



INVESTING IN CONSUMER HEALTH ADVOCACY THROUGH OPERATING SUPPORT

*Strengthening the
Voice for Access:
2011–2013*

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FOUNDATION
MASSACHUSETTS

INTRODUCTION

The Blue Cross Blue Shield of Massachusetts Foundation's *Strengthening the Voice for Access* grant program supports advocacy organizations whose missions and activities are focused on promoting the health and health care interests of low-income and vulnerable Massachusetts residents. The Foundation's investments in consumer advocacy are closely aligned with its strategic priorities, which are to maximize access to health care and to address the challenges of health care affordability.

When the Foundation launched *Strengthening the Voice for Access* in 2001, it offered programmatic grants that supported the design and implementation of strategies aimed at improving health care access in Massachusetts. Funded activities included policy analysis, coalition building, targeted consumer education, and collaboration with other stakeholders and public officials. Within a few years, the Foundation made a strategic decision to shift its *Strengthening the Voice for Access* grants from programmatic support to general operating support.

Foundation president Audrey Shelto explains: "The advocacy community played a critical role in the passage of Chapter 58, which resulted in near universal health coverage in Massachusetts. The Foundation's decision to provide general operating support for advocacy gave grantees the flexibility they needed to represent consumer interests and stay at the forefront of reform. Today this grantmaking approach remains critically important during the implementation of the Affordable Care Act and Chapter 224, our state's most recent cost containment legislation."

Strengthening the Voice for Access grantees use the Foundation's general operating support to strengthen organizational capacity and infrastructure, enhance community-based policy activities, increase citizen participation in public policy development, and promote collaboration among policy and advocacy organizations.

Celeste Lee, the Foundation's senior director of grantmaking, points out that general operating support helps to ensure the ongoing presence of "a strong, informed, and engaged consumer voice" wherever health care policy, regulation, or implementation issues are being discussed. "Grantees are able to strengthen their long-term capacity to address the interests of low-income and vulnerable communities by investing in critical but often under-resourced infrastructure priorities."

This report demonstrates how a general-operating-funds approach to grantmaking can forge stronger and more effective partnerships between the philanthropy and consumer health advocacy communities. It includes examples of the positive impact this approach has had on access to health care in Massachusetts and highlights some of the activities and achievements of *Strengthening the Voice for Access* grantees during the 2011–2013 grant period.

SHARED GOALS AND A TRACK RECORD OF RESULTS

A cornerstone of health policy development in Massachusetts has been the extraordinary degree of collaboration not just among consumer advocates but among the broader community of business and labor groups, health plans, provider organizations, and government officials. Over the years, these various interests have maintained strong support for the shared goals of expanding access to coverage, improving care, and reducing overall costs, despite varied ideas about how to get there.

Since its inception in 2001, the Foundation has contributed to the advancement of public policy solutions by participating in this collaborative effort, bringing health care stakeholders together in meetings that encourage open dialogue and debate, conducting in-depth research and analysis, and helping ensure that consumers have a strong voice at the table before, during, and after policies are formulated.

During its 2011–2013 grant period, the Foundation invested \$1.37 million in 11 advocacy organizations through the *Strengthening the Voice for Access* grant program. This report offers examples of how six of these grantees influenced the direction and success of health policy during this period.

- *The Boston Center for Independent Living* and the *Disability Policy Consortium* are co-leaders of Disability Advocates Advancing Our Healthcare Rights (DAAHR), a statewide coalition of disability, mental health, elder, and health care advocacy groups.
- *The Greater Boston Interfaith Organization* (GBIO) is a coalition of 55 congregations and communities from different faith traditions that have united to train, organize, and activate their members for the public good across religious, racial, ethnic, class, and neighborhood lines.
- *Health Care For All* (HCFA) is one of the nation's leading state-based consumer health care advocacy organizations. Its work includes public policy, advocacy, education, and, through the group's HelpLine, consumer information and assistance.
- *Health Law Advocates* (HLA) is a public interest law firm that provides free legal assistance to income-eligible individuals who live or work in Massachusetts and are having difficulty obtaining or paying for health care or insurance coverage.
- *The Massachusetts Law Reform Institute* (MLRI) is a statewide nonprofit poverty law and policy center specializing in legal initiatives that address the root causes of poverty, remove barriers to opportunity, promote economic stability, and create a path to self-sufficiency for low-income individuals and families.



KEY ISSUES IN MASSACHUSETTS HEALTH CARE, 2011–2013

In 2006, Massachusetts passed landmark legislation aimed at making health care coverage nearly universal, and by 2008, that goal had been effectively achieved. An estimated 97 percent of Massachusetts residents had health insurance, and expanded coverage was accompanied by improved access to care, especially among low-income adults. Nevertheless, the need for strong advocacy on behalf of the state's low-income and disadvantaged residents continued. The organizations featured in this report were especially active in three areas:

- **Maintaining the Gains in State Health Reform**

Sustaining the state's significant gains in coverage and access required consumer assistance, monitoring, and, in some cases, legal or policy interventions to prevent setbacks.

- **Containing Health Care Costs**

After extensive research on the drivers of the state's historically high health care costs and spirited debate over potential remedies, lawmakers enacted an ambitious cost containment law in 2012.

- **Improving Care for People with Disabilities**

Massachusetts was one of 15 states to receive a federal planning grant to develop a new integrated care model for people with disabilities who are eligible for both Medicaid and Medicare.

With unprecedented changes taking place in both the public and private sectors of health care, the Foundation's general operating support helped the advocacy community play an invaluable role in shaping policy and protecting the interests of consumers.

MAINTAINING THE GAINS IN STATE HEALTH REFORM

Consumer advocates were at the leading edge of a very successful outreach and enrollment campaign conducted by the state government and the private sector during implementation of the 2006 Massachusetts law. Within two years, the combination of Medicaid (MassHealth) expansion and subsidized coverage brought more than 400,000 previously uninsured residents into the health care system. Health reform is an ongoing process, however, and the Foundation's general operating support has given advocates the flexibility they need to address new issues and potential setbacks.

The need for consumer education and enrollment assistance related to the law's eligibility rules and subsidized coverage remained critical.

The population that has the most to gain from health reform is constantly changing. Many of the most disadvantaged have little or no experience with health insurance, and they often face social, linguistic, and cultural barriers to obtaining coverage and care. Maintaining continuous enrollment in a system that requires income verification is complex and can be confusing to navigate. And

no matter how successful current health reforms are, there will always be a significant number of people who have serious health needs but no insurance.

Health Care For All (HCFA), its legal partner, Health Law Advocates (HLA), and the Massachusetts Law Reform Institute (MLRI) are committed to maximizing enrollment and retention in public insurance programs, monitoring health reform from the perspective of consumers, bringing issues from the front lines of reform to the attention of policymakers, and working to ensure that Massachusetts maintains a strong health care safety net for people who remain uninsured.

HCFA has years of experience with outreach, education, and enrollment assistance, so state officials often look to the organization for feedback and advice on how to make improvements. Each year, English-, Spanish- and Portuguese-speaking staff and volunteers at HCFA's free consumer HelpLine field tens of thousands of inquiries from people looking for assistance with health plan application assistance, choice, selection, and navigation.

HCFA's consumer assistance program manager, Kate Bicego, points out that HelpLine interactions are a rich source of data. "We can take the real experiences of consumers who are living within the complex health care system every day and use their voices on behalf of changes that will actually work for them, not what policy wonks or politicians think will work for real people."

At HLA, staff attorneys provide free services to low-income consumers who have been denied health care access or who need legal advice on program eligibility and benefit issues. HLA also combines legal and policy advocacy with educational outreach to address systemic health care access issues facing low-income consumers. HLA's current strategic initiatives include children's access to mental health care, medical debt, insurance coverage for mental health and addiction services, immigrants' access to health care, and health reform implementation.

HLA's executive director, Matt Selig, says the Foundation's general operating support is invaluable at a time when the need for legal services keeps growing. "We're constantly faced with unforeseen issues, and we can jump right on them, putting resources where they're needed. We can be the eyes and ears of people who may not otherwise be represented."

At MLRI, health care advocates have developed close and effective relationships with the state agencies involved in health reform, working with them to make systemic changes that will reduce erroneous denials of subsidized health coverage and the lapses in coverage that individuals can experience when transitioning between different state programs. MLRI also produced an authoritative guide to help advocates and attorneys navigate the intricacies of the MassHealth program and obtain access to necessary health care services for their clients.

The state's commitment to offering subsidized health coverage to low-income documented immigrants was at stake because of budget cuts made during the height of the economic recession.

When health reform was enacted in 2006, the legislature decided to include low-income documented immigrants in Commonwealth Care, a subsidized insurance program for uninsured adults who met certain income and eligibility requirements. This decision was made even though the federal government did not provide matching funds for a subset of this population of about 40,000 resident immigrants, most of whom had been in the U.S. for fewer than five years. However, in 2009, when tax revenues fell as a result of the recession, the state withdrew Common-

wealth Care eligibility for this population. Some low-income documented immigrants were offered a new program with scaled-back benefits, a limited provider network, and greater member cost sharing, while others were left with no subsidized coverage option.

With broad support from other consumer organizations, HLA filed a class action lawsuit on behalf of low-income documented immigrants who were being denied participation in Commonwealth Care. In early 2012, the Massachusetts Supreme Judicial Court unanimously ruled that the change violated the equal protection provisions in the state's constitution, and Commonwealth Care coverage was restored for this population.

Some provisions of the Affordable Care Act led to significant changes in the way Massachusetts' health reform was implemented.

Although the 2006 Massachusetts health reform law was the template for major provisions of the ACA, there are significant differences between the two laws that required changes in the state's subsidized coverage options, eligibility and enrollment policies and procedures, private insurance market, and cost containment initiatives.

All six of the organizations featured in this report are members of ACT!! (Affordable Care Today!!), a statewide coalition of community and health advocacy organizations, labor unions, faith groups, doctors, hospitals, community health centers, legal services organizations, and public health advocates. The coalition was a driving force behind passage of health reform in 2006, and one of its top priorities for the past three years was to make sure low-income residents and vulnerable groups did not lose ground as the state reconciled differences in the two laws.

Members of the ACT!! coalition worked in partnership with state officials on behalf of legislative and regulatory changes that will preserve and even strengthen key elements of the state's health reforms. For example, Massachusetts will supplement federal premium tax credits and cost-sharing reductions for residents with incomes below 300 percent of the federal poverty level to maintain the affordability standards established by the state law and cover health care for documented immigrants who are ineligible under the ACA.

MLRI provided legal analysis on how the Massachusetts law and the ACA could be reconciled, and they, along with other advocacy organizations, participated in the Massachusetts Office of Medicaid working group on ACA implementation issues. When the Massachusetts Health Connector, the state's health insurance exchange, took up the issue of whether residents at or below the poverty level should pay small premiums for some coverage plans, MLRI and HCFA successfully made the case for maintaining pre-ACA levels of coverage with no premiums.

Neil Cronin, MLRI's senior policy advocate, says that the Foundation's support for positive change is multifaceted. "The Foundation has always articulated a very clear mission, which is that everyone should have access to affordable health care, and they've backed it up with funding, policy work through MMPI [the Massachusetts Medicaid Policy Institute], and research, analysis, and reports on state and national health reform."

CONTAINING HEALTH CARE COSTS

Once Massachusetts' coverage reforms were in place, the health care community turned its attention to the state's historically high rate of per capita spending. In 2012, after extensive examination of cost drivers and potential solutions, a cost containment law, Chapter 224, was enacted, with the ambitious goal of bringing health care spending growth into line with growth in the state's overall economy. Individually, and as members of the ACT!! coalition, advocacy groups that received support from *Strengthening the Voice for Access* were influential in shaping critical elements of the law.

For more than a decade, the Greater Boston Interfaith Organization (GBIO) has been mobilizing its participating congregations, keeping them informed about the issues, and developing health care leaders to bring GBIO's proposals to policymakers and legislators. "Health care is complicated and filled with jargon, so we put a lot of staff time into figuring out how to break an issue down and make it understandable in a way that can lead to action," says Larry Gordon, GBIO's lead organizer. "The Foundation is investing in the process we go through with house meetings, church gatherings, and training sessions, long before you see any specifics from us."

As the policy debate in Massachusetts shifted from access to affordability, GBIO drew upon the real-life experiences of its constituents to make the case for action, showing how rising health care costs are threatening gains in access to care for people with low incomes while driving up out-of-pocket expenses for workers and the middle class. The organization decided to concentrate on three central issues: a benchmark for limiting health care spending increases, government support for public health and prevention, and the wide variation in what providers charge for medical services.

Health Care For All and GBIO incorporated these and other principles into a blueprint for patient-centered cost containment, and HCFA organized the Campaign for Better Care, a consumer-driven coalition that made specific policy recommendations for cost containment. Ultimately, the consumer advocacy community had an impressive impact on the final bill. For example, Chapter 224 established a health care spending growth target tied to the gross state product (GSP), created a \$60 million Prevention and Wellness Trust Fund, and designated a seat for a health care consumer advocate on the new Health Policy Commission. Dr. Paul Hattis, a GBIO health care leader, was appointed to fill that slot on the commission's 11-member board.

"Foundations have too often viewed consumer advocacy as the voice that's going to come in and point out everything that's wrong and then walk away," Dr. Hattis says. "But the Blue Cross Blue Shield of Massachusetts Foundation invested in us to be continually engaged in that dialogue. They invested in our mission."

On the first anniversary of the law's enactment, GBIO organized a "progress report" meeting with CEOs of major hospitals and health plans, who were asked to explain what they were doing to control costs and improve quality of care. State officials charged with enforcing the spending growth target were also in attendance. One observer wrote of the meeting: "The evening easily could have been a formula for anger, yelling, and finger pointing. What happened instead was intense listening and a pumped-up commitment to stay on top of the issue by all in the room."

IMPROVING CARE FOR PEOPLE WITH DISABILITIES

The Boston Center for Independent Living (BCIL) and the Disability Policy Consortium (DPC) act as co-leaders of Disability Advocates Advancing Our Healthcare Rights (DAAHR), a statewide coalition created to influence the development of a federal pilot project aimed at improving outcomes and reducing the cost of care for people with disabilities who are eligible for both Medicaid and Medicare (commonly referred to as “dual eligibles”).

The new program, called One Care, was launched in late 2013 with three Integrated Care Organizations (ICOs) participating in a joint contract with Medicaid and Medicare. The program offers expanded benefits and services, with individualized, coordinated care plans for people dealing with complex health issues, including chronic medical problems, intellectual or developmental disabilities, mental illness, or a history of substance abuse.

“One Care is offering a new, largely untested product to a vulnerable population with a lot of needs,” says Dennis Heaphy, a health care analyst and organizer for DPC and a leader of DAAHR. “It’s a radical integration of services that have been traditionally separate, so the stakes are very high. Without the Foundation’s support for our advocacy, it would be like jumping out of a plane without a parachute, because there’s so little understanding about the needs of people with disabilities.”

DAAHR convinced state and federal officials to hold public forums on the demonstration project and organized consumer testimony on the draft proposal, with the majority of attendees being individuals with disabilities. As a result, the state incorporated many of DAAHR’s recommendations in setting standards for participating plans, including the creation of ombudsman and independent-living long-term services and supports coordinator positions, and requirements that providers become culturally competent with respect to disability and undertake efforts to become compliant with the American with Disabilities Act. The state also established a One Care Implementation Council with over 50 percent representation from consumers and three DAAHR leaders serving as Chairs.

“DAAHR is all about infusing policy discussions with people with disabilities who can talk effectively about their personal experiences,” says Bill Henning, executive director of BCIL and a DAAHR coalition leader. “We’re aggressive about asserting that voice but it’s what anyone would want—it’s just harder for people with disabilities to get heard within the health care system.”



CONCLUSION

A decade ago, Grantmakers in Health (GIH) convened a group of experts from the fields of philanthropy, advocacy, and policy to explore effective strategies for funding health advocacy, and in a subsequent Issue Brief enumerated some of the benefits for foundations. They include: advancing a foundation's mission and goals; complementing grants for direct services as a way to influence systemic change; helping advocacy organizations build the capacity and flexibility they need to respond to newly emerging policy issues; and building stakeholder relationships that make broader and longer-lasting reform possible. The investments the Blue Cross Blue Shield of Massachusetts Foundation has made through its *Strengthening the Voice for Access* grant program have clearly paid off in each of these areas.

As Brian Rosman, research director at Health Care For All, sees it, “Foundations are in the business of spending charitable money to make good things happen in the real world, and public policy is a huge part of that. Policy advocacy, when it's grounded in the real day-to-day experiences of people in the health care system, is enormously effective and it's a great way for foundations to invest in change.”

Foundation president Audrey Shelto recalls that the breadth of challenges faced by the Massachusetts health care community during the 2011–2013 time period was formidable: holding the gains in state health reform, controlling health care costs, preparing for ACA implementation, and improving care for people with disabilities, to name a few.

“The Foundation's general operating support was designed to help advocates respond in a timely and effective manner to the unprecedented changes taking place in health care and also equip them to anticipate and shape the issues that will most affect their constituents,” she says. “We believe that the systemic changes that will meet the access, cost, and quality needs of our most vulnerable neighbors will only come about if we have a stable, strong, and engaged consumer health advocacy community. Supporting advocacy organizations through general operating grants is really an extension of our mission, and I would strongly urge foundations elsewhere to make similar investments in their own communities.”

INTERVIEWS AND RESOURCES

- **Disability Advocates Advancing Our Healthcare Rights (DAAHR)**
 - Dennis Heaphy, health care analyst and organizer for the *Disability Policy Consortium (DPC)* and a leader of the DAAHR coalition
 - Bill Henning, executive director of the *Boston Center for Independent Living (BCIL)* and a leader of the DAAHR coalition
- **Greater Boston Interfaith Organization (GBIO)**
 - Rev. Burns Stanfield, pastor, Fourth Presbyterian Church of South Boston, GBIO president
 - Larry Gordon, GBIO lead organizer
 - Dr. Paul Hattis, former co-chair of the GBIO health care team, senior associate director of the Masters of Public Health Program at Tufts University Medical School, and member of the Health Policy Commission's Board of Directors
- **Health Care For All (HCFA)**
 - Brian Rosman, research director
 - Kate Bicego, consumer assistance program manager
- **Health Law Advocates (HLA)**
 - Matt Selig, executive director
- **Massachusetts Law Reform Institute (MLRI)**
 - Neil Cronin, senior policy advocate
 - Vicky Pulos, staff attorney
- *Funding Health Advocacy*, Grantmakers in Health Issue Brief No. 21, November 2005
http://www.gih.org/usr_doc/IssueBrief21_Funding_Advocacy.pdf

2011-2013 STRENGTHENING THE VOICE FOR ACCESS GRANTEE ORGANIZATIONS

- Boston Center for Independent Living
- Disability Policy Consortium
- Greater Boston Interfaith Organization
- Health Care For All
- Health Law Advocates
- Massachusetts Association of Community Health Workers
- Massachusetts Immigrant and Refugee Advocacy Coalition
- Massachusetts Law Reform Institute
- Massachusetts League of Community Health Centers
- Massachusetts Public Health Association
- Massachusetts Senior Action Council

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