



## Massachusetts Health Reform Reflects Consumers' Voice

Ensuring the consumer voice in coverage, quality, and payment reform in Massachusetts

### SUMMARY

From 2006 through 2012, [Health Care for All](#), a Boston-based consumer advocacy organization, worked to ensure that consumers had a voice in implementing a state law designed to expand affordable health insurance to most of Massachusetts' estimated 530,000 uninsured residents. Project staff also organized a coalition to focus consumer organizations on health care payment reform, and worked to engage consumers in dialogue. From May 2007 through April 2010, Carolyn Needleman, PhD, conducted an evaluation of this effort.

### Key Results

The project director, Brian Rosman, reported the following results to the Robert Wood Johnson Foundation (RWJF). Staff at Health Care for All:

- Expanded a broad-based coalition, Affordable Care Today, to monitor and guide implementation of the Massachusetts health care reform law
- Facilitated enrollment in new insurance programs, both by training state and community-based organizations and through the HelpLine, a telephone resource that provided information about coverage
- Established the Consumer Health Quality Council, recruiting members who had a personal experience with a serious medical error to engage in a variety of patient safety and quality improvement initiatives
- Organized the Campaign for Better Care, a coalition of consumer organizations concerned about health care costs and payment reform
- Produced a wide variety of educational materials for consumers, health groups, public officials, the media, and other stakeholders about implementing health reform and reforming payment systems

## Key Findings

Needleman's May 2010 report on her evaluation, *Ensuring the Consumer Voice in Coverage and Quality in Massachusetts*, presents the following key findings:

- Consumers can play a critically important role in the process of health reform when they have the right kind of support.
- A partnership between health care consumers seeking a voice in policy and advocacy organizations is a gain for both.
- As a focus for engaging consumers, expanding coverage is a starting point, but the broader goal is to deliver quality, affordable, accessible health care.
- The project revealed three interrelated “secrets of success” for building the consumer voice: (1) informal, “below-the-radar” activities to generate enthusiasm and smooth any ruffled feathers; (2) presenting consumers with diverse perspectives to increase their sophistication; and (3) formal ground rules for coalition work.
- Engaging consumers in health reform policy requires active outreach, but the tools for outreach are often underfunded.

## Funding

RWJF supported this project and its evaluation with four grants totaling \$2,434,293.

## CONTEXT

In April 2006, Massachusetts passed a landmark law (Chapter 58 of the Acts of 2006) to expand affordable health insurance to most of the state's estimated 530,000 uninsured residents. The ambitious law included an individual mandate with government subsidies to make insurance affordable for people with low incomes. It also positioned coverage and quality as complementary and reinforcing priorities.

While hospitals, physicians, insurers, and other groups have the resources and expertise to advocate for their positions on health reform issues, consumers often do not. A strong consumer voice was needed to ensure the effective implementation of the Massachusetts law.

Health Care for All, a health care advocacy group based in Boston, has been an advocate for major health policy improvements in Massachusetts for more than two decades. The organization has a history of initiating and managing coalitions and engaging individuals in expanding coverage and improving quality. It played a key role in the public education and outreach efforts that placed comprehensive health reform on the Massachusetts agenda between 2004 and 2006.

## RWJF's Interest in This Area

Engaging consumers in demanding better quality from their health care system reflected the strategic objective of RWJF's recently formed Quality/Equality Program Management team, which combined funded efforts to improve quality with those to ensure equality of care for everyone.

It was also consistent with the Coverage Program Management team's effort to support state-based advocacy to promote stable and affordable coverage for all. Thus, this project presented the Foundation with a unique opportunity to address two of its priority areas, which it typically tackled independently, and to learn how to better coordinate its quality- and coverage related projects.

"We wanted to see how a successful advocacy organization could fare as it shifted its thinking to focus on quality issues for health reform—getting consumers engaged in the debate about quality as well as coverage, particularly consumers who had a patient safety issue or a quality problem," said Brian Quinn, an RWJF senior program officer. "We were looking to see if advocacy organizations could support the objectives of both teams simultaneously."

Also, notes Lori Grubstein, an RWJF program officer on the Coverage team who was interviewed for this report, "We realized that if states don't solve the cost problem, then the whole reform can unravel. So we added advocacy work around payment reform."

Grubstein also noted that *Consumer Voices for Coverage: Strengthening State Advocacy Networks to Expand Health Coverage*, RWJF's \$27 million program that started in May 2007 and is working in 23 states, seeks to spread what Health Care for All did in Massachusetts.

## THE PROJECT

From 2006 through 2012, RWJF supported [Health Care for All](#) to establish an informed, focused consumer voice in policy debates about health coverage, quality improvement, and payment reform in Massachusetts.

While Health Care for All had been engaged with consumers and consumer-oriented organizations, its work had been largely carried out on behalf of consumers rather than by them. The RWJF grants enabled it to shift its focus to more direct participation by consumers and to increase the effectiveness of the consumer voice.

"All of these grants are about trying to make sure there is a strong consumer perspective in these policy decisions," said Grubstein. "RWJF's stance is that we wanted to try to help consumers be on equal footing with the other stakeholders. We also want to make

sure that consumers are part of the implementation so that they are satisfied with the outcomes.”

With its first two grants,<sup>1</sup> Health Care for All worked to involve consumers in the implementation of health reform in Massachusetts and to align efforts to improve coverage and ensure quality care. Much of the work involved the Commonwealth Health Insurance Connector Authority (“the Connector”), the state agency charged with administering the new health reform law.

With a third grant,<sup>2</sup> Health Care for All educated and organized consumers to be effective, knowledgeable participants in efforts to reform the way that doctors, hospitals, and other providers are paid in order to align incentives for patient-centered care. With health care costs rapidly increasing, coverage gains under the 2006 health reform law were in jeopardy.

No RWJF funds were used for lobbying activities. When Health Care for All did engage in lobbying, it used other funds.

## Evaluation

Needleman states that the intent of her evaluation of Health Care for All’s efforts was “to test the idea that consumers could be empowered to play a meaningful role in the details of implementation and have a place at the table in shaping health policy.”<sup>3</sup>

## Methodology

Data for the evaluation came primarily from three sources:

- Ongoing review of electronic and print commentary relevant to Health Care for All’s consumer activities, Massachusetts health reform, and health reform issues in general
- Site visits to observe Health Care for All-sponsored consumer advocacy activities in action and hold discussions with the organization’s leadership, staff, consumer partners, other advocates, experts, and state officials connected with the project. The evaluator also participated in about 12 meetings a month by phone.
- Open-ended telephone interviews with staff members who played key roles in the project, Health Care for All’s executive director, and some of the consumers and consumer representatives who work with Health Care for All

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<sup>1</sup> ID# 57399 (\$350,542, from August 2006 through August 2007) and ID# 58234 (\$1.5 million, from February 2007 through February 2010).

<sup>2</sup> ID# 67314 (\$300,000, from February 2010 through January 2012).

<sup>3</sup> ID # 61137 (\$284,121, from May 2007 through April 2010).

## Other Funding

Over the course of the grants, Health Care for All received approximately \$1.59 million in additional funding from the W.K. Kellogg Foundation, Health Foundation of Central Massachusetts, Boston Foundation, Public Welfare Foundation, Nathan Cummings Foundation, Blue Cross Blue Shield of Massachusetts Foundation, Partners HealthCare System, Philip Evans Scholarship Fund, UMass Medical Center, Open Society Foundations, Smith Family Foundation, and the National Campaign for Better Care.

## RESULTS

Rosman, project director of Health Care for All, reported the following results to RWJF. Staff at Health Care for All:

- **Expanded a broad-based coalition, Affordable Care Today, to monitor and guide implementation of the Massachusetts health care reform law.** The coalition, which had played a key role in passing the law in 2006, added safety-net insurance providers, disability groups, women’s groups, AARP, and a number of community-based organizations to its membership, which had consisted of businesses, nonprofits, and unions.

Coalition members worked with other consumer and grassroots organizations in five workgroups: (1) public programs; (2) legislative advocacy; (3) private insurance; (4) outreach; and (5) affordability/individual mandate.

These groups monitored the work of the Connector, as well as state budget-related activity that had an impact on health coverage and access.

- **The workgroups played a role in establishing the following consumer-friendly policies as the law was implemented:**
  - Meaningful affordability standards for individuals who are eligible for subsidized coverage (see sidebar on page 6: “[How Consumers Helped Lower Insurance Premiums](#)”)
  - A process that takes individual circumstances into account when considering whether to waive the requirement for health insurance
  - Prescription drug coverage and no-deductible primary care in the basic benefit package that satisfies the individual mandate requirement
  - Preservation of a basic level of coverage for legal immigrants despite a severe state budget crisis
  - Numerous administrative simplifications making it easier for consumers to apply and qualify for coverage

- **Produced educational materials for consumers, health groups, public officials, and the media about health reform implementation issues.** Health Care for All staff created a [blog](#) that provided up-to-the-minute information, published an article in *Health Affairs* that reported on implementation progress,<sup>4</sup> accepted numerous speaking engagements, and spoke with reporters to discuss the health reform law and its implications for national health reform.

In addition, staff worked closely with its partner, Community Catalyst, through RWJF’s *Consumer Voices for Coverage* initiative, to educate state-based consumer health advocates across the country about the Massachusetts model.

- **Facilitated enrollment in new insurance programs.** Health Care for All trained staff at numerous state and community-based organizations in the eligibility and enrollment requirements of the new law so that they could pass the information on to their constituents.

Through its HelpLine (a telephone resource line about health coverage), staff also facilitated enrollment in the state’s Medicaid program and its subsidized private health insurance program for at least 10,500 families. “The one call a family made to us was the last call they had to make,” said Project Director Rosman. “We helped them get approved, explained about primary care, explained how to use insurance for the first time.”

- **Established the Consumer Health Quality Council in 2006 to educate policy-makers and the public on the need to address quality issues.** All of its members had either suffered some type of serious medical error themselves, or a family member had. “They wanted to do something in a systematic way, rather than just rail against doctors or hospitals,” said Rosman. “We taught them how the

#### *How Consumers Helped Lower Insurance Premiums*

*When the Massachusetts health reform law went into effect, the state had to determine “affordable” premiums for the insurance that residents were required to carry. After proposing an affordability schedule based on expert advice, the Health Connector Board held a series of public hearings to hear reactions.*

*To demonstrate that many consumers could not afford the proposed rate, Health Care for All presented the monthly budgets of more than 600 Massachusetts residents showing their available income after meeting basic needs. “Based on our outreach work with families, a lot were dependent on credit cards just to get by every month. . Forcing them to pay a significant amount for health care each month was untenable,” said Project Director Rosman.*

*To reinforce the consumer survey data, about 100 people attended a public hearing wearing brightly colored T-shirts that showed up in media coverage. The Connector board later set an affordability schedule lower than its original proposal.*

<sup>4</sup> McDonough JE, Rosman B, Butt M, Tucker L and Kaplan Howe L. “Massachusetts Health Reform Implementation: Major Progress and Future Challenges.” *Health Affairs*, 27(4): w285–w297, 2008. Available [online](#).

process works, how to write a letter, how to talk to policy-makers. They decided what they wanted to work on.”

Through their advocacy work, the Consumer Health Quality Council helped to contribute to state requirements that hospitals:

- Institute rapid response mechanisms when a patient appears to be in danger—that can be initiated by hospital staff or patients and families
- Establish Patient and Family Advisory Councils to advise the hospital on patient and provider communication, quality improvement initiatives, and other matters
- Disclose “serious reportable events” (i.e., events that should never occur, such as operating on the wrong limb) and “health care-associated infections” (infections that occur in the hospital)
- Cannot charge for care provided in connection with preventable “serious reportable events” and “health care-associated infections”
- **Engaged in a variety of other patient safety and quality improvement initiatives.** These included:
  - Establishing a 12-member Quality Advisory Council that met several times a year with Health Care for All staff or Consumer Health Quality Council members. These state and national experts shared new developments and offered their perspectives on how the consumer voice could be more integrated into quality work in Massachusetts.
  - Participating on numerous quality-related committees and panels. For example, either Health Care for All staff or Consumer Health Quality Council members participated on the state’s Public Health Council, the Patient-Centered Medical Home Advisory Committee, the Massachusetts Health Care Quality and Cost Council Advisory Committee, and expert panels involved with hospital mortality, workforce issues, hospital-based infections, and re-hospitalizations
  - Developing a section on quality of care on the Health Care for All [website](#). This included YouTube videos publicizing personal stories of medical errors, which received thousands of hits from around the world. A separate [website](#) provides information from hospitals and other agencies about grievance and complaint processes as well as other patient resources.
  - Developing an e-newsletter focused on patient safety and health care quality, distributed every six to eight weeks to about 700 individuals
  - Helping the Massachusetts Health Care Quality and Cost Council make its website more publicly accessible and consumer friendly
  - Identifying areas for policy improvement in patient safety and quality improvement and educating policy-makers about them. Follow-up reform

legislation (“An Act to Promote Cost Containment, Transparency and Efficiency in the Delivery of Quality Health Care”) contained many of these ideas, including establishing a special commission on payment reform.

- **Provided a consumer voice in the development of e-health initiatives in Massachusetts.** A key focus was a project developed in three communities by the Massachusetts eHealth collaborative and the Blue Cross Blue Shield of Massachusetts Foundation to connect providers’ offices with one another and with local hospitals.

Ultimately, the collaborative could not generate sufficient interest to complete that project. Health Care for All continues to monitor state-level e-health activities.

- **Organized the Massachusetts Campaign for Better Care, a coalition of 36 consumer organizations concerned about health care cost and payment reform.** This state affiliate of a national collaboration, included the Massachusetts Public Health Association; Boston Health Care for the Homeless; Health Care for Artists; and the Greater Boston Interfaith Organization, which represents more than 50 local institutions.

The coalition initially articulated 10 principles as benchmarks for successful payment reform, but then simplified these to focus on an immediate, winnable goal. At a State House rally in April 2011 attended by more than 200 people, they issued a single demand—freeze health insurance premiums for one year.

Responding in part to this public pressure, the governor insisted that insurers re-examine their proposals. The premium increases that were ultimately approved in October 2011 and January 2012 were the lowest in a decade.

- **Created consumer-accessible outreach and education materials on payment reform.** These materials, posted on the Health Care for All’s [website](#), help consumers understand payment reform at whatever level of detail is of interest to them.
- **Cultivated ties with other stakeholders concerned about payment reform and participated in national and state-level forums.** To advance consumer interests, Health Care for All staff educated policy-makers, developed relationships with medical practices, health plans, and employers. Staff participated in a variety of briefings, workshops, and other convenings. These included Families USA’s 2011 Health Action conference and a conference on implementing federal health reform co-sponsored by the Georgetown Center on Children and Families and the Center on Budget and Policy Priorities.

## FINDINGS

According to Needleman's May 2010 report, *Ensuring the Consumer Voice in Coverage and Quality in Massachusetts*, the evaluation yielded the following key findings:

- **Consumers can play a critically important role in the process of health reform when they have the right kind of support.** “The way that consumers’ voices in health policy are usually heard is at town meetings or speak-out events,” Needleman wrote. “Consumers aren’t connected with the machinery of policy...[This project] demonstrated that consumers can play a major role and that an effective consumer voice is an incredibly useful tool for policy-makers and can lead to much more effective implementation.”
- **A partnership between health care consumers seeking a voice in policy and advocacy organizations is a gain for both.** Linking consumers with advocacy resources that are hard to develop from scratch—including knowledge of policy-making procedures and existing alliances—helps consumers gain equal footing with other health care stakeholders. In turn, the advocacy organization enhances its credibility, gains information, and gets a useful reality check on its own assumptions about consumer concerns.
- **As a focus for consumer voice, expanding coverage is a starting point, but the broader goal is to deliver quality, affordable, accessible care that improves health.** Without effective parallel advocacy efforts to keep out-of-pocket costs realistic and to maintain adequate benefits, rising coverage rates may lead to insurance policies that provide little real protection for consumers.
- **The project revealed three interrelated “secrets of success” for building a consumer voice:**
  - **Consumer engagement requires enormous amounts of what one might call “invisible work.”** Not only with Health Care for All’s advocacy resources, but with a great deal of informal, under-the-radar activity by staff, were both Affordable Care Today and the Consumer Health Quality Council supported.

This included phone calls to participating consumers and consumer organizations before and after meetings to discuss special concerns, informal “schmoozing,” spontaneous unstructured brainstorming sessions, taking time to celebrate successes and share jokes, and diplomatic interventions to smooth ruffled feathers. Such work is hard to describe in a grant proposal and hard to link directly to outcomes but is crucial to success.
  - **Familiarizing consumers with a range of perspectives is complicated and time-consuming, but very useful for increasing the sophistication of the consumer voice.** Discussions that include diverse perspectives, rather than emphasizing a single point of view, help consumers to appreciate complexities in

health reform policy and to advocate for policy measures that are practical, politically viable, and less likely to backfire in unexpected ways.

- **Formal ground rules help keep consumer-based advocacy coalitions focused on system change.** One helpful tool for managing disagreement was a set of written principles that member organizations agreed to honor when they joined the Affordable Care Today steering committee.

For example, expectations included “no side deals” (avoid secret deals with other members) and “no surprises” (give advance warning if you’re going to oppose another member’s position publicly). Likewise, the Consumer Health Quality Council established governance procedures after its initial enthusiasm for “unfettered democracy” proved impractical.

- **Consumer engagement in health reform policy requires active outreach, but the tools for outreach are often underfunded.** To develop an effective voice, consumers first have to be persuaded that their health concerns have policy solutions and that they can make a difference. In effect, potential consumer volunteers need to be courted.

For example, Health Care for All’s HelpLine counselors were able to identify individual consumers willing to volunteer time or contribute vivid personal stories. To firm up these connections, a staff member had to meet with them over a cup of coffee and discuss how their work or story could help others, explore their comfort level with going public, and explain how Health Care for All support could make their contribution easier and more effective.

- **The need for a consumer voice in health reform has no clear end point.** Legislation is only the beginning of a multi-year process of implementing policy, and consumer engagement is important at all stages of that process. Without it, as the drama of new legislation fades, “victories” for consumers are likely to be undermined gradually by weakened regulations, noncompliance, non-enforcement, and lack of public awareness. The activities that support the consumer voice in health reform need to continue more or less indefinitely.

## LESSONS LEARNED

1. **Evaluations can provide vital feedback to an organization when structured correctly and led by the right evaluator.** The Health Care for All evaluator took the time to establish relationships with the organization’s staff members and provided “real-time” feedback. Her perspective enabled the organization to calibrate its strategies as opportunities arose or the environment shifted. Project staff said their work was strengthened substantially because of the evaluation. (Project Director/Rosman)

“We wanted to create a collaborative environment,” said RWJF’s Quinn. “You want to ensure that your evaluation is going to remain objective, but if you can do that and

bring that firewall down a bit, it will help the evaluation and the program. It's ultimately a richer and more effective evaluation."

"The evaluator is less like a judge and more like a confidante," added evaluator Needleman.

2. **Have a constant "ear to the ground" when seeking consumer input on health policy.** Health Care for All staff used the HelpLine, its network of community-based organizations and agencies, and the coalition's outreach working group to gain feedback from the public about how the Massachusetts health reform was being rolled out. "We found it absolutely critical to be in direct touch with the people who were affected by this work," said Project Director Rosman.

Health Care for All staff shared that information with policy-makers, including the state's Health Connector staff, as part of a continuous quality improvement process. Without this kind of unfiltered "real-world" information, it is difficult to know whether a program or policy is actually doing what it is supposed to do.

3. **When involving consumers in policy implementation, it is vital to take the time to involve the right people.** The Consumer Health Quality Council could easily have devolved into a support group for people who had been harmed by problems in the patient safety system. Health Care for All developed a screening process for potential members to clarify expectations and keep the focus on policies to improve safety for all. (Project Director/Rosman)
4. **Ensure that complex concepts, such as payment system reform, are explained as clearly and simply as possible.** Health Care for All's early messages were too complex to be understood by many consumers, and staff changed them to emphasize the effect on individual consumers (e.g., reform could save them \$2,000 a year in insurance premiums). They also used analogies, such as likening the fee-for-service payment system to building a house without a general contractor (resulting in too many electrical outlets because the electrician is paid for each one). (Project Director/Rosman)
5. **It is necessary to part ways with traditional allies in the provider community on some health system reform issues.** When Health Care for All began working on payment reform, the organization could no longer work closely with allies such as health providers and hospitals because their interests diverged. Staff decided to keep those allies apprised of their work but not to collaborate directly with them. (Project Director/Rosman)

## AFTERWARD

Health Care for All is continuing its work to ensure a consumer voice in health reform. It has received a RWJF grant from May 2012 through April 2013<sup>5</sup> to represent the consumer perspective, including that of vulnerable populations, in policy discussions regarding implementation of the Affordable Care Act.

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