some of its benefits are already in place, including

- A ban on lifetime limits,
- No denial of coverage for children with preexisting conditions,
- Coverage for children on their parents' coverage until they turn 26 years of age,
- No denial of coverage for adults with preexisting conditions starting in 2014,
- Prevention and wellness benefits for seniors at no cost,

- Help for seniors who reach the "donut hole" in prescription coverage, and
- Preventive services for women.

As a more detailed example of the new services in place, James listed the preventive services that now are covered for women:

- Well-woman visits;
- Domestic violence screening;
- Gestational diabetes screening;
- Breastfeeding support, supplies, and counseling;
- Sexually transmitted infections counseling;
- HIV screening and counseling;
- Contraception and contraceptive counseling; and
- Human papillomavirus testing.

### Staying Informed and Involved

James encouraged everyone to get engaged and stay informed. Proposed regulations are being posted in the *Federal Register* for comments. The website healthcare.gov has information for consumers to learn about the ACA and its implementation. "We rely on you to help us to make sure that we are doing the best that we can for the populations that we are trying to serve."

> "[We need] a very strong ground game to help get the word out, get people covered, and get them the assistance they need to apply for coverage and select a qualified plan."
>
> —*Cara James*

Communities of color have much to gain from the ACA, James concluded. But these communities need to be connected with the health care system, which will require that all parts of that system take steps to engage more fully with these communities. As James said, quoting Lao-tzu, "A journey of a thousand miles begins with a single step."

### Health Equity and the ACA: An Insurer's Perspective

Many provisions in the ACA related to health disparities affect insurers, said Wayne Rawlins, national medical director for racial and ethnic equality initiatives at Aetna. Under the ACA, insurers will provide plans and health insurance exchange marketplaces, and all insured patients must receive culturally and linguistically appropriate information on appeals procedures and explanations of coverage. Experts predict that by 2016 more than 19 million new consumers will purchase commercial insurance in the individual market. In addition, Medicaid expansion will bring probably 6 million new enrollees into the Medicaid market, and many of these will be handled under Medicaid plans managed by insurers.

The characteristics of the 19 million people who will be in the exchange marketplace will be somewhat different from the characteristics of people in the commercial marketplace, Rawlins noted. They will be more racially and ethnically diverse. They will be poorer and have less education. One in four will speak a language other than English at home. More than 65 percent will have been uninsured. They will have ways of accessing and using health care services different from those that are routinely seen in the commercial marketplace.

Insurers must provide first dollar coverage (no deductible) for major health benefits surrounding prevention and wellness. Many will be either contracting with or collaborating with ACOs and other entities focused on improving population health. They will also be taking part in the data collection activities around race, ethnicity, language, and other patient characteristics.

ACOs were created in the ACA as entities for eligible Medicare enrollees. They are provider-run organizations in which the participating providers are collectively responsible for the care of a particular population. Their goal is to deliver seamless high-quality care for enrollees while at the same time improving quality and reducing costs. ACOs can share in any savings associated with improvements in the quality and efficiency of the care that they deliver. For minority populations, one benefit of these organizations is the increased attention to keeping patients healthy. "Like the rising tide that raises all boats, we hope this will shrink the current disparities we see in health care delivery," said Rawlins.

The increased racial and ethnic diversity of the health care workforce and the strengthening of cultural competency training for all health care providers will affect insurers through their network development and physician outreach activities, Rawlins said. Also, the results of comparative effectiveness research on health outcomes for minority populations conducted by the Patient-Centered Outcomes Research Institute (PCORI), which is described in more detail in Chapter 6, will need to be embedded into the business models of health plans.

Aetna is participating in the collection of data on health care disparities. For example, Aetna has an analytical tool called the racial and ethnic equality dashboard that compiles racial and ethnic information from its members. About 6.5 million currently active Aetna members have voluntarily provided their race and ethnicity, and this information has been combined with medical claims, pharmacy, and laboratory information to get a precise view of disparities within Aetna's membership. Aetna also has quality measures that cover about 70 different areas, such as asthma care, behavioral health, cancer screening, cardiovascular care, and maternal and child health. For example, it measures hemoglobin A1C, which is a test of diabetes control. These data have shown that African Americans and Latinos in Aetna's population have poorer control of diabetes than their white counterparts. Poorer control of diabetes can result in more episodes of blindness, kidney failure, heart attacks, and premature deaths.

The National Health Plan Collaborative, which was established in 2004 and includes nearly a dozen major health plans, brings together major health insurance companies to identify ways to improve the quality of health care for racially and ethnically diverse patient populations. The goals of the collaborative are to collect racial, ethnic, and primary language data to inform efforts to reduce disparities in health care within their respective memberships; improve health care access and quality by enhancing language services for patients whose primary language is not English; support investments in efforts to reduce disparities by making a business case for addressing disparities; and improve knowledge management and the dissemination of disparities-related information.

> "It is very important for America to have the healthiest population in the world. We're paying the most for health care of any country in the world, and we're actually not getting our value for it."
>
> —*Wayne Rawlins*

Rawlins pointed to multiple arguments for addressing health care disparities, including social justice, clinical quality, and financial sustainability. Health care disparities are affecting American businesses and employers through increased medical costs, worse health outcomes, and lost productivity. "It is very important for America to have the healthiest population in the world. We're paying the most for health care of any country in the world, and we're actually not getting our value for it. As a consumer and as a citizen, I personally would be okay with paying as much as we do as long as we get the absolute best value for it," he concluded.

## THE EXPERIENCE IN CONNECTICUT

Kevin Counihan, the chief executive officer for Connecticut's Health Insurance Exchange, described the operational challenges in setting up and running an exchange, which can be "quite complicated," he said. The

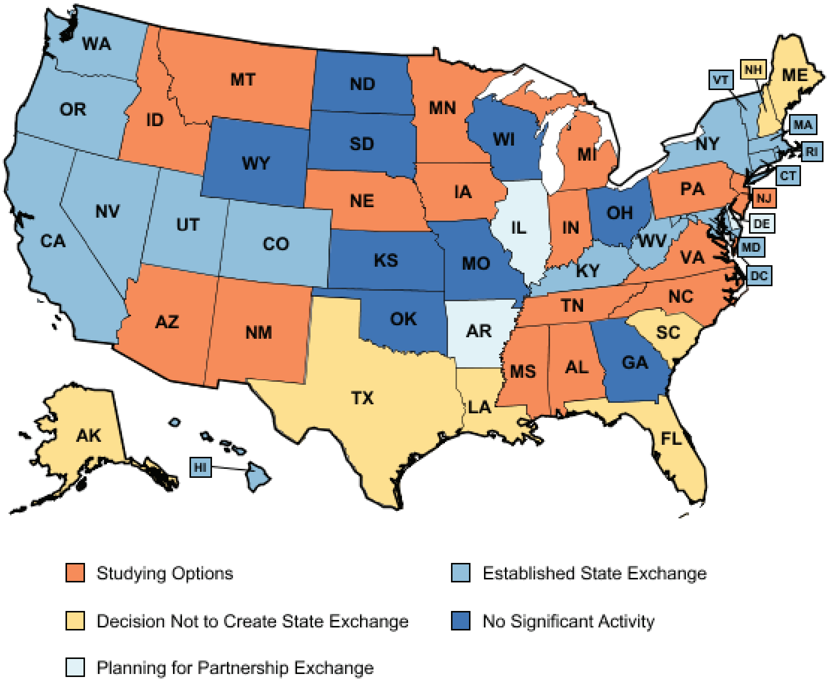

**FIGURE 2-4** State-based exchanges.
SOURCE: Kaiser Family Foundation.

options for exchanges are a state-based exchange (as in Connecticut), a federal partnership program, and a federal "default" exchange. Roughly 13 state-based exchanges are in the process of being established (see Figure 2-4).[2] Officials in some other states, however, have expressed their desire to do as little as possible to comply with the ACA.

According to Counihan, about 9.6 percent of the population of Connecticut—about 344,000 people—is uninsured. In the first year of the ACA's implementation, the state hopes to reduce that number by one-third. It hopes to enroll about 100,000 people in the exchange, with 85,000 in the individual market and about 15,000 in the small-group market, and another 30,000 covered from Medicaid expansion. A longer-term goal is to reduce the 9.6 percent rate to 2 to 3 percent, as in Massachusetts. "I think that is practical to do, although there are situations in the law that are very different than in Massachusetts." One issue is that the penalty for

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[2] The current number of states with exchanges is 19, as of July 2014.

not being insured in Connecticut is just $95, which is at more of a nuisance level and is unlikely to drive behavior. In Massachusetts, the penalty will be at the $1,000 level in 3 or 4 years, which is a level more likely to reduce the number of uninsured.

One concern of insurance companies has been that changes in the law would saddle the companies with high-risk patients, but Counihan cast doubt on this idea. Many people are uninsured because they consider themselves to be healthy and at low risk. Data about the health status of the uninsured are scarce, and much remains to be learned about the effects of the ACA. For example, small companies tend to know their employees better than large companies, which can make it more difficult for them to make decisions that result in a loss of coverage. "I always caution audiences not to think that the sky is going to fall when [the ACA] comes about, because that certainly was not the experience that we had in the one state pool on which this is clearly patterned."

In Connecticut, the exchange enrollment process will be defined by six major steps (see Figure 2-5). As of October 1, 2013, an individual, small business, broker, navigator, or in-person assistor will go to a website, AccessHealthCT.com, where he or she will be able to enter demographic and financial information. This information will be validated through a data hub by a series of federal and state agencies to determine eligibility. Plan options will be displayed and individuals will be directed into one of

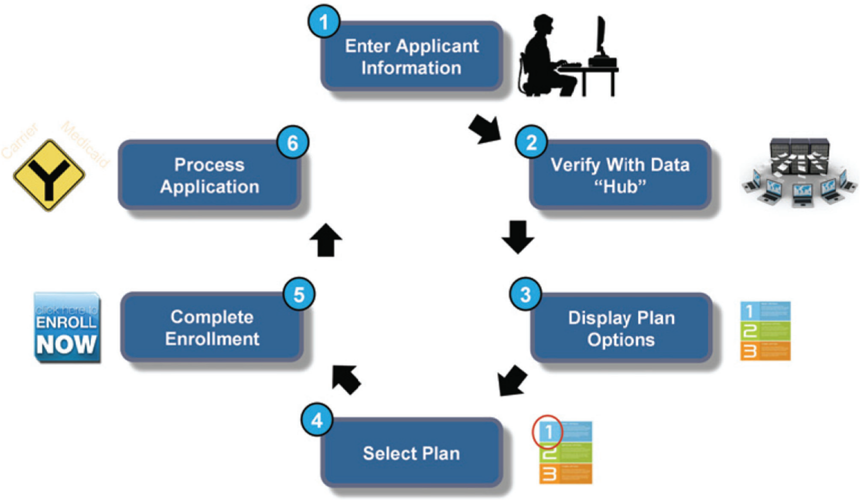

**FIGURE 2-5** The exchange enrollment process in Connecticut.
SOURCE: Counihan workshop presentation, April 22, 2013.

three areas: Medicaid, subsidized insurance, or unsubsidized insurance. The individual will be able to compare different plans, such as which benefits and which providers are included, and then choose the appropriate plan, with decision support tools available to help the individual make a choice. Once a decision is made, the individual will be enrolled in a plan and issued an identification card.

"Is this going to go smoothly all the time? Absolutely not," said Counihan. "Are there going to be times when the federal data hub is down? Yes. Are we going to build contingencies in place for when that happens? Yes we are. Is our system ever going to go down? You bet it is. But that's just the way things in life happen." Though the process appears to be complex, in Massachusetts enrollment took an average of just 22 minutes. "This is the type of enrollment experience that we aspire to."

Customer service, including an empathetic and effective call center, will be critical to the process, Counihan said. The uninsured tend to view buying insurance as confusing, complicated, and expensive. "When people get on the phone, we want them to feel comfortable and safe to ask any question, no matter how stupid they think it is, and not feel in any way they are being intimidated. For example, our call center is expecting that the average call is going to be between 20 and 30 minutes. . . . We're staffing up to that point, because we want people not to feel afraid and intimidated by calling."

Outreach will be important. It needs to be broad-based, so that it reaches everyone in a state. It also needs to be population-based, so that it reaches groups that have the lowest levels of insurance coverage. And it needs to work closely with navigator and in-person assistor programs, to enroll people and keep them enrolled. The one-on-one relationships at the community level made possible through in-person assistors will build trust and personal relationships. "Everyone talks about health care being local. It's completely true. That's also true about enrollment," said Counihan. Insurance is not a sexy product like an iPhone or a car. Lack of insurance is associated with poor health, and people tend to shy away from those thoughts. In Massachusetts, an organization of churches and synagogues called the Greater Boston Interfaith Organization went door to door to encourage enrollment. The Massachusetts program also partnered with the Boston Red Sox to do outreach. "There is a lot to be learned from consumer product marketing techniques in terms of enrollment and advocating for health insurance."

Counihan pointed out that the state-based exchanges have strong and detailed privacy and security features, which will be especially important in addressing concerns about federal agencies revealing personal information. "I am completely confident that we are going to be fully conforming with the security requirements of CMS in this, and I think that those requirements are going to be very sufficient and adequate." However, he acknowledged that the exchanges have not devoted sufficient attention to the concerns of people who fear government reviewing their personal data. "We need to think about it, and we haven't."

Technology will be a factor. In Connecticut, the zip codes of 85 percent of the uninsured are known, whereas those data did not exist in Massachusetts. Also, the collection and analysis of data will "provide a level of transparency around cost and [quality] which has been unprecedented in our state." For example, with these data, it should be possible to identify high-performing networks of providers and provide greater health care efficiency and value to particular populations.

Health care is a shared responsibility, Counihan said, especially since everyone has the potential of ending up uninsured if things go wrong. "We're all in this together, whether you're insured or uninsured, as a business or not. To make this work, everybody has to feel that they have a stake in this game." The system will not be perfect on the first day or even after several years. "This is going to take 3 to 4 years to settle down." People's expectations should be high but realistic. The program is "going to evolve and get better every year."

> "To make this work, everyone has to feel that they have a stake in this game."
>
> —*Kevin Counihan*

## REACTION AND DISCUSSION

The first question for the panelists was about what activities are taking place around informing and engaging new health insurance consumers. James noted that HHS has created a navigator program and the in-person assister programs to help educate people. Counihan added that the goal in Connecticut is to not only get people enrolled, but also to keep people engaged in their health over the long term.

Jeff Henderson of Black Hills Center for American Indian Health asked about HHS's plans to ensure coverage for American Indians and Alaska Natives under the ACA. Kevin Counihan responded that Connecticut has been "actively engaged" with the tribal leadership and they are working together on a policy. This policy will outline how best to engage the tribes, both in terms of access to coverage and in the communication of unique benefits for tribal members." James added that the secretary of HHS engages in consultation with tribes on a regular basis. She noted that HHS is focusing on the urban American Indian population, as this group has particular needs that are not met on a reservation.

Terri Wright of the American Public Health Association asked how the exchanges will be made available to individuals with low health literacy. She also said that there is an issue with trust, given that the data collected at the exchanges are shared with other federal agencies. Counihan responded that there is "a very strong and detailed privacy and security feature" to which exchanges must conform. With regard to reaching people with low health literacy levels, staff at the call centers and in-person assisters are trained to deal with these issues.

The final question focused on the requirements in the ACA for the collection of data on race, ethnicity, and primary language. The attendee asked about the scope of these requirements: do all commercial insurers have to do this? James responded that the requirements apply to activities supported and financed by HHS.

# 3

# The ACA and Health Equity

**Important Points Made by the Speaker**

- Children and their parents with gaps in insurance coverage have higher odds of experiencing unmet met medical needs and difficulty accessing health care. (DeVoe)
- Insurance needs to be affordable for families to have continuous coverage. (DeVoe)
- Information technology offers a way for insurers, educational services (including schools), medical homes, and social services and public health to share information designed to keep people covered by insurance. (DeVoe)
- Networks of patient-centered medical homes, community health centers, school-based health centers, rural health centers, and other organizations could constitute patient-centered "medical villages" that could share resources, develop and replicate best practices, and spread successful innovations. (DeVoe)

Keynote speaker Jennifer DeVoe, associate professor of family medicine at Oregon Health & Science University, identified several of the specific problems addressed by the ACA and possible ways of solving those problems. As both a family physician and a health services researcher, DeVoe focused in particular on the potential of innovation and evaluation to point the way toward advances in practice.

## CONTINUOUS VERSUS NONCONTINUOUS COVERAGE

Whether children are covered continuously by insurance over the course of 1 year is a major determinant of their health outcomes, DeVoe noted. Children with gaps in insurance coverage have higher odds of experiencing unmet medical needs and difficulty accessing health care. Even children with less than a 6-month gap in coverage had five times the odds of unmet medical needs (DeVoe et al., 2008). DeVoe noted that despite the availability of additional insurance programs for children in the past decade, children still experience preventable gaps in coverage, and those children whose parents lack continuous coverage are less likely to have continuous coverage themselves (Yamauchi et al., 2013).

Adults, too, have unmet medical needs when they are not continuously covered by insurance. Among more than 4,000 adults with diabetes who received health care services at federally qualified health centers (FQHCs) from 2005 to 2007, only 64 percent of those partially insured but 82 percent of those continuously insured had received cholesterol screening (Gold et al., 2012). In fact, according to these results, more but incomplete coverage is no better than less coverage.

DeVoe played a recording, collected during her research, of a parent who faced stark choices in paying for insurance (DeVoe et al., 2012):

> When we had jobs . . . we were able to do it, but there were times we'd have to pick, "Let's see, the first of the month, do we pay the insurance or do we pay the water, sewer, and electricity?" . . . If you have to choose between water and electricity and insurance that you're not using on a daily basis, you have to pick your utilities. . . . We doubled up the next month, and then after two times in a row we had to pay $550. . . . We just said, "We're cutting our throats, we can't afford to do this." So we just stopped the insurance, and it was hard because we wanted to keep the insurance for the kids. . . . That really hurt. I didn't want to have to do that.

In the first decade of the 21st century, insurance coverage for children increased somewhat, which offers lessons for the ACA, DeVoe said. She and her colleagues used the Medical Expenditure Panel Survey to evaluate trends in children's health insurance coverage from 1998 to 2009. During that time, the percentage of low-income children who had continuous insurance coverage over the course of 1 year, as opposed to discontinuous coverage or no coverage, rose from less than 70 percent to approximately 80 percent (see Figure 3-1). In contrast, insurance coverage for middle-income children fluctuated but held at slightly more than 80 percent; toward the end of that period the middle-income group had a rise in coverage gaps, and insurance coverage for upper-income children remained stable at about 90 percent. Also, older children were more likely to have gaps, whereas younger children

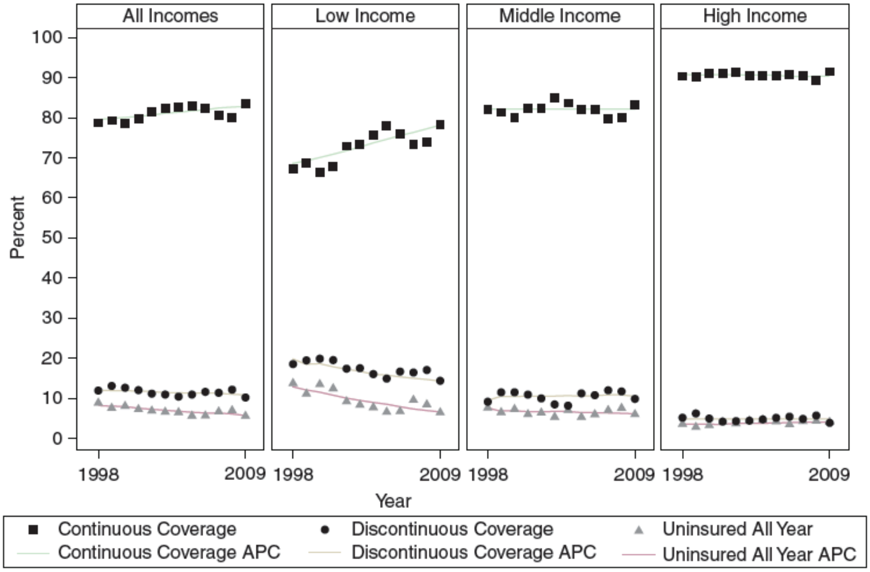

**FIGURE 3-1** Child health insurance continuity by family income, 1998–2009.
NOTE: APC = annual percent change.
SOURCE: DeVoe workshop presentation, April 22, 2013.

were less likely, and racial and ethnic disparities were somewhat reduced. Disparities persist, she said, but "some progress" has been made in closing the gap in insurance coverage.

However, as more children have gained coverage, their parents have lost coverage (see Figure 3-2). This is especially the case among low-income parents, which puts their children at risk of insurance gaps. If both parents have coverage gaps or are uninsured, a child is 10 times more likely to experience a coverage gap, said DeVoe. "The parents really matter in terms of keeping the kids covered, . . . and that number is still very high."

> "The parents really matter in terms of keeping the kids covered."
>
> —*Jennifer DeVoe*

In many ways, insurance is "all or nothing," said DeVoe, adding that "you have it continuously or you don't. . . . We really need to work on getting people continuously covered."

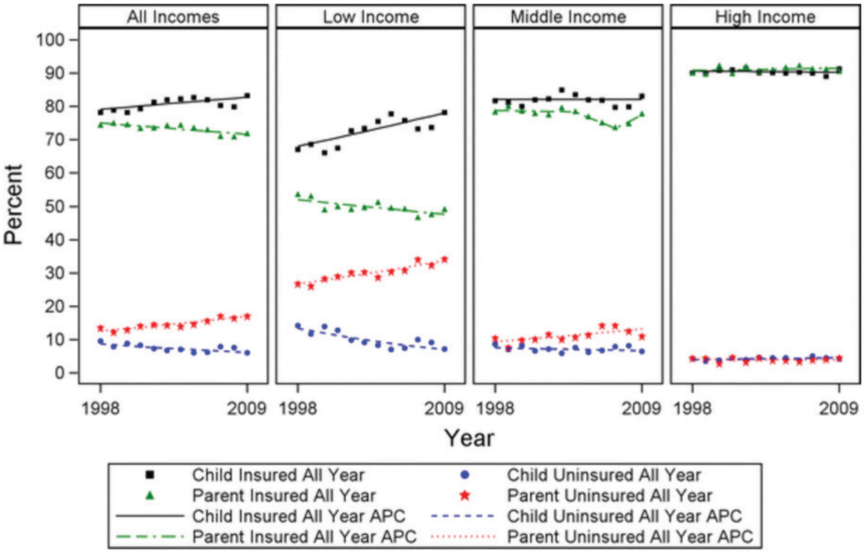

**FIGURE 3-2** Child and parent full-year health insurance status, 1998–2009, by family. Source data medical expenditure panel survey-household component, 1998–2009 APC annual percentage change.
NOTE: APC = annual percent change.
SOURCE: DeVoe, 2013. With kind permission from Springer Science and Business Media.

## THE AFFORDABILITY OF INSURANCE

Coverage also needs to be affordable, said DeVoe, playing another audio clip from a parent:

> At this point the health coverage my husband has offered to him through his job is so astronomically expensive, it's almost like, "Holy crap, why did you sign up for that?" . . . They [the kids] will [soon] be on his insurance, but I honestly don't know how we'll pay for it. If it's too much more than $600 a month, I don't know how we'll pay for it.

Employee premiums and out-of-pocket costs are currently rising much faster than family incomes. If current rates were extrapolated into the future, the average household would be paying half its income in health care costs by the year 2030 and all of the family's income by 2040.

These rates of increase will have to change quickly for insurance coverage to be affordable, said DeVoe. Today, middle-income families are already cutting back on elective expenses to cover health care costs, but low-income families are cutting back on essentials. Families often face a choice of whether to pay for health insurance or to pay for the medical needs that are not covered by insurance, such as glasses, orthodontics, counseling, and uncovered medications. Either benefits packages need to be adequate to cover what families need, or, if packages are more limited, they need to be affordable enough for families to buy the things they do not cover.

DeVoe also discussed the importance of health care beyond health insurance. The ACA focuses on insurance, but insurance needs to be accepted by providers and cover the services that are needed. Even with insurance, costs can be high because of deductibles, copays, and uncovered expenses. When costs are high and people with medical problems face difficulties paying for care, they have an added emotional burden.

The United States already spends much more money on health care than other high-income countries, yet its population has worse health status than the populations in those countries. Furthermore, as health care costs continue to rise, other valuable investments, such as spending on education, are inevitably squeezed.

## RETAINING THE SAFETY NET

The idea that an expansion of insurance will eliminate the need for community health centers and other safety net providers of health care is a "myth," said DeVoe. The safety net in health care will need to be strengthened, not eliminated. Studies in Massachusetts have shown that as insurance coverage expanded, the demand for safety net services increased, and the same thing has occurred in Oregon (Ku et al., 2011a,b). For example, DeVoe's group studied insured people with diabetes and found that they used safety net services more often than those who are partially insured or uninsured (Bailey et al., 2015; Gold et al., 2012).

Uninsured people may not be eligible for insurance even under the ACA, and for them, FQHCs will continue to be vital. Also, as partially insured and uninsured patients gain coverage, they are more likely to use the safety net for services that they have delayed or have not been able to afford. "As more and more people get health insurance, the safety net is going to be used much more frequently, and we're going to need to be ready with the workforce to meet that demand." For this reason, said DeVoe, the ACA's provisions for expanding FQHCs and the National Health Service Corps need to be supported.

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> "As more and more people get health insurance, the safety net is going to be used much more frequently."
>
> —*Jennifer DeVoe*

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## CARE MODELS

DeVoe discussed several different models that could both extend coverage and ensure that coverage remains in effect.

One model involves new linkages among four different groups: insurers, educational services (including schools), health homes,[1] and social services–public health. New information technologies provide ways of sharing information about the patient among these four components as well as with the patient. For example, DeVoe and her colleagues have been studying the use of electronic health records (EHRs) to monitor children's health insurance status through community health centers. They analyzed more than 185,000 children who had a visit to a community health center and found that about one-fifth of the children were uninsured, including many of whom were likely eligible for the Children's Health Insurance Program and more than half the uninsured children continued to be uninsured at subsequent visits (Hatch et al., 2013). Using information technologies, the group has been building tools to connect children with the health insurance products for which they are eligible and keep them enrolled. Data from the EHR are available for outreach and "in-reach" efforts to inform health care providers and social services workers about insurance applications and enrollments (see Figure 3-3). Text messages and emails can then be sent to social workers and others to notify them about new and existing insurance products and to monitor coverage over time. The group will be testing the effectiveness of these tools in pilot clinics over the next several years.

Another model relates to what is known as the "ecology of health care" (see Figure 3-4). In any given month, among an average sample of 1,000 people in the United States, 800 report some sort of symptoms, more than 300 consider seeking medical care, more than 200 visit a physician's office (half of that in a primary care physician's office), 65 visit complementary or alternative health care providers, 13 visit emergency departments, 8 are hospitalized, and 1 is hospitalized in an academic medical center (Green et al., 2001). However, academic health centers are where the health care system trains new providers and does the majority of research, DeVoe pointed out.

To expand the number of sites where training and research take place, health care services need to be better organized, coordinated, and delivered. Primary care is the foundation of health care, DeVoe stated, and the Primary Care Extension Program, which has been authorized but not funded, could speed the transformation of primary care centers into a hub for

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[1] As defined under the ACA, a health home provides comprehensive care management, care coordination and health promotion, comprehensive transitional care, patient and family support, referral to support service, and use of information technology to link services (if applicable).

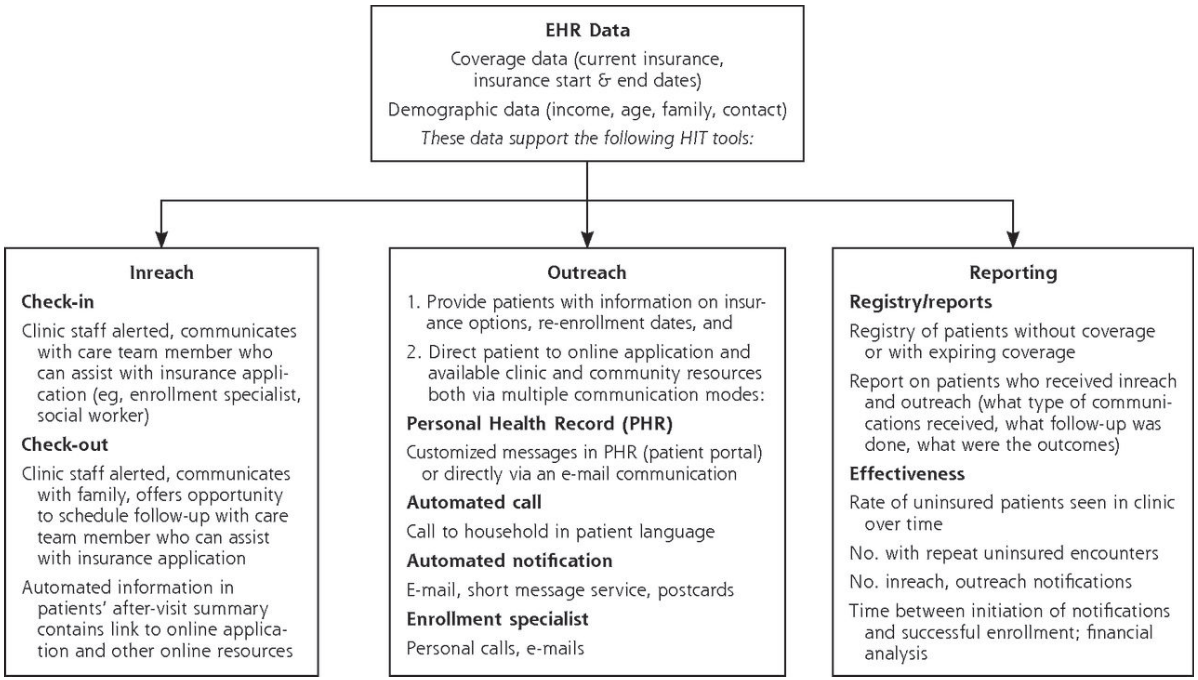

**FIGURE 3-3** Electronic health record data.

NOTE: EHR = electronic health record; SMS = short message service, commonly known as text messages.

SOURCE: Angier, 2014. Adapted or reprinted with permission from Health Information Technology: An Untapped Resource to Help Keep Patients Insured, November/December, 2014, Vol. 12, No. 6, Annals of Family Medicine Copyright © 2014 American Academy of Family Physicians. All Rights Reserved.

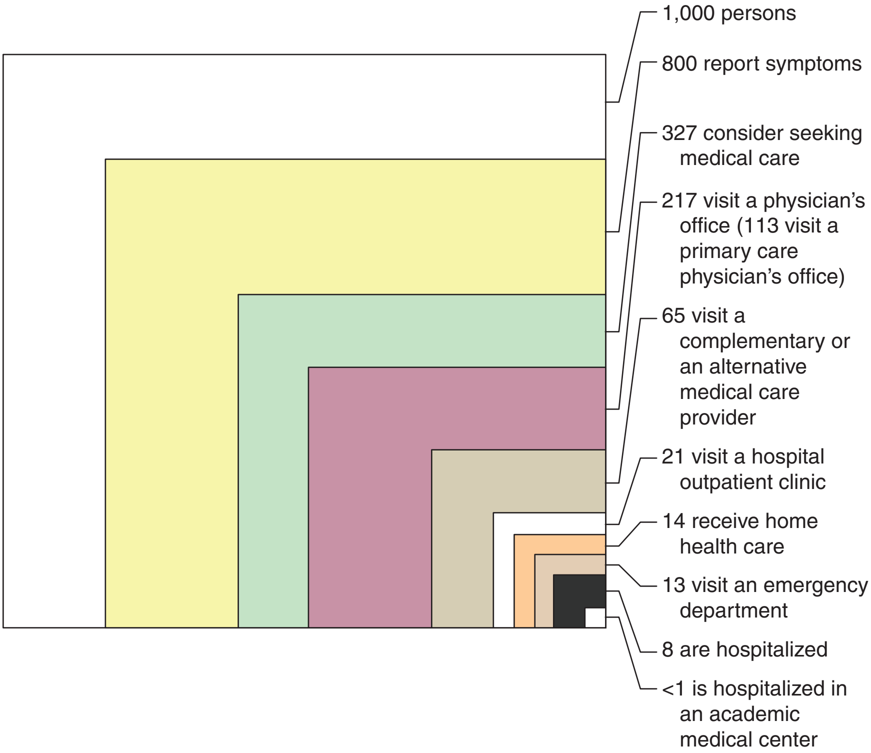

**FIGURE 3-4** Symptoms versus hospitalizations.
SOURCE: Green et al., 2001.

training and research. Networks of patient-centered medical homes could allow the sharing of resources and the development and replication of best practices, with primary care "champions" spreading innovations. More training sites in the community would allow medical residents to provide care while learning in settings where care is needed.

As an example, DeVoe cited the OCHIN group, with which she has been involved. An independent nonprofit founded in 2002 and headquartered in Portland, Oregon, OCHIN is one of the nation's largest health information networks and is recognized for its innovative use of information technology to improve the integration and delivery of health care services across a wide variety of practices. OCHIN has demonstrated how health homes, community health centers, school-based health centers, rural health centers, and other organizations could be organized into a patient-centered medical village that would use information technologies and data sharing to integrate public health and primary care (see Figure 3-5).

At the same time, DeVoe pointed to the need for more research to continue surveillance and to develop and test solutions. Continued research on disparities is needed to monitor changes, to determine which problems are being fixed, and to identify new problems. Funding agencies need to make strategic investments in innovative solutions and evaluate the effectiveness of innovations. Demonstration projects for the transformation of primary care need to be continued and expanded through the use of community laboratories that support the development of the primary care infrastructure. As an example of infrastructure development, DeVoe highlighted that OCHIN is part of a larger network funded by the Health Resources

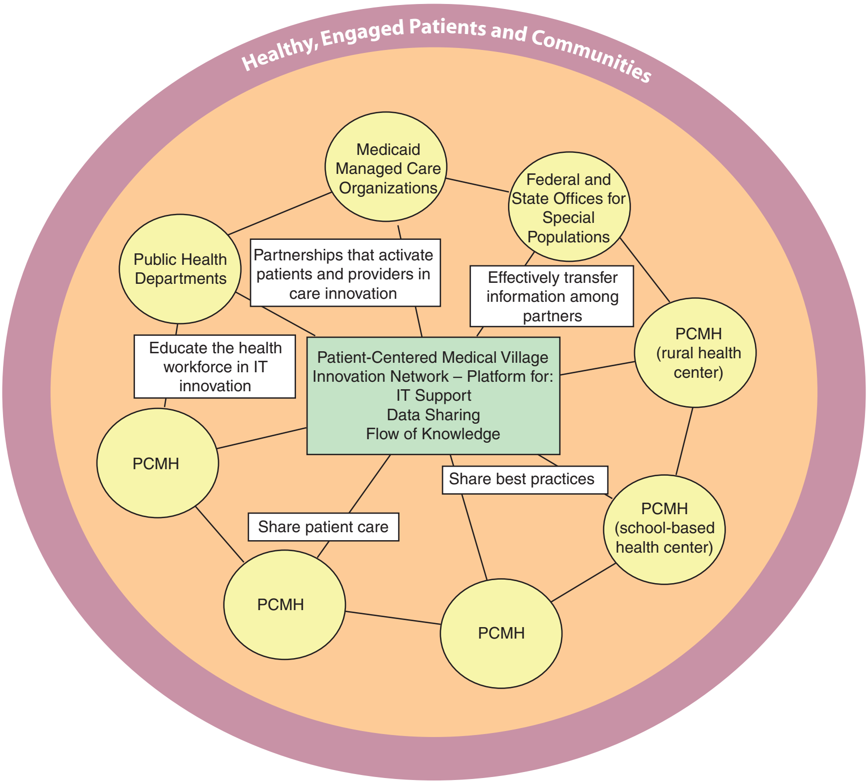

**FIGURE 3-5** Information technologies and building patient-centered medical bases.
NOTE: IT = information technology; PCMH = patient-centered medical home.
SOURCE: DeVoe and Sears, 2013.

and Services Administration that focuses on research that is applied in a community setting. Such networks could help move training, research, and innovation out of academic health centers and into communities.

## AN UNPRECEDENTED OPPORTUNITY

DeVoe concluded with an audio recording of another parent interviewed in her study:

> Maybe they've never been poor, or had to live in their car, or had to stand in line for food, maybe they've never been there. . . . Maybe they need to walk in those people's shoes and hear from those people. . . . There are people that really just want to provide the best home they can for their kids and the best environment, and part of that is being able to treat their kids when they're sick and not worry about where the money is going to come from.

The ACA poses some risks, DeVoe acknowledged, such as the possibility that employers will reduce employees' hours to avoid providing them with health insurance. Also, some of the programs authorized by the ACA have not been funded in a sustainable way, such as the Primary Care Extension Program and teaching health centers.

Nevertheless, the ACA offers an unprecedented opportunity, DeVoe said. Health equity is about ensuring that people in the United States have their basic needs met, and one of those basic needs is access to health insurance and health care. "There are going to be struggles, . . . but we need to make sure that we're doing all the good we can with the means that we have."[2]

"There are going to be struggles, . . . but we need to make sure that we're doing all the good we can with the means that we have."

*—Jennifer DeVoe*

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[2] This session did not include a question-and-answer period.

# 4

# The Patient-Centered Medical Home

**Important Points Made by the Speakers**

- Financial, cultural, or linguistic barriers can result in health care that is fragmented and uncoordinated. (Wong)
- The patient-centered medical home—a relationship with a health care provider and health care team that knows a person's health issues and is accountable for taking care of that person—offers multiple opportunities to advance health equity. (Bau)
- Performance standards for patient-centered medical homes can drive quality improvements, but feedback needs to be immediate and continual. (Bau)
- Many people tend not to see issues around diversity, disparities, and equity to be a concern, and the complexity of the ACA has detracted from the necessary discussion around diversity. (Andrulis)

In introducing the session on patient-centered medical homes, Winston Wong, director of disparities improvement and quality initiatives at Kaiser Permanente, recounted the story of Mr. Kwong (not his actual name), whom Wong met in the community clinic where he sees patients. Mr. Kwong was a recent immigrant from China who was struggling with hypertension, arthritis, and other problems. After a period when Mr. Kwong was not seen at the clinic, Wong learned that he had suffered an acute psychotic break. "I was haunted by the fact that, as a primary care physician, I had not known that he had been hospitalized in such a situation," Wong recalled. Mr. Kwong did not know English, and the institution into which he was placed probably did not know his linguistic issues, family situation, or cultural competency issues. "What could I have done for Mr. Kwong?" Wong asked. "How could we have made Mr. Kwong's experience one that we would have said that we could be proud of?"

Mr. Kwong's situation happens repeatedly in the U.S. health care system, Wong continued. Because of financial, cultural, or linguistic barriers, the care that patients receive may be fragmented and uncoordinated. Furthermore, the social determinants of health may compound those barriers. For someone like Mr. Kwong, who lived in a single-room residence hall with few support services or points of contact with other people, coordination is a great challenge.

Caring for such patients will require a multifaceted approach, explained Wong, including

- Supporting and coordinating care across the care delivery experience;
- Addressing cultural, linguistic, social, and financial factors that affect clinical outcomes;
- Involving multidisciplinary health care teams across the continuum of care; and
- Supporting institutions so that they provide the best possible care to their patients.

Two other speakers at the workshop explored these and other aspects of patient-centered medical homes. Both emphasized the promise of the ACA to promote racial and ethnic equity as well as the many practical difficulties that must be overcome to realize this promise.

> "How could we have made Mr. Kwong's experience one that we would have said that we could be proud of?"
>
> —*Winston Wong*

## STANDARDS FOR PATIENT-CENTERED MEDICAL HOMES

The term "patient-centered medical home" may not be the best name for the concept, said Ignatius Bau, who has been a consultant to many different groups on how to meet the needs of vulnerable populations. It is too narrow because it refers to a place more than to a relationship. A patient-centered medical home is essentially a relationship with a health care provider and health care team that knows a person's health issues and is accountable for taking care of that person.

Patient-centered medical homes offer multiple opportunities to advance health equity. For example, community health centers could improve their quality outcomes and their competitiveness in today's health care market by becoming patient-centered medical homes. The Health Resources and Services Administration and Centers for Medicare & Medicaid Services (CMS) are helping community health centers make the transition. At 500 sites around the country, federally qualified health centers are taking part in demonstrations of Advanced Primary Care Practice, which are designed to result in the development of patient-centered medical homes. Similarly, many public hospitals with ambulatory clinics are moving in this direction. Such hospitals often function like community health centers in the neighborhoods where they operate, said Bau. "Their challenge is to say they're not just a walk-in place where you can go when you have no place else to go, but you can come to the hospital clinic's medical home where you have a consistent provider who knows who you are and what your needs are," he explained.

Individual and small medical practices can also serve as medical homes. Bau pointed to data from the 2010 National Ambulatory Medical Care Survey that reported that most office visits occur in physicians' offices, rather than community health centers or hospital clinics. Furthermore, many of these offices are small, with just one or two providers. A study with which Bau was involved—conducted by the California Medical Association Foundation and looking at racial and ethnic minority doctors in California—found that these physicians are in fact part of the safety net but are not recognized as such (Maas et al., 2008). They accept Medicaid, Medicare, and uninsured patients or do not charge their patients. A similar study of Asian American physicians (Bau and Tran, 2012) reported similar findings, said Bau. These practices, too, need to be included in the movement toward medical homes, and organizations such as the National Committee for Quality Assurance (NCQA, 2009) and the Center for Health Care Strategies (CHCS, 2010) are providing support for this transition.

The National Committee for Quality Assurance (NCQA) has established six standards for patient-centered medical homes, and Bau discussed how each could affect health disparities.

### 1. Enhance Access and Continuity

Providing access to continuous care requires culturally and linguistically appropriate services, which entails assessing the racial and ethnic diversity of one's patients, assessing the linguistic needs of one's patients, providing interpretation or bilingual services to meet those needs, and providing printed materials in the appropriate languages. For practice teams, this standard includes training and assigning care teams to support patients and families in self-management, self-efficacy, and behavior change; training and assigning care teams for patient population management; and training team members in communication skills and designating team members to be responsible for communication. Medical homes should be explained to patients in a culturally and linguistically appropriate way, patients should be matched with culturally and linguistically concordant providers and care teams, and team members should reflect the patient population.

### 2. Identify and Manage Patient Populations

The standard for identification and management of patient populations mirrors the meaningful use requirements for electronic health record incentive payments, Bau observed. It calls for the use of an electronic system that records race, ethnicity, and preferred language as structured (and thus searchable) data for more than 50 percent of patients, with the suggested proportion being 80 percent at a later stage. It also asks for information about family, social, and cultural characteristics and communication needs as part of a comprehensive health assessment. Who are the patient's caregivers and support network? Who needs to be involved and informed about the patient's care plan? Does the patient use the Internet? Does the patient use mobile technology? "All that is part of that assessment," Bau said. This information can document granular demographic information, provide information about health disparities and additional relevant screenings, and identify cultural, linguistic, and literacy barriers to care for high-risk and high-need patients.

### 3. Plan and Manage Care

Every patient needs a care plan with individualized goals. This requires health care providers to engage the patient, family, and caregivers in the care plan and shared decision making about care. The care plan needs to be culturally and linguistically appropriate. Similarly, patients, families, and caregivers need culturally and linguistically appropriate tools to make informed decisions about treatment options. Bau explained that "our Western, American way of autonomy, where everything is about 'my decision,' isn't going to work in a family context in which those decisions are made by the family, or the wife is deferring to the husband. So are you then engaging that entire family in the decision-making process?"

Making and sticking with a care plan will require time and an ongoing relationship with a medical home provider, said Bau. "You're going to create it, you're going to work on it, you're going to change it, you're going to continue to come back to it," he added.

### 4. Provide Self-Care and Community Support

Making a shared plan for care that is centered on the patient requires that the patient and community be empowered. Providers and community health centers will need to address the social determinants of health over which they do not have much control but they can provide linkages, coordination, and referrals. The current standards are "gentle," said Bau, and currently require the provision of educational resources or referrals to at least 50 percent of patients and families to assist with self-management, use of an electronic health record to identify patient-specific educational resources and provision of these resources to more than 10 percent of patients if appropriate, and maintenance of a current resource list on five topics or key community service areas of importance to the patient population. "It's a start," said Bau.

Effective self-care and community support are particularly challenging in the context of health equity because they require access to health information in multiple languages, channels, and formats and the use of community resources that are focused on diverse communities and health disparities. Community-based organizations have already done good work on patient-education materials that need to be in the hands of medical homes, said Bau. Community-based organizations such as mental health, substance abuse, and social services organizations must assess their role in health care reform. They need to ask their clients where they go for medical care. They then need to become partners with those providers, because the providers will not be able to offer all of the services expected of a medical home. "There is shared responsibility here. We all need to step up as well to offer the resources. If you are in the community, you need to be on that list of community resources that medical homes know about so that those patients can come to you for the services that they need," he added.

### 5. Track and Coordinate Care

The tracking and coordination of care is the heart of the medical home concept. When a provider makes a referral, is the specialist going to be able to speak the patient's language? Will laboratory results be provided to the patient in a language and in a way that the patient can understand? A medical home will not necessarily be able to control other providers in the community, but a primary care provider has the obligation to be an advocate for patients vis-à-vis other providers.

That is one problem with the term "patient centered," said Bau, adding that "in many of our communities, it's not just about me as the patient. It's about me, plus my family, the caregivers, and the community." Care coordination recognizes these interdependencies by recognizing the roles of families, caregivers, communities, and patients to better engage patients.

### 6. Measure and Improve Performance

The driving force of patient-centered medical homes is outcomes. Does health get better? "We're holding medical homes accountable," Bau emphasized. Performance data need to be gathered and stratified for vulnerable populations in order to assess disparities in care. Furthermore, this process must start on Day 1 in the medical home so that feedback is immediate and continuous. This feedback also needs to come from patients and families through qualitative means. "We want specific feedback from those populations we usually don't hear from and we usually overlook," he said.

Medical homes need to implement continuous quality improvement to reduce disparities. This effort will require engaging patients and families in quality improvement teams or on a practice's advisory council, oversampling vulnerable patients for feedback on their experience of care, improving the patient experience for vulnerable populations, and engaging diverse patients in improvement efforts.

Quality improvement programs save money, but the savings can be hard to demonstrate because of the complexity of life and health, said Bau. The goal needs to be to move practices along a quality improvement and equity continuum.

### Diversity in Implementation

Patient-centered medical homes are being implemented in many different ways. For example, medical homes in Minnesota receive additional payments if they have a linguistically diverse patient base. Connecticut has made the reduction of racial and ethnic disparities a critical goal in its implementation of medical homes. In San Francisco, California, the Healthy San Francisco program, which provides health care regardless of immigration status or income, requires that patients choose a medical home, and the Healthy Way LA program in Los Angeles, California, takes a similar approach.

The answers will be different from one place to another, said Bau, depending on the stakeholders and the providers. He explained that "what Vermont can do is not what California can do. What San Francisco can do is not necessarily what Connecticut can do." Markets may be based more on regions than on states or counties, though counties may work together to create regional systems.

Bau closed with four recommendations based on his experiences with patient-centered medical homes:

- Educate diverse and vulnerable patients, families, and caregivers about medical homes and engage them in the use of medical homes.
- Highlight opportunities to reduce disparities and promote health equity, including the establishment of additional requirements and payments, when establishing medical home initiatives.
- Each patient-centered medical home should monitor the NCQA standards specific to health equity to ensure compliance with these standards. The NCQA framework is still evolving, and issues such as patient-centered care and equity require continued advocacy.
- Develop and disseminate technical assistance to medical home practices to achieve health equity.

Providers have an uphill climb to become a medical home, Bau said. They need assistance, guidance, and support to achieve the promise of health equity as they move toward this new vision of health care.

> "In many of our communities, it's not about me as the patient. It's about me, my family, the caregivers, and the community."
>
> —*Ignatius Bau*

## LEVERAGING OPPORTUNITY IN A CHANGING HEALTH CARE LANDSCAPE

The ACA is like a roundhouse with many trains (that is, the law's provisions) that are leaving and heading in different directions and at different speeds, said Dennis Andrulis, senior research scientist at the Texas Health Institute and associate professor at the University of Texas School of Public Health. Some of the trains are barely moving, whereas others are roaring down the tracks. The provisions of the ACA are filled with variation, he said, "and those variations are fraught with both opportunity and concern."

The Texas Health Institute has been monitoring about 60 provisions related to race, ethnicity, equity, language, and culture that are part of the ACA, with a particular focus on five broad areas:

1. Health insurance exchanges;
2. The health care safety net;
3. Workforce support and diversity;
4. Data, research, and quality; and
5. Public health and prevention.

Reports are being released in each of these areas and the report on health insurance exchanges—the first in the series—was released 1 month before the workshop (Andrulis et al., 2013). That report, which synthesizes information from interviews, the literature, and other sources, cited Connecticut as one of the states that has done the most to establish health insurance exchanges. It also provided recommendations for states that are actively moving ahead and for those states that are lagging behind.

Ten provisions in the ACA explicitly mention "health homes" or "medical homes." Those 10 provisions also specify priorities for advancing racial and ethnic equity. Andrulis divided these 10 provisions into four categories: state actions, workforce and delivery of care, research and innovation, and insurance and payment. Some of these trains are already leaving the station, he said, whereas others have not made it out of the gate.

## State Actions

The ACA created a state option to provide health homes for Medicaid enrollees with chronic conditions. At the time of the workshop, 10 states had approved health home plans: Idaho, Iowa, Maine, Missouri, New York, North Carolina, Ohio, Oregon, Rhode Island, and Wisconsin. Currently, equity activities in state health homes include the provision of culturally and linguistically appropriate patient communication and individual and family support, evidence-based culturally sensitive wellness and prevention activities, and patient health assessments that include measures of language and cultural factors. States that have undertaken these activities can qualify for 2 years of enhanced federal funding to be used for the development of coordinated care for patients with chronic conditions and patients with mental illness.

Though the advantages of health homes that focus on chronic conditions or mental illness have not yet been demonstrated, Andrulis said, these initial steps to target specific populations may be of value. In particular, information from these initial steps can inform efforts in other states.

Under the ACA, states with Medicaid 1115 waivers[1] that explicitly focus on health system restructuring may consider using matching funds to test health homes for diverse patient populations. Some states are using this provision to undertake initiatives not directly supported by the ACA, such as using community health workers to support health homes and advance equity.

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[1] Medicaid 1115 waivers are granted by the Secretary of HHS to states that want to create demonstration or pilot projects. This is so the state will have added flexibility to design and improve their Medicaid programs.

## Workforce and Delivery of Care

Several provisions of the ACA link health homes directly to workforce development and service delivery. One example is the use of funding from the Health Resources and Services Administration for training, curriculum development, and continuing education for primary care residencies and physician's assistants. Another example is the use of health extension agents in four states (New Mexico, North Carolina, Oklahoma, and Pennsylvania) to further the adoption of medical homes that prioritize cultural competency and the use of the patient's language.

Andrulis suggested that three areas related to equity should be monitored within workforce and delivery initiatives. The first area is to evaluate training curricula. How are cultural competency, language, and health literacy addressed in training providers in implementing health homes across professions? The second is to identify supportive best practices. What actions support equity in health homes? The third is to measure equity-focused processes and outcomes. What are the effects of these initiatives on patient satisfaction, quality improvement, disease management, and treatment adherence?

Another opportunity to advance racial and ethnic equity through the workforce and the delivery of care is the expansion of health home and equity programs to other practice settings supported by the ACA, including teaching health centers, nurse-managed clinics, and school-based health centers. For example, Maryland is coordinating its workforce efforts with the Governor's Health Care Reform Coordinating Council to improve access to care and highlight team-based approaches to care.

## Research and Innovation

One of five research priorities for Patient-Centered Outcomes Research Institute (PCORI) (see Chapter 6) is health disparities. In addition, the CMS Innovation Center has been making grant awards for research on primary care, payment, and delivery, though relatively few have explicitly addressed racial and ethnic equity. Andrulis also cited the Advanced Primary Care Practice demonstrations as an opportunity to make progress on equity issues.

Evaluations could consider disparities in outcomes at different health homes, the metrics used to evaluate the effects of interventions to achieve equity in health homes, and short-term as well as long-term outcomes. Other community initiatives funded by the ACA may yield progress on these issues. For example, Community Health Needs Assessments (see Chapter 5) can provide both information and support for goals such as the establishment of medical homes.

## Insurance and Payment

The trains have been much slower to leave the station in the areas of insurance and payment, Andrulis said. The ACA encourages health plans offered through the exchanges to incentivize providers to improve health outcomes by adopting health homes or taking other actions to reduce disparities, though little or no federal guidance has been provided thus far. Rules on quality reporting in health plans that reimburse providers for the use of health homes are expected, but the focus has been on getting the health plans offered through the exchanges up and running.

The overriding need is to integrate and align key features of medical homes with the plans offered through the exchanges and active purchasing to advance equity, said Andrulis. For example, exchanges opting to be "active purchasers" may require health plans to implement quality improvements that include quality reporting, establishment of the features of health homes, and the actions that they will take to address racial and ethnic disparities in health and health care. Another promising option is to encourage pilot payment programs to test new patient-centered models of care, including health homes that disproportionately serve diverse patients.

## Continuing Challenges

Andrulis mentioned several challenges determined, in part, from conversations that he and his colleagues have had with people around the country. Currently, many people tend not to see issues around diversity, disparities in health and health care, and equity as a priority to be addressed through the ACA. As a result, these issues tend to be overlooked or equity provisions are not well funded.

The complexity of the ACA has also detracted from the necessary discussion around diversity and cultural competency, said Andrulis. People tend to be overwhelmed by what the ACA is asking them to do and are struggling with change at a broader level. Deadlines are looming, and guidelines are insufficient. Political forces are also hard to predict and control.

Furthermore, some health care providers are engaged in competition rather than collaboration. For example, an important incentive for community health centers is enrollment, and some centers are concerned about losing their base. As one safety net interviewee stated, "How do providers navigate this new system while keeping their souls intact?"

Finally, Andrulis mentioned the issue of siloes. Currently, hospitals are focused on procedures like surgeries, not on prevention. "There are these business silo elements that need to be considered," he said.

Again, Andrulis mentioned several key areas to monitor.

### *Policy and Advocacy*

- State-level uptake of health homes and integration of equity objectives
- Federal guidance and rules for health homes and integration of equity

### *Research and Innovation*

- Integration of equity into announcements of funding opportunities, outcomes research, and metrics on health homes
- Inclusion of metrics on health homes by race and ethnicity, for example, continuity of care, access, quality, disease management, and adherence

### *Workforce and Delivery*

- Training in cultural competency and diversity in health homes
- Impact of scope-of-practice laws in states on health homes and access for diverse patients

### *Payment and Exchanges*

- Market-based incentives for health homes and reductions in disparities in health and health care
- State active purchasing requirements[2] and the inclusion of health homes and equity

Efforts to break down siloes and integrate care are still at a small-scale, demonstration level. States will eventually have to take the next step. Active purchasing may be a small step, Andrulis observed, but it is a step in the right direction. Some safety net providers are aggressively pursuing opportunities for change and transformation, and some hospitals are trying to move toward community-based and integrated care, but the examples are still rare.

It is still early in the process, Andrulis said, adding that "this is such a major redirection of the health care world. Don't look so much to the past. Look to what's coming out."

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[2] Active purchasing in those states with state-based exchanges means that those states must help organize the insurance marketplace and promote competition among health plans.

> "This is such a major redirection of the health care world. Don't look so much to the past. Look to what's coming out."
>
> —*Dennis Andrulis*

## DISCUSSION

Cheri Wilson of the Center for Health Disparity Solutions at the Johns Hopkins Bloomberg School of Public Health asked the first question, which focused on the NCQA standards. She wondered why those standards did not incorporate the NCQA multicultural health care standards into the overall framework. Bau responded that this is an evolving concept, and what is needed is to advocate that NCQA incorporate the patient-centeredness and equity pieces into the overall framework.

Ned Calonge of The Colorado Trust asked about the fact that in his home state (Colorado), the hospitals there are still concerned about "filling their beds." Andrulis raised the idea of an active purchasing model that might be a place to begin. Additionally, Andrulis believes that some hospitals are recasting themselves toward more community-based care. Andrulis also noted that the readmissions issue was one potential trigger for hospitals.

The final question was about the concept of a "neighborhood home." A participant wondered how local agencies and community-based organizations can get a seat at the table.

Bau responded that the best way to begin is to ask the organization's clients where they receive medical services. Those clinics can then become a partner with the community organizations.

# 5

# The Safety Net and Beyond

**Important Points Made by the Speakers**

- Federally qualified health centers (FQHCs) are well positioned to serve as efficient and high-quality patient-centered medical homes if given the proper resources. (Fiscella)
- Better care for the 2.2 million people who are in prison or jail will be essential to reduce health disparities. (Fiscella)
- Health information technology could enable planning, needs assessment, accountability, efficiency, and care processes that promote equity. (Fiscella)
- The community health needs assessments required of tax-exempt hospitals can be an important lever for health equity. (Somerville)

Safety net institutions such as FQHCs, free clinics, and local hospitals will continue to play a pivotal role in reducing health disparities under the ACA. These institutions are embedded within their communities and understand the challenges faced by the people they serve. However, there are some key issues that these facilities must address under health care reform, such as financing, workforce issues, and moving toward integrated systems. Two speakers discussed ways in which policy actions could foster more effective and efficient operations of these vital organizations.

## ALIGNING RESOURCES AND NEEDS WITHIN THE SAFETY NET

Ten years ago the state of Delaware decided to make disparities in outcomes from colorectal cancer[1] a statewide priority, said Kevin Fiscella, professor of family medicine and public health sciences and associate director of the Center for Communication and Disparities Research at the University of Rochester Medical Center. The state made colonoscopies affordable for the uninsured, paid for treatment for those with cancer, and partnered with community-based organizations at a grassroots level using navigators.[2] Over the course of the decade, Delaware increased rates of colorectal cancer screening among African Americans by 50 percent, which completely closed the gap in colorectal cancer screening between whites and African Americans; eliminated the disparity in colorectal cancer incidence according to the stage of diagnosis; and virtually closed the gap in colorectal cancer mortality according to race or ethnicity. "It is possible when there is commitment and one truly turns that commitment into action," he stated.

Fiscella built his presentation around 11 recommendations that he labeled "provocative."

### Fiscella's Recommendation 1: Adopt the National Quality Forum's definition for health care disparities.

The National Quality Forum has defined health care disparities as "differences in health care quality, access, and outcomes adversely affecting members of racial and ethnic minority groups and other socially disadvantaged populations" (NQF, 2012). Other definitions have become outmoded, Fiscella said, and a common definition is needed to establish a common base of reference.

### Fiscella's Recommendation 2: Adopt blended payments for FQHCs, such as prospective payment systems, in addition to global payments, through affiliations with accountable care organizations (ACOs).

FQHCs and correctional facilities (jails, prisons, and detention facilities) are the providers of primary care to a large group of socially disadvantaged patients, and both are under-resourced relative to patient needs. FQHCs serve more than 22 million patients across the country, are patient operated,[3] culturally diverse, and mission driven, with services being based on documented community needs assessments. They provide comprehensive services

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[1] Although colorectal cancer rates have declined among whites, rates have increased for African Americans.

[2] For reports on the project, see http://www.dhss.delaware.gov/dhss/dph/dpc/consortium.html (accessed July 26, 2013).

[3] This means that at least 50 percent of the board of directors for an FQHC must be actual patients of that FQHC.

that research has shown to be of high quality and efficiency. They are well positioned to implement the patient-centered medical home concept if they are given the proper resources.

Payment to FQHCs through the prospective payment system, which provides an enhanced Medicaid rate for each visit but not for other aspects of care, has kept these centers afloat over time but the prospective payment system has not given most FQHCs sufficient capital to implement changes or to move ahead. Fiscella advocated a global payment system that would provide FQHCs with the resources to support essential features for patient-centered medical homes while enhancing access to specialty care through ACOs. Such a system could also help preserve community governance and autonomy for FQHCs. In addition, health information technology could enable the planning, needs assessment, accountability, efficiency, and care processes that promote equity. Once data on race, ethnicity, language, and health indicators are collected in structured fields, these data can be transmitted and manipulated, making it possible to monitor equity.

**Fiscella's Recommendation 3: Expand the structured data elements required for meaningful use to include key measures relevant to safety net patients, for example, cancer screening and other evidence-based procedures, along with hospitalizations and emergency department use.**

This step would enable the creation of dynamic report cards on equity at various levels of aggregation for use in planning and accountability. It could also reduce the costs and errors associated with manual data entry and foster effective population management and clinical decision support for FQHCs. Today, information from a colonoscopy report, for example, still arrives as a scanned report, which required that someone doing a report on colorectal cancer screening examine the actual patient record rather than run a report from a cancer registry. In addition, such data could facilitate clinical decision support for population management.

The meaningful use standards defined by Centers for Medicare & Medicaid Services (CMS) provide payments to physicians and hospitals based on patients' use of online personal health records. The downside of this initiative, said Fiscella, is that it is worsening health care disparities because of inequities in Web access and health literacy.

**Fiscella's Recommendation 4: Offer larger payments to providers for online use of personal health records by patients who need more assistance, including patients with Medicaid.**

Payments that depend on a graduated percentage of Medicaid patients being served (i.e., bonus payments increase with a greater proportion of Medicaid patients) would better align resources with needs and encourage safety net providers, including some hospitals, to support poorer minority patients in accessing their online personal health records. This could be done through personal assistance, instruction, and partnerships with libraries and other community-based organizations, though it will inevitably require effort and resources.

**Fiscella's Recommendation 5: Implement team training through the use of principles from team science with adaptation to the primary care safety net. This will require support for a training infrastructure.**

Creation of patient-centered medical homes requires a fundamental transformation of practice design and work flow, said Fiscella. Providers need to change their routines, stop believing that they have to do it all, and share the duties associated with the delivery of care. This requires a fundamental shift from clinician-centered to team-based, patient-centered care. The science of teams has been applied to aviation, the military, and some fields of medicine, but it has not yet been effectively applied to primary care, much less to safety net providers. Achieving equity and value requires sharing and delegation of tasks.

**Fiscella's Recommendation 6: Require accreditation of all health care providers who provide care in correctional facilities.**

At any given time, about 2.2 million people, most of whom are poor and members of minority groups, are in prison or jail. Members of these populations have high rates of mental health morbidity, substance use disorders, and other health problems. Most inmates lack any health insurance, and most health care providers in these institutions lack electronic health records (EHRs) and to date have not been eligible for meaningful use incentives. The coordination of care on entry, for the exchange of information, and on release is poor. The greatest risk of death for inmates is during the two weeks following their release, said Fiscella.

There is no systematic system for accountability of health care quality in correctional facilities. Therefore, a requirement for accreditation would represent an important step toward ensuring appropriate health care in correctional facilities.

**Fiscella's Recommendation 7: Promote insurance enrollment and continuity of insurance coverage in jails and prisons.**

Inmates need to have insurance and be enrolled in health exchanges before they are released so their care can continue without interruption. Insurance navigators could interact with inmates to make sure that they get insured and are connected with care when they leave jail or prison. This will help reduce rates of recidivism and save money in the long run because of the great expense of keeping people in correctional systems.

**Fiscella's Recommendation 8: States and localities should actively promote eligibility of physicians who work in correctional facilities in federal meaningful use programs by suspending rather than terminating an inmate's Medicaid eligibility.**

Although physician eligibility for participation in meaningful use programs may seem like a technical issue, it is important, said Fiscella. In many correctional facilities, when inmates go into jail or prison, their Medicaid coverage is terminated, which means that inmates cannot be counted toward meaningful use criteria for physicians. Suspending rather than terminating their eligibility would help correctional institutions qualify for meaningful use payments. Persons with suspended but not terminated Medicaid count toward the minimal percentage of individuals in the population with Medicaid coverage needed to qualify for CMS meaningful use payments. This additional revenue could fuel the adoption of EHRs and foster participation in health information exchanges in correctional institutions.

**Fiscella's Recommendation 9: Create dedicated program announcements among existing federal funding agencies to establish and maintain the research infrastructure necessary to inform best practices for care within the safety net.**

Successful health care systems, such as the U.S. Department of Veterans Affairs, Kaiser Permanente, and Group Health, have the infrastructure needed for applied research and development. On the other hand, safety net practices have few opportunities to build such infrastructure. The Community Health Applied Research Network, supported by the Health Resources and Services Administration, and the partnership between Connecticut's Department of Corrections and the University of Connecticut represent notable, worthy exceptions. Dedicated funding is needed from both federal and non-federal funders to establish and maintain the research infrastructure necessary to inform best practices within the safety net, Fiscella said.

**Fiscella's Recommendation 10: States and the federal government should prohibit the segregation of health care by payer. This proscription could be linked to the receipt of federal (Medicare or Medicaid) or state (Medicaid) payments.**

Social psychology has demonstrated that perpetuation of two-tiered systems of care, such as practices composed of clinic patients (often poor, minority, Medicaid, or uninsured patients) and private patients creates a culture among health care trainees, clinicians, and staff that perpetuates unconscious bias. Dual systems of care also undermine the continuity of care for socially disadvantaged patients, who are disproportionately cared for by trainees who come and go.

"Separate but equal failed in education and has failed in health care," said Fiscella. "The creation of integrated systems of care offers potential for reducing bias and promoting equity in care continuity and improved access."

**Fiscella's Recommendation 11: Foster natural health care career ladders for low-income and minority health care workers as a means of promoting workforce diversity and team-based cultural competency.**

Both the ACA and the *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* (HHS, 2011) promote workforce diversity but successful strategies are in short supply. Today, the health care workforce in FQHCs, correctional institutions, and hospitals is quite diverse; however, it is typically a pyramid that gets less diverse as pay grades rise toward the top of the pyramid. Minority and low-income workers need a natural career progression with support from community and institutional partnerships, tuition assistance, flexible working hours, and mentoring, with high-need areas given priority. Many people who work as personal care aids in uncertified fields want to become certified technicians and then move up to nursing positions. Fiscella indicated that most of the people with whom he works already have full-time jobs and are going to school. By "shortening the distance between the rungs on the career ladder," low-income and minority health workers could move up the pyramid and bring greater diversity to the health care workforce at higher pay grades.

## Conclusion

The HHS Action Plan is unprecedented and represents "a critical step toward improving equity," Fiscella said. However, it would be improved by aligning resources with need, especially for safety net providers. It could also have articulated more clearly specific benchmarks for each federal agency. Each federal agency should establish specific and actionable metrics and then publicly report on the progress that it has made to meet those metrics and on the steps that it will take to improve in areas where no progress has occurred. Such efforts will have the additional benefit of setting expectations for states to take the same actions.

> "Separate but equal failed in education and has failed in health care."
>
> —*Kevin Fiscella*

## DRIVING HEALTH EQUITY THROUGH PUBLIC POLICY

The definition of health equity that Martha Somerville, director of the Hilltop Institute's Hospital Community Benefit Program in Baltimore, Maryland, prefers is "attainment of the highest level of health for all people." She believes that "achieving health equity requires . . . focused and ongoing societal efforts to address avoidable inequalities, . . . injustices, and the elimination of health and health care disparities" (National Partnership for Action to End Health Disparities, 2011, p. 9). This distinction between health and health care disparities, Somerville noted, is one of the guiding principles behind the Hospital Community Benefit Program.

Hospital community benefits are initiatives, activities, and investments by tax-exempt hospitals to improve health in the communities they serve. These benefits are an expression of the charitable missions of these hospitals and are also a condition for their tax-exempt status.

The ACA reinforces and clarifies the expectation that tax-exempt hospitals provide benefits, in addition to fully reimbursed health care services, to their communities.

It also establishes new sanctions for failure to meet federal community benefit requirements. For example, it provides for the imposition of a $50,000 excise tax for non-compliance as an intermediate sanction, short of taking away a hospital's tax-exempt status.

The ACA also establishes processes to ensure that hospitals' community benefits are responsive to the needs of the community. The ACA requires that hospitals conduct a community health needs assessment at least every 3 years to identify needs and priorities and develop a strategic plan to address those needs. It also requires that hospitals adopt written financial assistance policies that clearly state the hospital's eligibility criteria for financial assistance and requires that these policies be clearly communicated to patients and the community. In addition, it establishes financial protections for individuals who qualify or may qualify for financial assistance. For example, it limits hospital charges and prohibits extraordinary collections until a patient is determined to be ineligible for financial assistance.

The community health needs assessment is an important lever for health equity, Somerville said. First, a hospital must define its community. Although a hospital may use a geographic definition for its community, it is also permissible to target specific populations. For example, a pediatric hospital might want to define its community as the children within a certain geographic area, or several hospitals in a rural area might jointly conduct a community needs assessment for their aggregated service areas. Proposed Internal Revenue Service (IRS) regulations state, however, that a hospital "may not define the community to exclude medically underserved, low-income, or minority populations who are part of its patient populations, live in geographic areas in which its patient populations reside, . . . or otherwise should be included based on the method the hospital facility uses to define its community."

Second, a hospital must assess the health needs of its community, identify and prioritize significant needs, and identify potential measures and resources to address those needs. Every hospital must develop its own needs assessment report and make it widely available to the public, and members of the public can go to their neighborhood hospitals and ask for the schedules that hospitals file with the IRS.

The community health needs assessment needs to reflect input from persons who represent the broad interests of the community, and this must include input from "members of medically underserved, low-income, and minority populations in the community served by the hospital facility, or individuals or organizations serving or representing the interests of such populations," noted Somerville. For each significant health need identified by the assessment, a hospital must either describe how it will address the need or explain why it will not address the need. For example, a hospital might indicate that its resources are inadequate to meet a particular identified need or that the need is being or will be addressed by a collaborating hospital, said Somerville.

For community needs assessments, community benefit planning, and the implementation of health improvement initiatives, hospitals may engage in multisector collaborations with community health centers, public health agencies, businesses and employers, community-based organizations, schools, and public safety organizations. Such a collaborative approach captures diverse perspectives and expertise and facilitates leveraging of the community's public and private resources for the common purpose of community health improvement.

Somerville listed activities that the IRS recognizes as community benefits:

- Free and discounted care,
- Under-reimbursed care (under Medicaid and other means-tested government programs),
- Community health improvement services and community benefit operations,
- Health professions education,
- Subsidized health services,
- Research, and
- Cash and in-kind contributions to community groups.

A recent analysis looked at hospital community benefit spending in 2009, which was the first year that hospitals were required to report their community benefit expenditures or costs at the federal level, and found that community health improvement services represent only about 8 percent of total community benefits reported (see Figure 5-1). The IRS defines these services as "activities or programs carried out or supported by the health care organization for the express purpose of improving community health." To report an activity or program as a community health improvement service, a hospital must establish that the activity or program responds to a community need. It must also be seeking to achieve a community benefit objective, such as eliminating disparities in access to health services or disparities in health status among different populations. Community need may be demonstrated through:

- A community health needs assessment, or
- Documentation that the activity or program was initiated or continued on the basis of a request from a public health agency or community group, or
- Performance of the activity or program with unrelated tax-exempt or government organizations for the express purpose of improving community health.

In addition, the activity or program must seek to achieve a community benefit objective, such as eliminating disparities in access to health care services or improving disparities in health status among different populations.

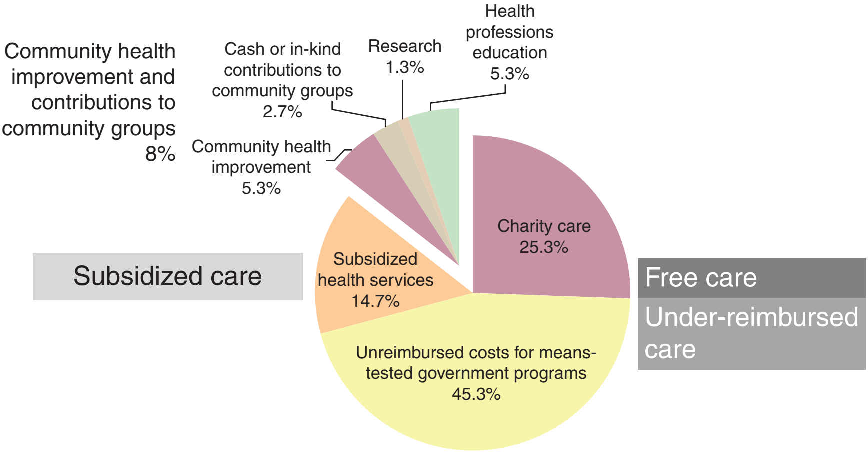


**FIGURE 5-1** Community health improvement and contributions to community groups.
SOURCE: Young et al., 2013.

Somerville concluded by urging hospitals to consider refocusing their community benefit resources on the broader determinants of health status, including unhealthy behaviors such as smoking and unhealthy eating. In addition, hospitals can support community-building initiatives that focus on upstream factors (social determinants of health) that negatively affect population health. Examples of negative determinants include economic decay and unemployment, low educational attainment, substandard housing, food insecurity, and unwalkable neighborhoods, all of which disproportionately affect poor and minority populations. "To the extent that we're talking about bending the cost curve of health care and reducing health care costs, we have to look beyond the walls of the hospital," she said.

Although the IRS has not recognized all community-building initiatives to be reportable as community benefits, if an initiative is undertaken for the express purpose of improving community health, responds to an identified need, and is based on evidence, said Somerville, it may be reported as community health improvement services, that is, as a community benefit. As examples, she cited a hospital in Ohio that trained and assisted local vendors subcontracting with its suppliers to develop the skills and infrastructure needed to become contractors themselves. By restructuring the supply chain to directly contract with local suppliers, the hospital created jobs and improved economic opportunities in its community. Another hospital supported paid internships for local high school students to help them complete their degrees and enter medical paraprofessional vocations. These are the kinds of creative interventions that hospitals can undertake to address the social determinants of health, said Somerville.

When communities mount initiatives to improve health, they can bring in hospitals as partners to combine community and hospital community benefits to address the communities' needs and improve population health.

## DISCUSSION

Roundtable member Francisco Garcia commented that very few correctional facilities use EHRs in Tucson, Arizona, where he works. He noted that a major challenge is to explain why this should be built into the contracting for the provision of health care services. Fiscella responded that correctional facilities likely do not use EHRs more often due to the costs; correctional facilities have highly constrained budgets.

> "To the extent that we're talking about bending the cost curve of health care and reducing health care costs, we have to look beyond the walls of the hospital."
>
> *—Martha Somerville*

A participant from the Partnership for Strong Communities, a statewide housing policy and advocacy organization, asked if there are examples of communities that have used community benefit funds for targeted initiatives around factors such as food insecurity and housing instability. Somerville responded that there are examples of this occurring.

# 6

# Consumer Engagement

**Important Points Made by the Speakers**

- The Patient-Centered Outcomes Research Institute (PCORI) has been designed to support research that gives people the information they need to make health care decisions that reflect their desired health outcomes, in part by continuously seeking input from patients and from a broad range of stakeholders. (Beal)
- Increasing the number of states that are willing to expand Medicaid is essential to realizing the potential of the ACA. (Miller)
- Community organizers need to identify unmet needs, the obstacles that must be overcome to meet those needs, and strategies to overcome those obstacles. (Lash)
- Grassroots activism is critical for policies made at the top levels to have an effect at the community and individual levels. (Kingwood-Small)

As noted in the first chapter of this workshop summary, consumer engagement will be critical to the ACA's success. This final chapter of the summary provides four perspectives on consumer engagement ranging from the national to the local level.

## THE PCORI APPROACH TO PATIENT AND STAKEHOLDER ENGAGEMENT

PCORI was created by the ACA as a 501(c)(1) independent nonprofit research organization, only about 30 of which exist in the United States. It was created and funded by Congress but is entirely separate from the federal government and has a private board. Its primary purpose is to fund comparative effectiveness research, which means that the institute "should be in a position to help answer questions commonly faced by patients and those who care for them in real-world settings," said its chief officer for engagement, Anne Beal. The answers to those questions will affect people's health by giving people the information they need to make informed choices. PCORI's independence was designed to make sure that there is no bias in the research that it supports.

PCORI is also unusual in that its budget has been appropriated through 2019, with most of its resources coming from fees on Medicare, private health insurance, and self-insured plans. Its budget was approximately $150 million in 2012, and that amount will grow to a projected $500 million annually from 2014 through 2019. Twenty percent of its funding goes to the U.S. Department of Health and Human Services (HHS) to support dissemination, training, and other research capacity-building efforts. Nevertheless, said Beal, "we have the resources to support a robust portfolio of quality research proposals, and 10 percent of that research funding will be dedicated to address health disparities."

"PCORI takes the 'P' in its name very seriously," Beal said. Its board has spent considerable time defining patient-centered outcomes research, and it has emphasized that the work that PCORI does needs to be meaningful to patients. To do that, PCORI plans to ensure that it continuously seeks input from patients and from a broad range of stakeholders.

The mission of PCORI is to help people make informed health care decisions and improve health care delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community. "The bottom line," said Beal, "is that the institute wants to support research that gives people the information that they need to make health care decisions that reflect their desired health outcomes."

Beal told the story of her 83-year-old aunt who had lung cancer. "I, as a physician, had very key ideas as to what I wanted in terms of her outcomes. She, as an 83-year-old woman, said, 'I have to die of something. What I want is to not be in pain, and I don't want to lose my hair,'" said Beal. "The philosophy behind PCORI," she said, "would be to respect her views."

PCORI's core duties are to

- Establish national research priorities,
- Establish and carry out a research agenda,

- Develop and update methodological standards, and
- Disseminate research findings.

The PCORI board has also established a set of national priorities for research, and these are outlined below.

### Assessment of Prevention, Diagnosis, and Treatment Options

- Comparing alternative clinical options to support personalized decision making and self-care
- Identifying differences in patients' responses to therapy
- Studying patients' preferences for various outcomes

### Improving Health Care Systems

- Improving support of patient self-management
- Focusing on coordination of care for complex conditions and improving access to care
- Comparing alternative strategies for workforce deployment

### Communication and Dissemination Research

- Understanding and enhancing shared decision making
- Using alternative strategies for dissemination of evidence
- Exploring opportunities to improve patient health literacy

### Addressing Disparities

- Understanding differences in effectiveness across groups
- Understanding differences in preferences across groups
- Reducing disparities through the use of findings from patient-centered outcomes research

### Accelerating Patient-Centered Outcomes Research and Methodological Research

- Improving study designs and analytical methods in patient-centered outcomes research
- Building and improving clinical data networks
- Establishing methods for training researchers and patients to participate in patient-centered outcomes research
- Establishing a methodology for the study of rare diseases

PCORI is a clinical comparative effectiveness research institute, Beal emphasized, so it is going to focus on comparing options to eliminate disparities rather than supporting studies to describe disparities. Also, in establishing its national priorities for research, PCORI chose not to mention specific diseases, to allow researchers and others broad latitude when they submit their best ideas.

Beal grouped the first category of research priorities—assessment of prevention, diagnosis, and treatment options—with classic comparative effectiveness research and noted that this category represents about 40 percent of PCORI's budget. However, PCORI is also interested in ways to get the results of such research into practice quickly, because patients need answers right away. About 20 percent of its research budget focuses on communication and dissemination research that is focused on reaching different populations. For example, young people are now more likely to communicate through texts than through emails. "The way that you get to different populations needs to be done and approached in a thoughtful manner," Beal explained.

PCORI is especially emphasizing patient and stakeholder engagement (see Figure 6-1). First, it is asking patients and stakeholders what PCORI should study. "What is the type of research that we should be doing? What are the challenges that you face?" said Beal. For example, shortly before the workshop, PCORI held a roundtable with a group of Latinas, because women are often the arbiters of health care decisions for families and their communities. The group helped identify opportunities to study different

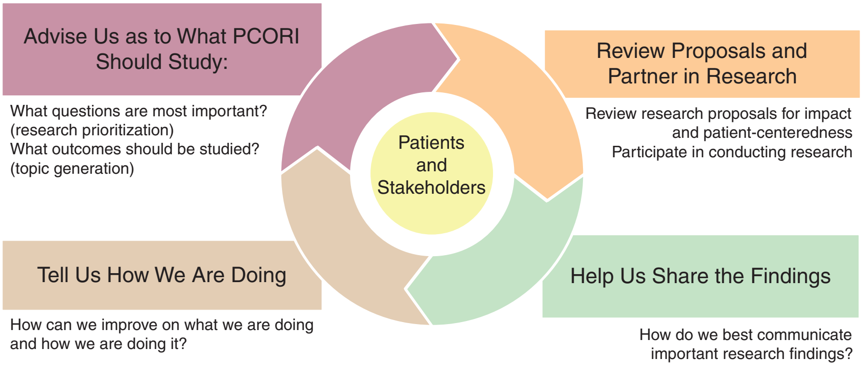


**FIGURE 6-1** Patient-Centered Outcomes Research Institute (PCORI) is seeking multiple ways to engage patients and stakeholders.
SOURCE: Beal workshop presentation, April 22, 2013. From PCORI.

models of community outreach, such as contact by telephone versus door-to-door visits by community health workers. Other meetings with targeted groups are identifying other challenges that can inform the research agenda.

PCORI has advisory panels that met for the first time just a few days before the workshop. The initial set of advisory panels focused on four areas:

- Addressing disparities;
- Assessing prevention, diagnosis, and treatment options;
- Improving health care systems; and
- Patient engagement.

The panels, for which more than 1,000 people applied for 84 positions, are helping to identify and prioritize research questions. Panelists also represent a wide range of professions, geographic areas, and groups to provide a diverse set of perspectives.

PCORI has an open webpage through which anyone can submit a research question, and it has already accepted about 850 questions and topics. Furthermore, the questions come not just from health services researchers but, for example, from mothers who are having difficulty managing a child's condition. In addition, PCORI has reached out to the public for help in reviewing proposals. It has determined that at least one-third of all the reviewers on study sections need to be either patients or other non-researcher stakeholders. Again, said Beal, many more people have applied to work with the institute than it has been able to accommodate, adding that "we take a lot of pride in making sure that the perspective of the entire health care community is reflected."

Every research project supported by PCORI must have a patient and stakeholder partner. The engagement of patients and stakeholders should include participation in the formulation of research questions; definition of the essential characteristics of study participants, comparators, and outcomes; monitoring of study conduct and progress; and dissemination of research results. "It's not just a check-off box," said Beal. "We want to see their time and effort reflected in the research."

PCORI's inaugural funding cycle had the budget to distribute 50 awards, but it made only 25 because it was looking for projects of higher quality and with more patient involvement. "Our standards for including patients and other stakeholders in research are unique, and we are working with the research community to ensure that they are fluent in our criteria. Already we are seeing that work pay off in the recently submitted applications," she said.

PCORI's funding rate has increased in subsequent cycles, as the research community's understanding of its requirements has improved. PCORI made 71 funding awards totaling more than $114 million in its third funding cycle. The rate of applications approved doubled from the inaugural funding cycle to its third.

Finally, Beal discussed PCORI's framework for dissemination and implementation, even though it has just started funding research and does not yet have much to disseminate. The framework has been designed to

- Guide the organization in disseminating the research findings of funded research conducted in the national program areas,
- Enhance implementation by actively facilitating how PCORI's research findings can be used by health care decision makers, and
- Evaluate how the effect of the dissemination of such findings reduces practice variation and disparities in health care.

As an example of putting results into practice, Beal cited two findings: that mothers should have their babies sleep on their back to reduce crib death, and that doctors should use checklists to reduce central line infections for patients in an intensive care unit. Those are very different results aimed at very different populations, and different mechanisms should be used to disseminate and implement those findings. Important considerations include speeding the implementation and use of patient-centered outcomes research; becoming a trusted source of information; and engaging stakeholders across the health care community to include PCORI research in training, practice, and standards. Most researchers do not have much experience with the dissemination and implementation of their research results, but PCORI is asking them to develop partnerships and take other steps to get the word out and ensure that research results have an impact.

"One of the things that I've personally learned is there are a lot of moms and patient bloggers and listservs and tweeters out there," said Beal. "Those are the kinds of folks we would want to have actively involved and engaged and anticipating the results of our work so that when it comes out they can help to share and spread the word," she said.

Patient involvement tends to be an afterthought in the traditional research model, Beal noted, yet patients will have many new responsibilities in the work of PCORI. Patients will have to be involved for the research to have an impact and be successful and for health care reform to succeed.

> "There are a lot of moms and patient bloggers and listservs and tweeters out there. Those are the kinds of folks we would want to have actively involved and engaged and anticipating the results of our work so that when it comes out they can help to share and spread the word."
>
> *—Anne Beal*

## THE ROLE FOR CONSUMER ENGAGEMENT

Community Catalyst is a national nonprofit health advocacy organization that has been working to ensure that everyone has equal access to high-quality, affordable health care, said its director of strategic policy, Michael Miller. It collaborates with national, state, and local consumer organizations, policy makers, and foundations and has built and supported consumer advocacy networks in more than 40 states. In particular, it works to advance state health policy solutions and to bring state and local voices into the national health care debate.

Miller focused on three provisions related to community engagement that Community Catalyst sees to be critical to realizing the potential of the ACA: coverage expansion, delivery reform, and community benefits. Together, these three provisions can create a "new ecology" for reducing disparities, he said.

As an example of what can be achieved in expanding coverage, Miller cited the state of Massachusetts. Disparities have not been eradicated in Massachusetts, but significant progress in rates of coverage as well as access to care has been made (see Figure 6-2). Even uninsured individuals in Massachusetts are experiencing improved access to care, Miller noted, perhaps because the safety net is under less stress.

The ACA probably will not produce results as good as those that have been achieved in Massachusetts, partly because of the number of states that either will not participate or are leaning toward not participating in the expansion of Medicare (see Figure 6-3). This lack of state participation paints a "very disturbing picture with regard to racial and ethnic health disparities," Miller said. "If you look at what percentage of people would be eligible for Medicaid in the states that are not taking up the Medicaid expansion or have not yet decided to take up the Medicaid expansion, it is twice the national average. . . . If we are going to realize the health equity potential of the Affordable Care Act, it starts with getting states to take up the Medicaid expansion," he said.

Increasing the number of states that will expand Medicaid requires a robust grassroots effort, including active involvement of the affected communities. Toward that end, Community Catalyst has identified three major barriers to engaging communities of color in advocacy efforts. First, people have not yet grasped the magnitude of the opportunity. Second, resources to support such an effort are lacking. Third, greater trust is needed between state-based advocacy organizations and community-based organizations working on issues related to the health of their communities.

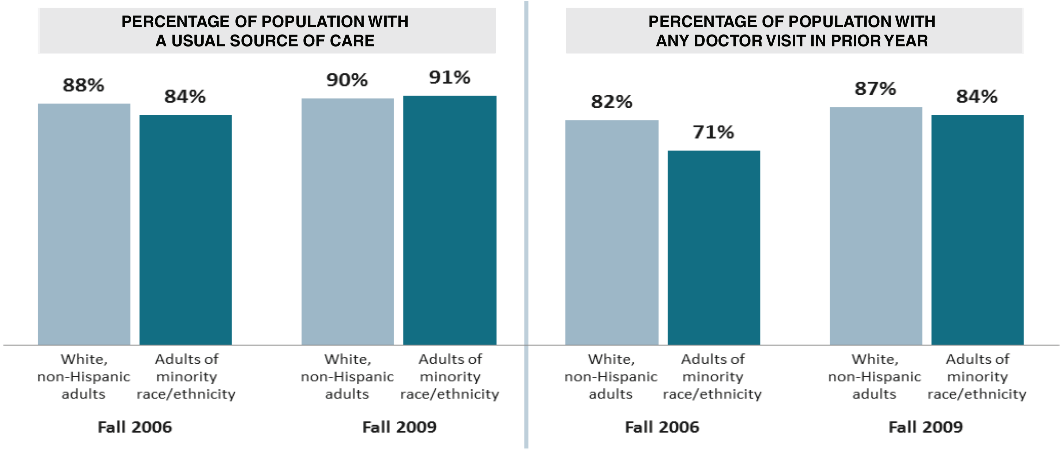
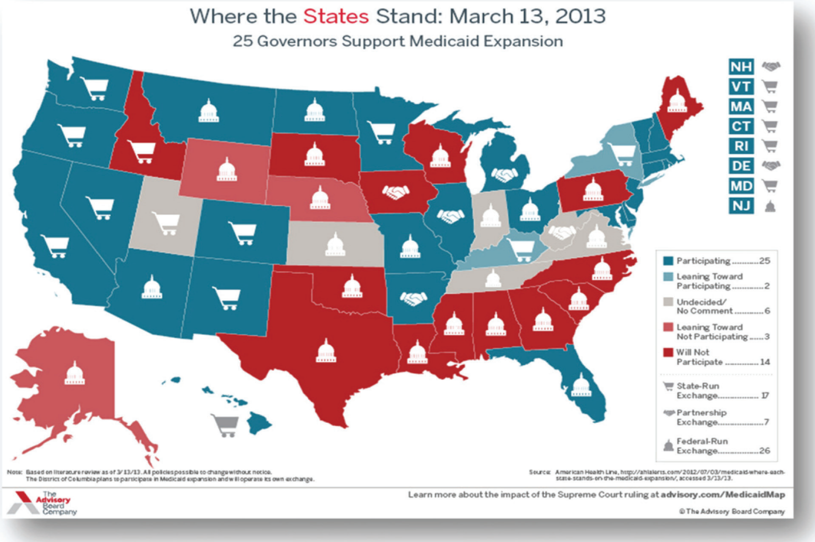


**FIGURE 6-2** Massachusetts racial and ethnic disparities.
SOURCE: Miller workshop presentation, April 22, 2013. From Urban Institute, Massachusetts Health Reform Survey, 2010.



Where the States Stand: March 13, 2013

25 Governors Support Medicaid Expansion

Note: Based on literature review as of 3/13/13. All policies possible to change without notice. The District of Columbia plans to participate in Medicaid expansion and will operate its own exchange.

Source: American Health Line, http://ahlalerts.com/2012/07/03/medicaid-where-each-state-stands-on-the-medicaid-expansion/, accessed 3/13/13.

Learn more about the impact of the Supreme Court ruling at **advisory.com/MedicaidMap**

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**FIGURE 6-3** Governors supporting the expansion of Medicaid as of March 13, 2013.
SOURCE: Miller workshop presentation, April 22, 2013.

Miller presented a set of recommendations to remove these barriers:

- Build and strengthen community-based organizations.
- Encourage groups striving to provide access to health care statewide to prioritize work on achieving equity.
- Build strong partnerships between state and local organizations.
- Demystify the policy-making process and provide opportunities for local activists.
- Develop a disparities reduction and health equity policy agenda.
- Hold meetings in target communities to increase understanding and participation.

"It starts with embracing a vision of health equity as an organizational priority," said Miller. State partners need "a plan for how they are going to engage with local communities of color," he added.

The establishment of exchanges will also be a critical aspect of coverage expansion, because the people who will be covered through the exchanges are more likely to be from communities of color. These exchanges need to implement six principles, Miller said:

1. Diverse inputs,
2. Language access,
3. Robust outreach,
4. Simplified enrollment and protections for privacy and confidentiality,
5. Robust networks of safety net providers, and
6. A disparities-reduction plan as part of an overall strategy to achieve quality health care.

Exchanges will create a structural opportunity for diverse communities to influence coverage in their states. The extent to which they are able to increase coverage depends on the extent to which state and local groups are at the table helping to shape what the exchanges do. Whether an exchange targets disparity reduction as a key goal and whether the quality improvement strategy incorporates that goal will be critical elements of realizing this potential.

Only $50 million has been allocated to the outreach effort for the 30 states that are going to be operating under federally facilitated exchanges. "That money is not going to go very far, unfortunately, and that's obviously a big concern," said Miller, noting that "just because you build, it does not mean they will come."

Populations eligible for Medicaid need to be a specific target of outreach and enrollment. Miller explained that "there are some real opportunities with the Medicaid population that we don't have as much with the exchange population." Large numbers of people who are eligible for the Supplemental Nutrition Assistance Program, who are currently receiving financial assistance through hospitals, or who are patients at health centers, can be moved quickly from not being covered to being covered. Also, the outreach workforce needs to look like the communities being targeted.

Turning from coverage to care, Miller flagged an important structural opportunity. People who are eligible for both Medicare and Medicaid are much more likely to be people of color. Creating organized delivery systems for this population also creates new opportunities for patient engagement.

Experiences in Massachusetts and elsewhere have shown that patient empowerment and engagement are associated with better health outcomes and lower costs, yet patients at lower socioeconomic levels tend to be less engaged. Experiments in places like New Jersey and Oregon have shown that health care reform can do much more to engage the community. In Oregon, for example, patients serve on the boards of coordinated care organizations as a means of increasing patient engagement. Patient involvement at the level of system oversight is another way to create patient-centered systems. "The motto of the disability community—nothing about us without us—in my mind applies very well to all of this work," he said.

Finally, Miller briefly discussed the community health needs assessments. The community benefit provisions in the ACA provide an opportunity to integrate financial assistance and health promotion for patients. To take advantage of that opportunity, however, communities need to be involved in the development of community health needs assessments. Are communities of color at the table, and are they helping to shape the planning for assessments? As hospitals move away from a fee-for-service payment system toward more integrated systems and a greater emphasis on population health, Miller noted that "there is real opportunity to integrate the community benefits program with the clinical programs of hospitals." This transition even provides an opportunity to think about the social determinants of health, economic development, and the hospital's footprint in the community. "It's somewhat like turning a battleship," said Miller, but "we know that these things have as much or more to do with the health of the population as access to medical care."

Miller provided 10 tips for engaging people of color:

1. Practice basic etiquette.
2. Engage beyond education.
3. Support meaningful engagement in policy change.
4. Do not ignore or forget to address racism.
5. Make a commitment.
6. Find the right messenger.
7. Communicate effectively.
8. Practice team building.
9. Provide financial support.
10. Celebrate wins.

The ACA provides many tools to address disparities, Miller concluded, "but tools don't build houses; people do." Fulfilling the potential of the ACA will depend on the extent to which people take advantage of the opportunities that it presents.

> "If we are going to realize the health equity potential of the Affordable Care Act, it starts with getting states to take up the Medicaid expansion."
>
> —*Michael Miller*

## CHALLENGES FOR EXCHANGES IN REACHING DIVERSE COMMUNITIES

The health care system is like a three-legged stool, said Alta Lash, executive director of United Connecticut Action for Neighborhoods. One leg consists of health care providers, who are very well organized. A second leg consists of health care payers, who also are very well organized. The third leg consists of the consumers of health care, "who interact with this system while sitting in a medical examining room on an examining table in a paper gown waiting to get your blood pressure taken and knowing inevitably they're going to put you on the scale," she said.

The ACA offers the promise of an entirely different model in which people actively participate in health care, said Lash. Realization of this promise, however, means reaching out to people who are not necessarily prepared to participate.

The group that Lash leads has been working with the community in Hartford, Connecticut, to prepare them for the new world of health care. The first task that the group faced was figuring out how to reach the people who it is targeting. That meant dealing not with just one community but with many: the hearing-impaired community, Latinas who are Puerto Rican versus Latinas who are Dominican, West Indian communities, African American communities, and so on. She noted that "we have to strategize about how to tailor the message for particular communities."

Community organizers use a technique called a "power analysis" to identify the communities that they need to reach, the obstacles to be overcome, and the strategies that will maximize strengths and minimize weaknesses. In the context of health care, that will mean dealing largely with people who are uninsured, said Lash. For the most part, these are working people who are sometimes working two or three jobs. They are probably paid by the hour and are not paid when they cannot get to work, which means that if they are sick, they may not have enough money for groceries by the end of the month. "This is the target constituency for the exchange, and we have to figure out what is the best way to reach that constituency," she commented.

Simply hiring a public relations firm will not get the job done, Lash said, explaining that "we've got to think much more creatively and outside of the box if we are going to be able to talk to the waitress, the hairdresser, the person who has a construction job 1 week and the next month he's not working." One organization that has done a good job of reaching these communities, said Lash, is H&R Block. H&R Block offices are easy to find. They advertise on buses and on media that many people use, like Univisión, Telemundo, and local radio stations. People carry their paperwork to the H&R Block office, and they get their taxes done at a reasonable rate. "If

H&R Block can reach them, we should be able to reach them, too, with the exchange message," she noted. Another good model is the public library system, said Lash, which can help spread the message about health care reform.

If people are going to participate in the exchanges, the product that the exchanges are providing has to be good. For the communities where Lash works, this means that the product needs to be affordable. Not everyone in those communities will qualify for subsidies, and the insurance that they purchase is going to have to provide them with value for the money that they spend. "I can't wait until I spend $5,000 of my own money in order to see the first dollar from the exchange. That just isn't going to cut it," Lash explained.

Finally, the people who are selling the product need to be good communicators. Complex ideas will need to be translated into concrete language that people can understand. For example, Lash said that "we use the term 'exchange' all the time. It took me weeks to figure out what exactly is an exchange." Assistants are going to need to sit down at a computer with the people buying insurance and walk them through the process. "This is the one that scares me," said Lash. "It has to be someone who knows and understands the community. But it also has to be someone who knows insurance and can explain insurance terminology to a group of people who don't know what a copay is, what a deductible is, what is cost-sharing, what is silver metal tier." Things that other people take for granted are not taken for granted in these communities, Lash said, adding that "when the person sits down with an individual to explain this, I think it's going to be much more labor intensive than we anticipate, because people don't have a clue of what they're buying. . . . Getting the word out is the easy part. Getting people to actually understand what they're paying their hard-earned dollars for is a whole other ball of wax."

Perhaps a useful analogy is car insurance, Lash continued, since everyone is supposed to have car insurance, but health insurance is still more complicated than car insurance. And people will not react calmly when something that they think is covered is not covered.

> "We've got to think much more creatively and outside of the box if we are going to be able to talk to the waitress, the hairdresser, the person who has a construction job 1 week and the next month, he's not working."
>
> —*Alta Lash*

"We have to think through some of these challenges," Lash concluded. "Old strategies won't work." At the same time, she emphasized the continued importance of political activism. Policies made at the top levels have momentous effects on people's lives, and the people who are affected by those policies need to monitor what policy makers are doing and hold them accountable. She ended her comments by adding that "people need to realize that their voice matters."

## REACHING THE PEOPLE

The Ashe Faith Project is a grassroots initiative of the Mount Aery Development Corporation whose goal is to close the health disparities gap in the Bridgeport, Connecticut, area by strengthening the partnerships between community and faith organizations and using knowledge, experience, and passion to maximize local synergies, collaboration, and service integration. "All that basically means," said Reverend Nancy Kingwood-Small, project director at the Ashe Faith Project, "is we are the little engine that could."

The Ashe Faith Project, which has been funded by the Connecticut Health Foundation and the Substance Abuse and Mental Health Services Administration, has been presented to Congress as a model program that can be replicated throughout the country. A volunteer initiative, it offers client-level services, including health screenings and support groups. Beginning with an initiative that addressed HIV and substance abuse about 3.5 years ago, it has established a network of more than 40 faith organizations and has expanded the infrastructure used to address health disparities. It has strengthened partnerships, gained the trust of community residents, held focus groups to learn about the needs of the community, and become an information hub for the community.

The Ashe Faith Project came out of an earlier initiative that Kingwood-Small started in her home about 7 years ago. A group of women came together on a weekly basis to look at the rate of HIV infection among women in the black community. Kingwood-Small wrote a 5-week training curriculum, and the group started engaging volunteers from the community. To date, more than 100 people have gone through the curriculum and have received their certificates of completion. Of that group, 27 women have received their trainer certificates, and 14 have gone on to full-time jobs working in the field of prevention.

One of the project's initiatives is a monthly support group for women of color called Sacred Women, which offers women a safe environment for them to share and receive support and information. Sacred Women also offers an array of services, including addressing trauma-related experiences and substance abuse.

Another initiative is the Power Source Leadership Academy, which is designed for black men to feel comfortable and share their experiences.

Beginning as a monthly group, Power Source now meets weekly and has established partnerships with the Aspen Institute and the Connecticut Health Foundation. It offers workshops and roundtables and seeks to initiate men into responsible adulthood and fatherhood. Power Source also offers training on the ACA and on health disparities among black men. Similarly, the Ashe Faith Project offers advocacy training for women of color to help them become better advocates for themselves and their families.

Two years ago the Ashe Faith Project entered into a partnership with the University of Bridgeport Naturopathic Medicine Clinic to offer free naturopathic services. It has also partnered with Optimus Health Care and established a referral system that ensures that patients seeking an appointment will be seen within 48 hours. In addition, Kingwood-Small works as deputy director of the Greater Bridgeport Adolescent Prevention Program, which offers screening for sexually transmitted infections as well as pregnancy testing.

Turning to the ACA, Kingwood-Small quoted Steven Covey: "Seek first to understand, then to be understood." The ACA is a paradigm shift in health care, but it requires that communities be brought through the transition. The Ashe Faith Project is helping in this process by providing help with applications, referrals, and even transportation. "We must learn to meet people where they are," she said.

The ACA has the potential to create a disconnect between the policy and the people, said Kingwood-Small. Policies made at the top level often do not trickle down to the grassroots level, she said, noting that "we need to keep these people in mind, because there for the grace of God it could be you or I. I know at one time in my life it was me."

The ACA can look like "a mess" in local communities, said Kingwood-Small, adding that "we need someone to help us educate, someone to raise awareness, someone to empower the community." For example, the Ashe Faith Project has been involved in the convening of community meetings with the health exchange and partner agencies to identify strategies around engagement, recruitment, and enrollment. Such meetings help agencies and community organizations cooperate rather than compete. "Collectively, we can do the work," she said.

> "Eventually that window is going to lift and blessings will come down."
>
> *—Nancy Kingwood-Small*

The faith community is involved and engaged, but it needs resources and people. The Ashe Faith Project now has a waiting list of churches and faith projects that want to partner with it. "We are on the front lines, and we continue to do the work with money or without money because we consider it a ministry. We know that eventually that window is going to lift and blessings will come down," she concluded.

## DISCUSSION

A participant who is doing a fellowship at the Aetna Foundation commented that she would like to know how to reach out and partner with media people. Lash replied that virtually all women's magazines publish health pieces.

Participant Rebecca Skye from New Hampshire observed that she has concerns that states cannot effectively do community engagement with the limited funds available. Miller agreed that there is not adequate funding to support robust outreach and education efforts regarding enrollment. Kingwood-Small noted that this makes working together in partnerships with the agencies involved critical to identify strategies around engagement, recruitment, and enrollment.

Roundtable member Winston Wong asked if community engagement and mobilization is an extension of patient centeredness. Beal commented that we do not know the answer to that yet.

Amos Smith of the Community Action Agency of New Haven asked if the funding was weighted to spend more at the top and middle ends of the economic spectrum, rather than at the bottom end where the most vulnerable people are. This vulnerable population has literacy issues as well. Miller replied that there is progress being made in this area.

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# Appendix A

# Workshop Agenda

**Achieving Health Equity via the Affordable Care Act:**
**Promises, Provisions, and Making Reform a Reality for Diverse Patients**

**April 22, 2013**

**Mark Twain House**
**351 Farmington Avenue**
**Hartford, CT 06105**

**8:15 a.m.–8:45 a.m.** *Welcome and Overview*

**Patricia Baker**
President and CEO, Connecticut Health Foundation

**Sanford Cloud, Jr.**
Board Chair, Connecticut Health Foundation

**The Honorable Dannel P. Malloy**
Governor of Connecticut

**U.S. Representative John B. Larson**
First Congressional District of Connecticut

**Nancy Wyman**
Lieutenant Governor of Connecticut

**8:45 a.m.– 9:30 a.m.** ***Keynote***
**Moderator: Antonia M. Villarruel, Ph.D., R.N., FAAP**
Chair, Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities

*How Do We Ensure That the Affordable Care Act Accelerates Momentum Toward Achieving Health Equity (and Not Away from It)?*
**Jennifer DeVoe, M.D., M.Phil., M.C.R., D.Phil., FAAFP**
Oregon Health & Science University

**9:30 a.m.–11:00 a.m.** **Panel #1**
***Expansion of Coverage***
**Moderator: Gillian Barclay, D.D.S., M.P.H., Dr.PH.**
Aetna Foundation

*Health Equity and the ACA: An Insurer's Perspective*
**Wayne Rawlins, M.D., M.B.A.**
Aetna Healthcare

*The Affordable Care Act and Its Potential to Reduce Health Disparities*
**Cara James, Ph.D.**
Centers for Medicare & Medicaid Services

*Access Health CT: A Vision for the Future*
**Kevin Counihan**
Connecticut Health Insurance Exchange

**Roderick Bremby**[1]
Commissioner, Connecticut Department of Social Services

**11:00 a.m.–11:15 a.m.** **Break**

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[1] Did not attend workshop.

**11:15 a.m.–12:30 p.m.** **Panel #2**
***The Patient-Centered Health Home***
**Moderator: Winston Wong, M.D., M.S.**
Kaiser Permanente

*The Patient-Centered Medical Home*
**Ignatius Bau**
Independent Consultant

*Health Homes, Equity, and the ACA: Working to Leverage Opportunity in a Changing Health Care Landscape*
**Dennis Andrulis, Ph.D., M.P.H.**
Texas Health Institute

**12:30 p.m.–1:15 p.m.** **Lunch**

**1:15 p.m.–2:45 p.m.** **Panel #3**
***Delivering on Health Equity: The Safety Net and Beyond***
**Moderator: Phyllis D. Meadows, Ph.D., M.S.N., R.N.**
The Kresge Foundation

*Achieving Health Equity: Leveraging Health Reform to Align Resources with Needs Within the Safety Net*
**Kevin Fiscella, M.D., M.P.H.**
University of Rochester Medical Center

*Driving Health Equity Through Public Policy: Hospital Community Benefits*
**Martha Somerville, J.D., M.P.H.**
Hospital Community Benefit Program, The Hilltop Institute at University of Maryland, Baltimore County

**2:45 p.m.–3:00 p.m.** **Break**

**3:00 p.m.–4:30 p.m.** **Panel #4**
***Consumer Engagement***
**Moderator: Elizabeth Krause**
Connecticut Health Foundation

*Health Equity in the ACA: The Role for Consumer Engagement*
**Michael Miller**
Community Catalyst

*The PCORI Approach to Patient and Stakeholder Engagement*
**Anne Beal, M.D., M.P.H.**
Patient-Centered Outcomes Research Institute (PCORI)

*Challenges for Exchanges in Reaching Diverse Communities*
**Alta Lash**
United Connecticut Action for Neighborhoods

*Community Engagement: Reaching the People*
**Minister Nancy Kingwood, M.S.H.S.**
Ashe Faith Project

**4:30 p.m.–5:00 p.m.** ***Concluding Remarks/Reflections/Discussion***

**Antonia M. Villarruel, Ph.D., R.N., FAAP**
Associate Dean for Research and Global Affairs
University of Michigan School of Nursing

**Patricia Baker**
President and CEO, Connecticut Health Foundation

**5:00 p.m.** **Workshop Adjourns**

# Appendix B

# Speaker Biographical Sketches

**Dennis P. Andrulis, Ph.D., M.P.H.,** is a senior research scientist at the Texas Health Institute, a health care policy research organization in Austin, Texas. He is also an associate professor at the University of Texas School of Public Health. In his positions, Dr. Andrulis leads the development of initiatives on urban health, health care for vulnerable populations, racial and ethnic disparities, and cultural competence. Previously, Dr. Andrulis was the associate dean for research of Drexel University's School of Public Health in Philadelphia and directed its Center for Health Equality. His current and recent work have focused on the Patient Protection and Affordable Care Act and its implications for racially and ethnically diverse populations, with a subsequent set of reports being issued in 2013, titled *The Affordable Care Act and Race, Ethnicity, and Equity Series*. An earlier, related report on diversity, the safety net, and the law appeared in the October 2011 issue of *Health Affairs*. Other work has focused on the creation of a National Consensus Statement on Diversity and Preparedness; a report on environmental and climate threats titled *Climate Change, Environmental Challenges, and Vulnerable Populations: Assessing Legacies of the Past, Building Opportunities for the Future* (2012); and a project on the effect of urban sprawl on health care for vulnerable populations. Other publications include a book chapter on diversity; the suburbanization of poverty and implications for health care (in Megacities and Global Health, 2011); a book titled *Managed Care in the Inner City: The Uncertain Promise for Providers, Plans, and Communities* (Jossey-Bass); *Preparing Racially and Ethnically Diverse Communities for Public Health Emergencies* (*Health Affairs*); and a compendium and analysis of national data sources on the nation's 100 largest cities and their surrounding areas, titled *The Social and Health Landscape of Urban and Suburban America*. Finally, Dr. Andrulis is also co-founder of a national conference series on quality health care for culturally diverse populations and has created a National Consensus Panel on Diversity and Preparedness. Dr. Andrulis has a Ph.D. in educational psychology from the University of Texas at Austin and a master's of public health from the University of North Carolina at Chapel Hill.

**Ignatius Bau** works to advance patient-centeredness and equity as an independent health policy consultant. He has expertise on issues of health care reform, health care disparities, language access, cultural competency, health workforce diversity, health information technology, immigrant and refugee health, and lesbian, gay, bisexual, and transgender health. His client organizations have included Consumers Union, National Partnership for Women & Families, ZeroDivide, National Council on Interpreting in Health Care, Asian & Pacific Islander American Health Forum (APIAHF), National Council of Asian Pacific Islander Physicians, Association of Asian Pacific Community Health Organizations, California Pan-Ethnic Health Network, California Health Care Safety Net Institute, San Francisco Senior Center, San Francisco Hep B Free, and Connecticut Health Foundation. Mr. Bau previously worked as a program director and program officer at The California Endowment, as deputy director, policy director, and program coordinator at APIAHF, and as a staff attorney at the Lawyers' Committee for Civil Rights of the San Francisco Bay Area. He has served on expert advisory panels for the Institute of Medicine, National Quality Forum, Joint Commission, Office of Minority Health, Office of National Coordinator for Health Information Technology, Centers for Disease Control and Prevention, National Institutes of Health, California Department of Health Services, and California Health Interview Survey. He has served on numerous boards of directors, including Cal eConnect, California's health information exchange governance organization.

**Anne C. Beal, M.D., M.P.H.,** is chief operating officer of the Patient-Centered Outcomes Research Institute (PCORI). A pediatrician and public health specialist, she has devoted her career to providing access to high-quality health care through the delivery of health care services, teaching, research, public health, and philanthropy. As PCORI's first COO, Dr. Beal is responsible for ensuring PCORI develops the structure and capacity needed to carry out its mission as the nation's largest research institute focused on patient-centered outcomes research. Dr. Beal joins PCORI from the Aetna Foundation, the independent charitable and philanthropic arm of Aetna Inc. Prior to her work at the Aetna Foundation, Dr. Beal was assistant vice president for the Program on Health Care Disparities at the

Commonwealth Fund. Early in her career, Dr. Beal worked with a mobile medical unit project delivering health care services to children living in homeless shelters throughout New York City. She was also a health services researcher at the Center for Child and Adolescent Health Policy at Massachusetts General Hospital. In addition, she was associate director of the Multicultural Affairs Office of Massachusetts General Hospital and attending pediatrician within the division of general pediatrics. Dr. Beal has also held faculty positions within both Harvard Medical School and the Harvard School of Public Health. In addition to publishing in the peer-reviewed medical literature, Dr. Beal is the author of *The Black Parenting Book: Caring for Our Children in the First Five Years*. Dr. Beal has been a pediatric commentator and medical correspondent. Dr. Beal holds a B.A. from Brown University, an M.D. from Cornell University Medical College, and an M.P.H. from Columbia University. She completed her internship, residency, and National Research Service Award fellowship at Albert Einstein College of Medicine/Montefiore Medical Center in the Bronx.

**Kevin J. Counihan, M.B.A.,** was chosen by Connecticut Governor Dannel P. Malloy as the state's health insurance exchange chief executive officer in July 2012. Mr. Counihan has more than 30 years' experience in the health care industry and previously held the position of president of CHOICE Administrators in California. Prior to CHOICE Administrators, Mr. Counihan served as the chief marketing officer for the Commonwealth of Massachusetts Health Insurance Connector Authority, was senior vice president for sales and marketing for Tufts Health Plan, and regional vice president for CIGNA and EQUICOR. Mr. Counihan holds an undergraduate degree from the University of Michigan and an M.B.A. in finance and marketing from Northwestern University's Kellogg School of Management.

**Jennifer (Jen) DeVoe, M.D., M.Phil., M.C.R., D.Phil., FAAFP,** is an associate professor of family medicine at Oregon Health & Science University (OHSU) in Portland, Oregon. She also serves as the part-time executive director of a practice-based research network of community health centers at OCHIN, Inc. She is the Institute of Medicine–American Board of Family Medicine James C. Puffer Fellow (2013–2015). As a practicing family physician and doctorally trained health services researcher, Dr. DeVoe studies access to preventive care for low-income populations. She has established a track record of developing community collaborations and using rich community electronic health record (EHR) data sources to conduct policy-relevant and practice-relevant studies. Dr. DeVoe is the principal investigator on several health services research and health policy research studies funded by the National Institutes of Health, the Agency for Healthcare Research and Quality, the Patient-Centered Outcomes Research Institute, and the Health Resources and Services Administration. She obtained her M.D. from Harvard Medical School in 1999. A Rhodes Scholar, Dr. DeVoe obtained her master's of philosophy (M.Phil.) and doctorate of philosophy (D.Phil.) from Oxford University in 1998 and 2001, respectively. She completed her residency in family medicine at OHSU in 2004. She received a master's in clinical research (MCR) from OHSU in 2010. She maintains a part-time clinical practice in her Southwest Portland neighborhood.

**Kevin Fiscella, M.D., M.P.H.,** is tenured professor of family medicine and public health sciences and associate director of the Center for Communication and Disparities Research at the University of Rochester. His research and policy work, including more than 170 peer-reviewed publications, has largely focused on practical strategies to reduce health care disparities and improve quality for underserved patients. He was recently named the recipient of the Hames Award for research in family medicine. He has served on numerous national committees related to health care disparities, including two for the Institute of Medicine. He currently serves on an advisory panel for addressing health disparities for Patient-Centered Outcomes Research Institute and services on the boards of directors for CHARN, a Health Resources and Services Administration–sponsored Practiced Research Network of federally quality health centers (FQHCs) and the National Commission for Correctional Care. He has worked in FQHCs for more than 30 years.

**Cara V. James, Ph.D.,** is the director of the Office of Minority Health at the Centers for Medicare & Medicaid Services (CMS). Prior to joining the Office of Minority Health at CMS, Dr. James was the director of the Disparities Policy Project and the director of the Barbara Jordan Health Policy Scholars Program at the Henry J. Kaiser Family Foundation, where she was responsible for addressing a broad array of health and access-to-care issues for racial and ethnic minorities and other underserved populations. Prior to joining the staff at Kaiser, she worked at Harvard University and The Picker Institute. Dr. James is a member of the Institute of Medicine's (IOM's) Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities and has served on several IOM committees including the Committee on Leading Health Indicators for Healthy People 2020. She has published several peer-reviewed articles and other publications, and was a co-author for one of the background chapters for the 2002 IOM report *Unequal Treatment: Confronting Racial and Ethnic Disparities Health Care*. Dr. James received her B.A. in psychology and her Ph.D. in health policy from Harvard University.

**Minister Nancy Kingwood-Small, M.S.H.S., BC-HSP,** is currently the deputy director of HIV services at GBAPP, Inc., and serves as project director at the Ashe Faith Project. She holds two degrees in human services and a master's degree in organizational management and leadership from Springfield College. She is a Human Service Board Certified Practitioner. Ms. Kingwood-Small is also a graduate of the Black Ministries Program at Hartford Seminary. She is a licensed associate minister at Mount Aery Baptist Church and in the process of working toward ordination. She is a 2012 graduate of the Connecticut Health Foundation Fellows program. In 2010, Ms. Kingwood-Small had the honor to join the HIV and Women of Color Congressional Briefing Committee to voice concerns of all women living with and at risk for HIV/AIDS.

**Alta Lash** is the executive director of United Connecticut Action for Neighborhoods (UCAN). She has been involved in community organizing for more than 35 years. UCAN's current project, Caring Families Coalition, is dealing with the health care issues of Connecticut's low-income communities. In addition, Ms. Lash teaches grassroots organizing at the University of Connecticut School of Social Work and an internship seminar in the Urban Studies major at Trinity College called Organizing by Neighborhoods.

**Michael Miller, M.P.P.,** is policy director at Community Catalyst, focusing on providing policy and strategy support to state-based consumer health advocacy groups. Over the course of his career, Mr. Miller has developed expertise in the areas of Medicaid, the State Children's Health Insurance Program, Medicare, and developing state-level options to expand coverage for the uninsured, small group and non-group insurance reform, long-term care financing and delivery, managed care reform, and hospital community benefits and uncompensated care. Prior to joining Community Catalyst, Mr. Miller was the policy director for Health Care for All. He also worked for the City of Boston Elderly Commission as a policy analyst and for the Alzheimer's Association of eastern Massachusetts as director of the Community Partnership Project. Mr. Miller holds a bachelor's degree from Brown University and a master's degree in public policy from Tufts University.

**Wayne Rawlins, M.D., M.B.A.,** is a national medical director for racial and ethnic equality initiatives at Aetna, reporting to Aetna's chief medical officer. In 2009, he was appointed to the Institute of Medicine's Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement. Dr. Rawlins also serves as a member of National Quality Forum's Cultural Competency Expert Panel, the National Business Group on Health's Racial/Ethnic Health Disparities Advisory Board, and has been appointed to the Regional Health Equity Council (Region 1), Office of Minority Health, U.S. Department of Health and Human Services (HHS). He has also been a faculty participant in Massachusetts General Hospital's Disparities Leadership Program. Dr. Rawlins is also a member of the National Vaccine Advisory Committee, working with HHS to support the development of a national immunization strategy. Dr. Rawlins received his medical degree from the University of Connecticut in 1980, then completed an internal medicine residency and chief residency at the University of Rochester in New York. He is board certified in internal medicine. Dr. Rawlins received his M.B.A. from Rensselaer Polytechnic Institute in 2001. He is a member of the National Medical Association, American College of Physicians, and the American College of Physician Executives. Dr. Rawlins also supports his community by participating on the boards of the United Way of Central and Northeastern Connecticut, the University of Connecticut Health Center, and the Connecticut Science Center.

**Martha Somerville, M.P.H.,** directs The Hilltop Institute's Hospital Community Benefit Program, a central resource for state and local policy makers, health departments, hospital regulators, and community stakeholders who seek to ensure that tax-exempt hospital community benefit activities are responsive to pressing community health needs. In addition to her work in community benefits, Ms. Somerville is an experienced legal analyst with expertise in the areas of administrative regulation, nonprofit hospital governance, health insurance reform, and Medicaid managed care. Before joining Hilltop, Ms. Somerville served as an assistant attorney general representing several health professional licensing boards. Before that, she provided private legal representation to nonprofit hospitals and other health care providers. Ms. Somerville studied law at the University of Maryland, and received a master's in public health from the Johns Hopkins Bloomberg School of Public Health.