



1982-2008 FUNDING MAKES A DIFFERENCE



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INTRODUCTION

Health care reform is again at the forefront of the national agenda, and a number of states are taking steps to expand health insurance coverage. Over the last 15 years states have served as catalysts for national health reforms, including children’s health coverage, insurance market reforms, and prescription drug coverage for seniors. This state leadership role is now a permanent fixture in our evolving health system. The most dramatic of these recent state efforts has been in Massachusetts, where an ambitious plan to provide coverage for all the state’s uninsured residents was launched by consumer advocates and other interest groups in 2004. The comprehensive legislation that resulted was the outcome of several years of negotiation between the Massachusetts Legislature, then-Gov. Mitt Romney, and health care advocates, who played a major role in moving health reform to the front of the state’s agenda.

The Massachusetts reform effort has garnered extraordinary attention from policymakers around the country, many of whom are looking for lessons they can apply to their own states. A number of factors came together to make health care reform a reality in Massachusetts. One of the key factors was the active participation of philanthropic organizations, which played a major role in creating the necessary advocacy momentum and policy framework.

This paper traces the complex history of health care reform efforts in Massachusetts over 25 years, focusing on the significant role that philanthropy played in the three key phases of reform—Generating Momentum, Changing Times, and Reaching a New Milestone—that culminated with the passage of the Massachusetts Health Care Reform Plan. It illustrates the interaction among policymakers, grant makers, and consumer advocates over time as the political landscape evolved and new strategies and alliances emerged.

The Massachusetts experience holds lessons for philanthropies across the country about affecting health care reform at the state level. While the specifics about organizations and leadership roles, as well as the political environment, may differ from state to state, the relevant lessons still hold true.

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Overarching Lessons from Massachusetts Health Reform

Investment in advocacy infrastructure and capacity is critical. For more than 25 years, many types of foundations—family-based, community and corporate—provided support for advocacy infrastructure. Investment in building specific capacities, such as grassroots organizing, communications, policy and legal analysis, and coalition-building, ensured that consumer interests were fully represented at the decision-making table.

Support for policy research matters. Research and reports commissioned by foundations or carried out with their support often challenged powerful interests. Examples include reports that focused on high infant mortality rates in Boston; hospitals' use of operating reserves for capital expansion rather than improved neighborhood services; missed opportunities to provide child health coverage; and a health policy reform "roadmap." Foundations accompanied these research-based reports with strong support for consumer advocacy to address the issues raised and frequently convened stakeholders to discuss these reports.

Foundations can play a critical role in bridging and convening stakeholder groups. Foundation support enabled consumer advocates to develop increasingly productive working relationships with other interest groups in each phase of reform. The willingness to tolerate tensions among stakeholders as new consumer voices emerged was important. Over time, foundations helped address strategic power imbalances between consumers and more powerful interests, as when they legitimized the concerns raised about Boston teaching hospitals' use of reserves to finance capital expansions rather than meet the needs of underserved neighborhoods. These efforts helped to change relationships among stakeholders, which allowed the foundations to convene stakeholders to facilitate new thinking about policy solutions and, ultimately, moved the agenda forward.

Collaboration creates new synergies. By collaborating with and learning from each other, foundations developed new funding strategies, starting with the shift from charitable funding to advocacy funding. Associated Grantmakers of Massachusetts convened funders to educate them about policy issues. Grantmaker networks created opportunities and tools for health funders to reframe their roles. Funders also maintained a dialogue with the leaders of consumer health advocacy organizations, ensuring that they understood the opportunities and challenges posed by the policy environment.

1982-1988

PHASE I: GENERATING MOMENTUM



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THE BEGINNING OF PHILANTHROPIC SUPPORT FOR ORGANIZED CONSUMER HEALTH ADVOCACY IN MASSACHUSETTS

In the early 1980s, major health policy decisions in Massachusetts were led by private-sector health care interest groups including hospitals, physician organizations, insurers and, to a lesser extent, the business sector. Rules governing payment to hospitals were privately negotiated among these interest groups and no consumer voice was sought or heard during the process.

In 1982, without debate, the state Legislature unanimously passed a state-run hospital rate regulation system that was protective of the hospital industry while giving the business sector the cost-containment it desired—no consumer voice was present at the negotiations. Within five years, however, organized consumer interests had established a role in policymaking and moved major health policy decisions from behind closed doors to the public arena.

Massachusetts foundations played a critical role in supporting this transition. During this period, Massachusetts philanthropy itself underwent an evolution in focus, shifting from support of more established institutions doing charitable work to increased support of constituency organizing and policy advocacy. This was partially in response to Reagan-era federal funding cuts and the increased demand on foundations to fill the gaps in health and social services. A small group of local funders, including the Boston Foundation, the Haymarket People's Fund, and the Hyams Foundation, began supporting constituency-based organizing and advocacy as a new strategy to achieve lasting policy change by focusing on grassroots engagement with policymakers. This influential group of Boston-based funders had shifted away from the “charity paradigm” in response to community pressure in the 1970s for greater responsiveness to neighborhood concerns. The new constituency-building focus of these foundations was predominantly in the areas of community development, housing, and poverty.

Funding Constituency Building

In 1982, a new philanthropy, the Villers Foundation, joined the existing foundation community. A national foundation with a local office in Boston, the Villers Foundation focused on empowering low- and moderate-income seniors. Its theory of change emphasized the importance of public policy in shaping people’s lives and social opportunities and the need for low-income seniors and other vulnerable groups to become directly engaged in the policy process. Through extensive consultation with senior groups and others, the Villers Foundation determined that health care access and affordability was a growing concern for seniors and that these issues resonated with other constituencies.

The foundation set up its Massachusetts office as a laboratory that could work closely with grassroots groups, community leaders, and other foundations on the premise that funders and advocates should nurture more of a peer relationship.

“We wanted to talk to the constituent groups and find out what they were experiencing,” said Kate Villers, former president of the Villers Foundation and president of Community Catalyst. “They were in the thick of it. They knew what the policy gains would mean in the everyday lives of consumers.”

With the goal of addressing systemic flaws in health care delivery, the foundation’s Massachusetts office set out to develop senior and other constituency engagement in health care issues, building on the grassroots organizing work that other foundations had been supporting on issues such as poverty and housing. The foundation hired staff to coordinate local groups, working to model the philanthropist–organizer peer relationship.

“We were easy to connect with,” said Villers. “Our office was permeable. It felt like home to a lot of folks. It was a neutral meeting place for policymakers, funders and advocates.”

In addition, the Villers Foundation created opportunities for formerly disparate groups to work together. In 1984 the foundation held a series of hearings on health care reform in Massachusetts that brought together constituency groups with legal service and other advocacy groups.

“It was so successful that we asked if people wanted to form a permanent coalition to work together for health care reform,” Villers said. “The answer was a resounding ‘Yes.’” The resulting coalition was the precursor to Health Care For All (HCFA), a consumer advocacy organization that would play a major role in the state’s health care reform efforts.

“Broad empowerment and this kind of direct action are important, but so are the leaders who stoke it. Foundation support helped us be poised to take advantage of political openings.”

CREATING COMMUNITY-BASED COALITIONS

In the mid-1980s, Bill Henning was the lone staff member of the Cape Organization for the Rights of the Disabled (CORD), a small but effective grassroots group advocating for disabled individuals, including on Medicaid and Medicare access issues. However, it was not connected to other activists working on health care reform or engaged in statewide legislative efforts.

That changed in 1985, when the Villers Foundation began looking for grassroots groups like CORD to help build a powerful consumer base to influence health care reform. The foundation supported CORD which used its experience in organizing and advocating as part of the foundation’s initial efforts to create a coalition to lobby for Medicaid and Medicare policy changes for disabled, low-income and senior citizens.

In the spring of 1985, the new statewide consumer health coalition decided to bring its message to the Massachusetts Medical Society’s annual meeting. “People came in busloads,” said Henning. “We wanted to deliver a speech to the meeting, but they wouldn’t let us in. There were about 250 of us trying to get in through the lobby. One of the community organizers put on a suit so he could blend in with the doctors and gained entry. At the designated time, he opened the back door and 25 people got into the room—many of us in wheelchairs—and we took over the podium. It was dramatic. In the commotion, we were able to let in the rest of our group and give our presentation.”

Henning noted, “Broad empowerment and this kind of direct action are important, but so are the leaders who stoke it. Foundation support helped us be poised to take advantage of political openings.”

In 1984 and 1985, with Villers Foundation support, senior, disability, and low-income advocates successfully worked together to increase access to physicians for Medicaid recipients and to end the practice of billing Medicare beneficiaries for the difference between what the government paid and doctors charged—a change that helped thousands of seniors. Villers said these initial victories were proof that “advocacy works.”

The initial campaigns employed a number of tactics from direct action, to grassroots organizing, to policy advocacy. Policy pressure took the form of proposed measures that would tie the granting of medical licenses to the acceptance of Medicaid patients and existing Medicare rates. Direct action included a dramatic takeover by advocates of the Massachusetts Medical Society’s annual meeting (see “Creating Community-Based Coalitions,” above). As new players, the consumers’ demand for a seat at the decision-making table was not without tension.

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Grassroots advocates also were supported with expertise from policy and legal advocacy organizations such as Greater Boston Legal Services and the Massachusetts Law Reform Institute, which drafted legislation and analyzed proposed regulations. As a result of these interlocking strategies, a law requiring acceptance of Medicare rates was ultimately passed. An agreement was reached among advocates, state government and physicians to make significant improvements in Medicaid payment rates, simplify administration, and conduct an aggressive physician recruitment campaign. The agreement dramatically improved physician access for Medicaid patients throughout the state. Equally important, senior, disability, and low-income activists in communities most affected by state-level health care policy moved from working in isolation to collective strategizing, linking affected constituencies with each other and with policy and legal advocates.

First Attempts at Health Care Reform

Just as the campaigns on Medicaid access and Medicare billing were nearing completion in 1985, a major opening for health care reform surfaced in Massachusetts. Business and insurance company discontent with the resource allocation from the state's hospital uncompensated care pool (financed by private payers to reimburse hospitals for uncompensated care) coincided with the need to renegotiate the state's hospital regulation law. Worries about the growing problem of the uninsured and its effect on health care costs were garnering increased attention from policymakers. The Boston Foundation helped put health access and the uninsured on the state's agenda by supporting a seminar series that engaged health care interest groups and stakeholders. The Goldberg Seminars drew policymaker and media attention to the growing numbers and needs of the uninsured. One seminar recommendation was to support a consumer voice in health policymaking.

Consumer advocates were determined to make their voice heard and now they had an organized coalition, greater policy knowledge, and increased visibility. The advocacy coalition, fresh off its Medicaid and Medicare access victories, was joined by advocates for Boston-area public hospitals concerned that negotiations over hospital regulation and reimbursement could affect care for the uninsured, particularly after documented cases of hospitals "dumping" uninsured patients. The issue was exposed partially with grant support from the Haymarket Fund and other foundations which helped public hospital and community health advocates form CommonHealth, an advocacy coalition. CommonHealth published *Staying Alive!*, a quarterly analysis of Massachusetts health policy and politics from a consumer advocacy perspective. For example, the May 1984 issue of *Staying Alive!* exposed cases of hospitals "dumping" uninsured patients onto Boston City Hospital.

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This broad collaboration of health care and public hospital advocates eventually became HCFA. Among the organization's initial members were the Massachusetts Senior Action Council, Cape Organization for Rights of the Disabled, Federation for Children with Special Needs, Massachusetts Fair Share, and SEIU 1475, which represented uninsured home health workers. Not only did HCFA create a unified voice and vehicle for health advocacy groups to demand a seat at the table, it also helped reduce tension among constituency, advocacy, and community-based groups that often competed for scarce funding, further strengthening collaborative efforts.

Local foundations including the Villers Foundation, the Jessie B. Cox Charitable Trust, the Charles H. Farnsworth Trust, and the Boston Foundation provided support to HCFA. The Boston Foundation provided a joint grant to HCFA and the University of Massachusetts to provide policy support to consumer groups. This pairing of HCFA, a relatively new organization, with an established policy center created the foundation's first involvement in consumer health advocacy.

The demand for a consumer seat at the health care decision-making table led the Massachusetts Legislature to establish a publicly-appointed study commission that included formal consumer representation from Susan Sherry, deputy director of Community Catalyst who was HCFA's executive director at the time. The commission was charged with crafting a plan to cover the uninsured as a key element in designing a new hospital reimbursement system. From 1986 to 1987, the commission engaged in intensive negotiations with officials from then-Gov. Michael Dukakis' administration, the Legislature and key stakeholders such as hospitals, which aggressively pressed for increased reimbursement and deregulation as HCFA pressed for increased access to coverage and a stronger health care safety net. With foundation support, HCFA put a human face on the health care crisis and mobilized constituencies for public events. For example, HCFA bused uninsured individuals to a key state Senate hearing in October 1987 as legislators and advocates made a final push to develop a universal coverage bill with broad-based support. This action helped to keep the issue in the public eye and to maintain expectations of a solution.

The state's innovative attempt to achieve universal health coverage received national attention. In August 1987 the New York Times reported that if Massachusetts lawmakers were successful, they "could turn the state into a testing ground for an idea that has been debated in Congress for years." This spotlight brought additional national funding for consumer health advocacy. Faith-based funders such as the Jewish Funds for Justice, Church of Christ, and the Unitarian Universalist Veatch Program were among the earliest national funders. The increasingly visible advocacy effort gained support from other national and local funders, including the Ford and Hyams Foundations, who were concerned about the harm caused to low-income working families by a lack of health insurance.

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Eventually a fragile political compromise was reached in 1988 and the Universal Health Care Law was enacted. Hopes were high that the new law would address the problem of the uninsured and provide a national model for health care reform. The national implications of the new law were seen in front-page New York Times coverage and the launch of Gov. Dukakis' presidential campaign which featured his work on health reform.

Many foundations that had invested in building the consumer advocacy voice to help win passage of the first-in-the-nation law understood that a continued consumer voice would be critical to ensure that the law fulfilled its promise. Local funders, in particular, continued or began supporting consumer advocacy. The Boston Globe Foundation and Burgess Urban Fund of the Episcopal City Mission joined their peers at the Villers, Hyams, and Boston Foundations and Cox Trust in funding these efforts.

However, at the end of 1988, just as advocates and policymakers began to focus on implementing the new law, the political climate suddenly grew more challenging. The economy faltered, a state budget crisis ensued, and anti-Dukakis sentiment rose after the governor's failed presidential bid. As a result, the excitement generated by the passage of the law was relatively short-lived and the next few years would prove challenging to health care advocates, policymakers and funders alike.

Major Provisions of the 1988 Universal Health Care Law

- a “play or pay” mandate for employers that required them to provide coverage or pay a fee to a state-run pool
- a “free care” pool to reimburse hospitals for uncompensated care
- standardized eligibility for free care for people with incomes up to 200 percent of the federal poverty level (FPL) and partial free care to those with incomes between 200–400 percent FPL
- created new state-run insurance vehicles for the disabled and unemployed
- required that college students have health insurance
- limited hospital rate increase to 2 percent above medical inflation

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BUILDING INFRASTRUCTURE

Rachel Pohl, a former program officer at the Jessie B. Cox Charitable Trust, was one of the funders who took a major role in supporting constituency-building after passage of the 1988 reform.

“When I first arrived in 1992 I came upon a bit of a train wreck, due to the fact that a major legislative victory in health reform was enacted at the same time the state was suffering from a major fiscal crisis,” she said.

“I saw the groups that made up the Health Care For All coalition as the backbone of health reform,” Pohl said.

From 1989 on, the Cox Trust focused on providing advocates with tools they needed—infrastructure, legal understanding and capacity for policy analysis—to ensure the success of reform.

“The reforms succeeded to the degree they did because grassroots groups worked so hard to build constituencies,” she said. “My goal was to focus on winnable victories, pulling together allies that hadn’t figured out how to work together.”

This approach echoed that of other funders who understood the value of investment in infrastructure. At the same time, other foundations provided specific support to HCFA for strategic organizational planning, new sustainability strategies, development of a public interest law firm, and greatly improved communications capacity.

Lessons learned

- Establishing an infrastructure for collaboration among grassroots, constituency-based, and policy advocacy organizations was key to creating momentum for statewide policy change. Foundations fostered collaboration by supporting both the individual organizations that were necessary to build coalitions and the coalitions themselves.
- Local foundations often know what is happening on the ground—from the political environment to the needs of consumer advocacy organizations to the intricacies of their relationships with one another—and can be valuable partners for national foundations.
- Funders worked to build trust among themselves, which emboldened other funders and allowed them to “hold hands and jump” toward innovative investment in advocacy. This collaborative mechanism was critical to moving the policy agenda forward.

1989-2002 PHASE 2: CHANGING TIMES



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THE EVOLUTION OF STRATEGIES TO DEAL WITH A CHALLENGING ENVIRONMENT

By 1989 health reform advocacy and organizing faced a hostile political environment. The Universal Health Care Law (UHCL) had been passed a year earlier with great fanfare and high hopes that it would provide a national model for addressing the growing problem of the uninsured and the high costs of their care. Suddenly, Massachusetts found itself in a recession while health care inflation soared. Fragile compromises between stakeholders started to fall apart: hospitals didn't get all the funding they had been promised; Medicaid was cut; and tensions mounted between advocates and hospitals as hospitals pushed hard for deregulation of hospital rates.

In addition, business groups were fighting the "play or pay" requirement, a centerpiece of the health care reform law that required businesses with more than 50 employees to provide coverage or contribute to an insurance pool.

"It was the most negative political environment I had ever seen," recalled Rob Restuccia, executive director of Community Catalyst who was the head of HCFA at the time. "Both gubernatorial candidates called for repeal of the 1988 Universal Health Care Law and the 1990 election brought a Republican state legislative landslide on the platform of repealing the universal health law and deregulating the health system."

The philanthropy environment was changing as well. The local foundations that coalesced in support of an ongoing voice for consumers in health care decision-making were joined by national foundations that shared the values of constituency engagement and policy change. In the time between the final passage of the UHCL and the emerging financial crisis of the early 1990s, the Nathan Cummings Foundation and the Public Welfare Foundation initiated support for Massachusetts consumer health advocacy to preserve the law's promise of coverage for vulnerable constituencies and build a sustainable consumer organization. In particular, these funders made additional resources available to HCFA which increased capacity and enabled effective responses to the challenging political environment. The media outreach, organizing, legal, policy, and coalition-building abilities of HCFA increased significantly as a result of these new philanthropic investments.

Responding Proactively to Negative Environmental Change

The UHCL was under constant attack from conservative talk show hosts such as Jerry Williams and Gov. William Weld. Without the broad coalition of interest groups that came together to pass the law, organizing support for the law was a critical task. The Cummings Foundation played a significant role in supporting HCFA's efforts to organize consumers who would benefit directly from new access programs created by the reform law, including disabled adults and children (the CommonHealth Program) and unemployed individuals (the Medical Security Plan). This allowed HCFA to create a much larger constituency; deepen the level of grassroots organizing to ensure effective implementation and continuation of these programs; and create new opportunities to involve the community in expanding access.

"We put major effort into organizing the constituency that benefited from the Medical Security Plan, which had accumulated \$40 million in unspent funds from employer contributions while nearly 70,000 unemployed workers and their dependents went without coverage," said Restuccia.

"Gov. Weld wanted to squeeze the plan, so we countered by making sure people knew about it and letting them know that they qualified for support if they were unemployed," said Restuccia. "We aired a radio public service announcement in an area of the state with high unemployment asking people to call HCFA to find out about eligibility. When they called, we provided them with the information they were looking for and we recruited them to call their legislator and help keep politicians tuned in to their constituency on this issue."

Meanwhile, the Boston Foundation began discussions with HCFA about its long-term organizational sustainability and building a stronger base in its home city of Boston. The foundation was especially concerned about racial and ethnic disparities in health care access, such as infant mortality—a topic about which it had commissioned a report "Boston At Risk: A Report From the Boston Foundation Primary Health Care Seminar." This dialogue gave rise to the Boston Health Access Project.

"A significant grant from the Boston Foundation allowed us to start holding community meetings to find out how the people living Boston's neighborhoods do or do not get access to health care," said Restuccia. "We got our hands dirty. We became much more oriented toward working in communities. We learned, for example, that the communities living in the shadows of the city's teaching hospitals felt these institutions were turning their backs on them. They were more focused on meeting the needs of suburban clientele."

The early work of the Boston Health Access Project led to a broader effort to ensure that nonprofit hospitals were meeting community health needs. The issue was crystallized by a May 1993 Harvard School of Public Health study "Report on the

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THE BOSTON GLOBE FOUNDATION: TRANSITIONING TO A COMMUNITY FOCUS

In 1989 The Boston Globe Foundation began a process of evaluation rooted in a desire to do more than review grant requests and deliver money. According to Suzanne Maas, executive director at the time, “We talked about listening and learning from others. We were interested in working collaboratively and sharing what we learned. We saw ourselves as a leader, but we were willing to be a follower. We broke new ground by deciding that we were willing and committed to influencing public policy.”

The foundation had avoided public policy to steer clear of violating IRS nonprofit guidelines. But Joan Divers of the Hyams Foundation had been educating Boston-area grantmakers about what they could do in terms of policy while remaining within nonprofit rules. During this period, according to Maas, the foundation came up with new principles to guide its work that emphasized community responsiveness.

In 1990 and 1991, they committed to giving more money to community-based organizations. It was a controversial transition for the foundation, which traditionally had supported large cultural institutions such as the Museum of Fine Art and the city’s noted hospitals.

“We worked through the debate by saying that we wanted to maintain the level of giving to culture by giving through organizations that were grounded in the community,” said Maas. “It wasn’t that we wouldn’t fund the MFA, but that we would fund them if they were connected to community. So when hospitals approached us for grants, we used the same model. We said, ‘Well, what are you doing with the community?’ And we leveraged that.”

Financial Resources of Major Hospitals in Boston” documenting the financial practices and priorities of 14 teaching hospitals in Boston. The study was initiated by Judith Kurland, commissioner of health and hospitals for the City of Boston. The research also received financial support from the Massachusetts office of Families USA (a successor to the Villers Foundation) and the Boston Foundation. The study found that these hospitals were using their significant financial reserves—generated in part by their nonprofit tax exemption—to finance capital expansions instead of meeting the health care needs of underserved residents in the community.

The Massachusetts foundation community decided it was important to understand the issue of community benefits, particularly in light of how the state’s constrained fiscal circumstances impacted access to health care and the competing demand for grant support from Boston hospitals.

“We were confused in many ways,” said Suzanne Maas, formerly of the Boston Globe Foundation. “The research indicated that nonprofit hospitals seemed to have enormous cash flow and reserves, so why were they coming to us for small grants for

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them, but large grants to us? We wanted to keep funding hospitals but only if they could show us how their programs served the community.”

Maas headed the public policy committee of the Associated Grantmakers of Massachusetts (AGM), now Associated Grant Makers, which took on the role of educating the philanthropy community about the importance of public policy. As one of its first projects, AGM hosted a series of forums to bring together grant makers, advocates, and hospital officials to discuss the findings and implications of the Harvard hospital finance study.

AGM worked hard to make the forums a neutral environment focused on information. “We carefully planned it. We didn’t want it to turn into a free-for-all,” said Maas. However, attendees included foundation trustees who were also donors and trustees of hospitals in the study. Several were angered at the idea of questioning hospitals about their community benefits performance. This situation created tension in foundation board rooms. “It was serious,” said Maas. “The board of directors at certain hospitals would call others and try to get people like me fired. They said, ‘This is not your role. You’re blowing things out of proportion. You’re undermining the entire hospital system.’”

An important lesson from this experience, said Maas, is that “nothing changes without tension.” These tensions would continue throughout the policymaking process and gradually receded as new players took their place at the table.

The AGM public policy committee continued its work to develop community benefit criteria despite the tension. “One of the most important things we did,” said Maas, “was to cultivate relationships with people in government. That was also some of the most difficult work, because the people were always changing with new elections and administrations.”

In particular, the committee cultivated a relationship with the attorney general’s office, which was important since the attorney general ultimately would be in charge of developing the state’s groundbreaking 1994 community benefit guidelines. The AGM’s attention to the issue and the forums it convened lent credibility to the issue of hospitals’ responsiveness to the community. It encouraged the attorney general to involve advocates, philanthropy, and hospitals in developing these guidelines that established statewide, mandatory annual reporting for hospitals based on standard definitions of community benefits. The Cox Trust played an important role at this point by funding local organizing efforts on hospital community benefits throughout the state, which helped to energize grassroots consumer coalitions on this issue.

The successful experience with the community benefits issue activated new constituencies, such as neighborhood activists, which helped to build a bigger

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HELPLINE: REACHING OUT TO HEAR CONSUMERS’ VOICES

In 1994 support from the Robert Wood Johnson Foundation, the Cummings Foundation, State Street Bank & Trust, and the Public Welfare Foundation enabled HCFA to develop a helpline that provided crucial assistance to consumers calling about access problems.

“With this tool, we had our finger on the pulse of the health care system,” said Rob Restuccia. “We had a sophisticated database and sufficient staff, so we could formalize a system for documenting all those calls. We used them to better monitor and understand what was going on in people’s lives, and we connected what we learned to the debates going on in the State House.”

consumer base for health reform. It also marked a turning point in the hospital industry’s traditional dominance over the health policy process, putting stakeholders on notice that community needs, articulated by consumers, had to be a priority in reform efforts.

Building New Relationships with Stakeholders

Throughout this period, local and national foundations served as consistent and reliable sources of funding for constituency engagement. Between 1993 and 1996, these philanthropies supported efforts by HCFA to develop stronger working relationships with other interest groups, such as physicians and hospitals, around achievable policy goals. Initially this new stakeholder collaboration focused on preserving and expanding children’s health coverage. An unpublished report funded by the Cox Trust, “Missed Opportunities,” focused attention on the failure of Gov. Weld’s administration to advance children’s health coverage.

The report provided a framework for change. HCFA and public health advocates conceived a campaign to raise the state’s tobacco tax to finance significant expansions of several existing publicly funded health programs. “Philanthropic support was critical to initiating the effort to expand the Children’s Medical Security plan,” said Margaret Blood who, as executive director of the Massachusetts Legislative Children’s Caucus, helped start the effort to expand state-funded health coverage for uninsured children.

The advocates established new alliances on a common agenda of preserving and expanding access with the Massachusetts Medical Society, the Massachusetts Hospital Association, the Massachusetts Teachers Association, some of the state’s HMOs (i.e. Harvard Health and Fallon) and individual business leaders such as Bank of Boston CEO Chad Gifford. The campaign, led by HCFA, followed a collaborative model and engaged key interest groups as well as the Massachusetts Teacher’s Union and a broad spectrum of consumer groups. The interest groups provided a significant amount of funding for the campaign, augmenting foundation support. This pattern—broader stakeholder funding for consumer advocates when there are common interests—persists to this day, including the most recent health care reform campaign.

The effort culminated in 1996 with the successful passage of the Chapter 203 MassHealth Law. To ensure passage, HCFA made a critical strategic decision to support repeal of the state’s “play or pay” mandate for employers, which had never been implemented because of resistance from the business community.

Major Provisions of the 1996 Chapter 203 MassHealth Law

- *expanded Medicaid coverage to all children up to age 12 living in families with incomes under 200 percent FPL*
- *expanded the state-funded Children’s Medical Security Plan for non-Medicaid eligible children to age 19*
- *expanded the CommonHealth Program for disabled adults and children*
- *expanded Medicaid eligibility for low-income adults*
- *created a Senior Pharmacy Program for low-income seniors*

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Consolidating Gains by Building Infrastructure

Following passage of Chapter 203, the Cox Trust provided a multi-year grant that enabled HCFA to continue its local community organizing work and to focus on increasing enrollment in Chapter 203. HCFA was crucial in mobilizing families to take advantage of the new plan. Approximately 30,000 families signed up very quickly for the program, demonstrating both the support and the need for the new program.

The expansion of children's health coverage in Chapter 203 became the model for the federal State Children's Health Insurance Program (SCHIP), a bipartisan success in expanding health insurance coverage. Following passage of the federal SCHIP, in 1997 the Robert Wood Johnson Foundation, through its Covering Kids Program, funded HCFA to organize and manage an extensive SCHIP enrollment outreach and simplification process.

"These multi-year grants gave us the opportunity to convene a broad group of constituents to ensure full implementation of the law. They also made it possible to strengthen our administrative and communications infrastructure and strengthen our partnerships with hospitals, doctors, and businesses," said Restuccia.

Having demonstrated strength and staying power, a dramatically different relationship was established between advocates and traditional health care stakeholders in the years between 1989 and 2002. Philanthropy played a large role in this second phase of reform by strengthening the organizational capacity of consumer health advocates, supporting policy work that garnered public attention for important issues, and making collaboration possible between advocates and other health interest groups. As a result, consumers gained credibility as collaborators in the reform process and as leaders capable of setting the state's health policy agenda. During this period, HCFA served as the lead—but not the only—organization working on policy reform and grew from a staff of four to 28 staff members and a \$2 million budget.

Lessons learned

- It is possible and necessary to do significant base-building work during times of political retrenchment. Sometimes a negative situation can re-energize advocates for change and give them cause for collaborating in new ways.
- Funders' willingness to tolerate tensions among stakeholders when new voices came to the table helped to cultivate stronger relationships with interest groups and improved the policymaking process.
- Funding aimed at outreach and enrollment helps to connect changes in policy with the needs of real people. These consumers, in turn, become part of the policymaking process.
- Foundation support for policy work can play a major role in bringing important issues to public attention. When coupled with support for consumer advocacy leadership on these issues, significant progress can be made.

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PHASE 3: REACHING A NEW MILESTONE



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THE CONSUMER VOICE IS HEARD

By 2003 consumer health advocacy was institutionalized in Massachusetts and consumer groups were recognized as full-fledged stakeholders in health policy decisions. Philanthropic support for HCFA remained strong from diverse local and national funders who recognized support for an institutionalized consumer voice in health policymaking as key to improving the lives of vulnerable constituencies. Organized consumer interests participated in setting the health policy agenda and had a say in major health policy decisions. Interest groups including stakeholders such as hospitals, insurers, and physicians worked with consumers, resulting in a new balance of power. At the same time, however, improving access to care for vulnerable populations was not on the agenda of the state's executive leadership. Years of budget cuts had weakened previously exemplary public health programs. Proposed cuts to Medicaid eligibility and benefits became an annual fight, with adults losing critical dental and vision services.

New Opportunities

In 2004 HCFA sensed a heightened opportunity to tackle health reform due to a number of key factors. As a result of a requirement in the state's federal Medicaid waiver, the state had to redirect funds that were being used to support "safety net" hospitals that cared for many of the uninsured to pay for insurance coverage instead. The state stood to lose \$385 million in Medicaid funds over two years if it did not pass a reform plan. Key business leaders had also begun to recognize that expanding health coverage was in the economic interests of the state. Finally, political leaders, including Gov. Mitt Romney, were looking to make their mark by expanding coverage and reinforcing Massachusetts' national leadership role in health policy.

HCFA convened a broad coalition that included consumers, patients, community and religious organizations, businesses, labor unions, doctors, hospitals, health plans, and community health centers to form a new coalition, the Affordable Care Today (ACT!) Coalition, dedicated to advancing health reform in Massachusetts. The Public Welfare Foundation provided initial national support for the newly launched campaign, joined by local and national funders including the Barr Foundation, BCBSMA Foundation, Boston Foundation, Cummings Foundation, Health Foundation of Central Massachusetts, Klarman Family Foundation, and Robert Wood Johnson Foundation. In addition, stakeholder investments came from Blue Cross Blue Shield of Massachusetts, Boston Medical Center, Cambridge Health Alliance, Partners HealthCare, and University of Massachusetts Memorial Medical Center.

As a tactic to move the health reform debate forward, the ACT! Coalition gathered the 112,000 signatures necessary to put an initiative on the November 2006 ballot that would require a much more substantial payroll tax-based contribution from employers to expand health coverage. The Legislature was informed by the coalition that the ballot effort would be dropped if it passed a comprehensive health care reform bill that would result in a significant coverage expansion. Grassroots members of ACT! such as Greater Boston Interfaith Organization (GBIO), the Coalition for Social Justice, and Neighbor to Neighbor (N2N) were critical to this effort, as they collected more than the 82,000 signatures necessary to get the measure on the ballot.

The world of Massachusetts philanthropy and health policymaking was enlarged in 2001 when the BCBSMA Foundation was established as an independent foundation by Blue Cross Blue Shield of Massachusetts. “The foundation was created with a single purpose — to expand access to health care,” said Andrew Dreyfus, former president of the foundation. “We knew right from the start that the foundation’s strategy to improve access and coverage would include a two-pronged approach: providing grants that would promote programmatic change while simultaneously advancing public policy that would have a meaningful impact on the community.”

As part of this focus on impacting public policy, the foundation had a full-time director of policy and research from its inception.

The Roadmap to Coverage

Leveraging the work already done by other funders and grassroots groups in building a voice for consumer advocacy, in 2004 the BCBSMA Foundation developed a focused, multi-year strategy to significantly expand health coverage in Massachusetts. The foundation funded “Roadmap to Coverage,” a three-year initiative to develop concrete solutions for covering the uninsured and to constructively engage stakeholders in the policy debate.

“We started with a series of public policy papers that provoked many conversations,” said Dreyfus. “I met with 50 to 60 of the key leaders from the Legislature, community and health care leadership and personally invited them to be part of the debate. We also commissioned an independent, third-party research group, the Urban Institute, to analyze the options for reform, providing a position of neutrality along with strong academic credentials.”

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The foundation also provided support that enabled HCFA to provide policy leadership and engage with stakeholders on key policy issues. This strategy of focused policy analysis accompanied by support from consumer leadership and policy advocacy had historically produced policy progress on health care issues in the state, so it held promise to do the same for covering the uninsured.

In a series of three reports, the Urban Institute provided specific policy options to achieve universal coverage while lessening disruption to the existing insurance market and employer-sponsored coverage, and minimizing the need for the expansion of government or the need for new revenue. All stakeholders were fully informed about the emerging research results, giving them time to think through the implications for their own constituencies and to engage their key leadership. This ensured that all parties were thoughtful and constructive in their public stances rather than having to react quickly and publicly to new concepts and policy ideas.

Each major roadmap report was released at a public forum that convened major stakeholders to discuss the findings. Key policymakers, including the speaker of the house, the Senate president, and the governor, gave keynote addresses about their policy views at the forums. A robust communications strategy and the presence of key players in state health policy ensured that the reports and forums would be front-page news, reinforcing the value of participation by all concerned parties. According to Dreyfus, the extensive and strategic process of engaging policymakers, stakeholders and the media around the roadmap ensured that it did not sit on a shelf but moved the policy debate forward.

The other core element of the BCBSMA Foundation strategy to expand coverage was to make a significant investment in greater community organizing and advocacy. Building on work that had already been done, the foundation contributed a significant amount of new, general operating support to existing health advocacy groups for increased organizing and advocacy capacity. The BCBSMA Foundation also began a long-term effort to support grassroots membership organizations through a new grant program area, called Strengthening the Voices for Access. The program awarded grants that helped health advocacy organizations build, educate, and mobilize their members around health coverage, adding additional voices to the policy debate. Because grassroots groups required time to educate members about a new issue, the foundation assured them resources would be available if they took on the issue. As a

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result of this new investment, two grassroots groups that were already involved in the process, GBIO and N2N, emerged as major players in the health coverage debate.

According to Phillip Gonzalez, the director of grantmaking for the BCBSMA Foundation, “It was a strategic move on the Foundation’s part to actively assist GBIO with resources to organize on health care issues. They recognized that GBIO was a large advocacy group who represented the ‘moral voice.’”

The Massachusetts Health Reform Plan

In 2006, after a period of intensive negotiation, Massachusetts passed comprehensive health reform legislation that was intended to provide affordable coverage for uninsured residents. The legislation represented a compromise among legislative leaders, the governor, and major health care stakeholders, including the ACT! Coalition under the direction of HCFA. The law crossed traditional ideological divides by imposing both an individual mandate for health insurance and an

The Massachusetts Health Care Reform Plan

The Massachusetts Health Care Reform Plan combines an expansion of existing public insurance programs and the creation of new, low-cost insurance vehicles with mandates that individuals buy and employers provide insurance. Among the key features:

- *Adults must purchase health insurance if it is deemed affordable or face a financial penalty.*
- *Employers with 11 or more employees are required to provide health insurance or pay a “Fair Share” contribution of up to \$295 per employee.*
- *A new, independent, quasi-public authority, the Commonwealth Health Insurance Connector, was created to implement the plan and oversee the various health insurance vehicles.*
- *The Commonwealth Care Health Insurance Program was created to provide free or low-cost health insurance to low-income residents through four Medicaid managed care organizations.*
- *Commonwealth Choice was created to provide commercial insurance products to individuals and businesses.*
- *Medicaid coverage was expanded to children up to 300 percent FPL and the cap on Medicaid enrollment was increased for certain populations.*

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employer assessment for employers who did not provide coverage. Much of the detail of the new plan, such as the definition of minimum creditable coverage, was left to the implementation process, which would be governed by a new public board with representation from key stakeholders, including consumers.

According to John McDonough, who was then the executive director of HCFA and is now a senior advisor on national health care reform for Sen. Edward Kennedy, “There are four major constituencies that are leading the way with the implementation phase: GBIO, HCFA, N2N, and the Coalition for Social Justice. The philanthropies supporting this next phase of implementation continue to be a mix of local and national funders, including Robert Wood Johnson, Public Welfare, BCBSMA Foundation, and the Boston Foundation. Robert Wood Johnson is funding two efforts to ensure that people receive quality coverage and quality care by supporting outreach and enrollment activities and the formation of a consumer council to oversee the care that is offered.”

The Public Welfare Foundation support for implementation is directed toward both the grassroots constituency groups above and to HCFA.

Lessons learned

- Funders and advocates need to be flexible and ready to take advantage of new situations, such as the opportunity for a renewed effort at health reform that presented itself in Massachusetts in 2004.
- Foundations can play an important role in funding credible policy research that is seen as objective and balanced. They can also work to ensure that key stakeholders including consumer advocates, business interests and policymakers, are able to absorb the lessons of the research.
- As consumer groups build capacity and grow in effectiveness, philanthropies that continue to invest in advocacy, local organizing, leadership, and building infrastructure create opportunities for comprehensive reform.

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**CONCLUSION:
CONTINUING
THE JOURNEY**



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Health reform in Massachusetts did not happen by accident. It was the result of 25 years of hard work, collaboration, and compromise. Foundations played a key role at every stage. In the early years, they funded the organizations and coalitions that put access to health care on the agenda. They also helped ensure that nontraditional stakeholders who had been shut out of the health care policymaking process, such as consumer groups and advocates for the elderly and disabled, had a seat at the policymaking table.

Expanding the number of voices with input in health care policymaking was not without tensions. Traditional stakeholders such as hospitals and insurers pushed back at attempts to enlarge the conversation but eventually acquiesced to the presence of new players thanks to the support of funders and the persistence of advocates.

As this report makes clear, health reform in Massachusetts took a number of twists and turns over the years. Despite setbacks, both funders and advocates were quick to find new opportunities to move the agenda forward. Also, foundations were willing to support what was needed at various points including increased capacity for organizing and educating consumer groups; support with the nuts and bolts of policy; research; and dissemination. National funders paired with local organizations at critical times and learned from one another.

This report also illustrates that very often policy studies created a public conversation about the need for health reform. From the Harvard Community Benefit study to the Roadmap for Change, policy studies energized advocates, attracted media attention and gave moral weight to the quest for a just health care system. Foundation support for many of these studies was crucial.

Implementation of the Massachusetts law requires ongoing advocacy and negotiation. Many important decisions were left for the implementation phase, including the definition of benefits and how to determine affordability of coverage. Enrollment has been greater and faster than originally anticipated. As of December 2008, more than 442,000 people enrolled in health insurance plans as a direct result of the passage of the Massachusetts health reform law. This created more pressure on funding streams. In response, advocates and stakeholders continue to build on the principle of shared responsibility. To that end, the state recently raised its tobacco tax by \$1 and instituted new financing requirements for insurers, providers, and employers to fill funding gaps.

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A recently approved bill that implements new approaches to cost control is viewed as an important next step in health reform. How to finance the new law in coming years and how best to contain rising health costs will continue to be issues. The current economic downturn, constrained state budget, and uncertain federal financial support add to these challenges. In October, the state received welcome news that the federal government had approved its Medicaid waiver, which provides crucial funding for the health reform law. Continued vigilance and engagement by consumers in the policymaking process will be critical, as will ongoing engagement by local and national foundations. Public support for the law remains at 70 percent three years after its passage—an unusually high level. However, the level of advocacy efforts required for implementation is at least as great, if not greater, than that required for the passage of the law.

Foundations are now applying the lessons learned to this critical implementation phase, supporting outreach, enrollment and engagement of affected constituencies; continued research and analysis to understand the law's impact and what proposed changes might mean; consumer advocacy engagement in regulatory implementation; and development of new policy to address unfinished issues.

Community Catalyst is a national advocacy organization that has been giving consumers a voice in health care reform for more than a decade. We provide leadership and support to state and local consumer organizations, policymakers and foundations that are working to guarantee access to high-quality, affordable health care and health coverage for everyone. Our contributions, which range from policy analysis and strategic assistance to managing national campaigns, enable consumer groups to provide leadership in the hard work of transforming the U.S. health care system. Since 1997, in states and communities across the country, we have been a catalyst for collaboration, innovation, and action in health care reform.

FOUNDATIONS

ASSOCIATED GRANT MAKERS (AGM)
(Formerly Associated Grantmakers of Massachusetts)

BLUE CROSS BLUE SHIELD OF MASSACHUSETTS FOUNDATION

BOSTON FOUNDATION

BOSTON GLOBE FOUNDATION

BURGESS URBAN FUND OF THE EPISCOPAL CITY MISSION

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