

**Evaluation of The Robert Wood Johnson  
Foundation's Initiative**

**Ensuring the Consumer  
Voice in Coverage and  
Quality in Massachusetts**

**Year 1**

**Interim Report**

EVALUATION (ID #61137)

November 2008

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Robert Wood Johnson Foundation

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## Websites Mentioned in This Report

<b>A Healthy Blog (HCFA)</b>	<a href="http://blog.hcfama.org">blog.hcfama.org</a>
<b>ACT!! Coalition (HCFA)</b>	<a href="http://hcfama.org">hcfama.org</a> , link to advocacy & policy, health reform
<b>Agency for Healthcare Research and Quality</b>	<a href="http://ahrq.gov">ahrq.gov</a>
<b>Boston Globe</b>	<a href="http://boston.com/bostonglobe">boston.com/bostonglobe</a>
<b>Chapter 58, full text</b>	<a href="http://mass.gov/legis/laws/seslaw06/s1060058">mass.gov/legis/laws/seslaw06/s1060058</a>
<b>Community Catalyst</b>	<a href="http://communitycatalyst.org">communitycatalyst.org</a>
<b>Connecting for Health</b>	<a href="http://connectingforhealth.org">connectingforhealth.org</a>
<b>Consumer Health Quality Council (HCFA)</b>	<a href="http://hcfama.org">hcfama.org</a> , link to advocacy & policy, quality of care
<b>Health Affairs</b>	<a href="http://healthaffairs.org">healthaffairs.org</a>
<b>Health Care For All of Massachusetts (HCFA)</b>	<a href="http://hcfama.org">hcfama.org</a>
<b>Kaiser Foundation Daily Health Policy Reports</b>	<a href="http://kaisernetwork.org/Daily%20Reports">kaisernetwork.org/Daily Reports</a>
<b>Massachusetts Health Data Consortium</b>	<a href="http://mahealthdata.org">mahealthdata.org</a>
<b>Massachusetts Coalition for the Prevention of Medical Errors</b>	<a href="http://macoalition.org">macoalition.org</a>
<b>Massachusetts Commonwealth Health Connector</b>	<a href="http://mahealthconnector.org">mahealthconnector.org</a>
<b>Massachusetts e-Health Collaborative (MAeHC)</b>	<a href="http://maehc.org">maehc.org</a>
<b>Massachusetts e-Health Collaborative Blog</b>	<a href="http://maehc.blogspot.com">maehc.blogspot.com</a>
<b>Massachusetts Government</b>	<a href="http://mass.gov">mass.gov</a>
<b>Massachusetts Health Policy Forum</b>	<a href="http://masshealthpolicyforum.brandeis.edu">masshealthpolicyforum.brandeis.edu</a>
<b>Medical News Today</b>	<a href="http://medicalnewstoday.com">medicalnewstoday.com</a>
<b>New York Times</b>	<a href="http://nytimes.com">nytimes.com</a>
<b>Robert Wood Johnson Foundation</b>	<a href="http://rwjf.org">rwjf.org</a>
<b>RWJF News Digest</b>	<a href="http://rwjf.org">rwjf.org</a> , link to program areas, or subscribe through <a href="http://rwjf.org/services">rwjf.org/services</a>
<b>Sorry Works! Coalition</b>	<a href="http://sorryworks.net">sorryworks.net</a>

## Preface: A Smart, Focused Consumer Voice in Health Reform

The focus of this report is a Robert Wood Johnson Foundation (RWJF) initiative titled **“Ensuring the Consumer Voice in Coverage and Quality in Massachusetts,”** originally titled “Massachusetts Quality Coverage and Quality Care” (QCQC).<sup>1</sup> The project unfolds against a backdrop of grim evidence that despite having the world’s highest per capita healthcare expenditures, the U.S. health care system is failing tens of millions of its consumers in terms of coverage, access, quality of care, patient safety, and affordability.

In the absence of federal leadership to solve these problems, numerous states are taking steps to help their residents deal with the current health care system’s gaps and flaws. The health reform law passed in Massachusetts in 2006 currently represents the most comprehensive of these state-level efforts, and its progress and impact are being closely watched by policy analysts and decision-makers nationwide in hopes of learning more about the potential and possible limitations of the plan’s central strategies.

The project under study here addresses a central concern in the Massachusetts health reform effort: **ensuring that health care consumers have an effective voice in the effort to achieve quality coverage and quality care** as the details of implementing the Commonwealth’s health reform are hammered out. This concern reflects a commitment to equity and democratic decision-making – ideas that resonate throughout U.S. history – but goes a step further. Experience has shown that “citizen participation” in policy making can sometimes be active without being productive, and sometimes becomes merely window dressing. Moreover, “civic engagement” in the U.S. has declined in recent years, and consumers today may feel unprepared to attempt policy influence even when they have serious interests at stake. Thus the challenge for consumer advocacy in Massachusetts’ health reform is to go beyond simply encouraging consumers to speak out. The more pressing need is for **specific organizational machinery, clear strategies, and customized tools to maximize the effectiveness of consumer participation in Massachusetts health reform, making consumer voice not only active but also informed, focused, coordinated, and strategically targeted within relevant policy-making arenas.**

The Robert Wood Johnson Foundation undertook QCQC to help meet this need, supporting the initiative with a three-year, \$1.5 million grant to a well-established Boston-based consumer advocacy organization, Health Care For All (HCFA). The project’s start date of February 29 2007, preceded by an initial six-month planning grant, overlaps with the start-up phase of implementation for the Massachusetts health reform law itself. Both the Foundation and the grantee organization see QCQC as a rare opportunity to combine an unusually fluid policy context with substantial funding support in order to learn more about building effective consumer voice in health system change.

As is customary for RWJF initiatives, the project’s progress is being assessed by an independent evaluator<sup>2</sup> contracted by the Foundation. Because the project itself is reactive to an unpredictable and rapidly shifting policy context, the evaluation’s design is by necessity formative, descriptive, and mainly qualitative. Its central aim is not to assess Massachusetts’ health reform as a policy approach, but rather to learn from HCFA’s efforts to strengthen consumer voice in health policy decision-making.

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<sup>1</sup> This Year 1 Interim Report, written before the title change was made, uses the initiative’s original title throughout the text. Subsequent reports will use the new title.

<sup>2</sup> The evaluator is Carolyn Needleman, PhD, a sociologist with over thirty years of involvement in public health and health policy research, professional education, and community-based advocacy practice. She is a Professor Emeritus on the faculty of Bryn Mawr College’s Graduate School of Social Work and Social Research and has headed numerous federal, state, and foundation-funded research projects and evaluation studies.

This first Interim Report describes QCQC's initial year of operation, roughly from March of 2007 through March of 2008. Massachusetts' health reform has produced some remarkable results during this period, including:

- Enrollment of over 340,000 residents who had previously lacked health insurance, estimated to represent about half of the state's uninsured.
- Strong public support for the health reform law (67% favorable in June 2007, up from 61% in September 2006).
- A 16% drop in the use of free care at hospital emergency rooms, suggesting that newly insured residents are now more able to access primary care better suited to their health care needs.<sup>3</sup>
- No evidence so far of the "crowd-out" pattern feared by the law's critics (72% of the Commonwealth's employers offered coverage in 2007, an increase over previous years for Massachusetts and much higher than the national rate of 60%).
- Growing attention to improvements in quality of care, prevention of medical errors, and development of electronic medical record systems – all increasingly being seen as necessary elements in healthcare cost containment.

Consumer engagement has been a conspicuous part of the process through which these results have been achieved. The present report describes in detail the strategies that HCFA has used to further consumer involvement, along with some lessons learned about what a well-organized and informed consumer voice can contribute to system change, where some possible pitfalls lie, and what it takes to support and focus this powerful force.

Of course, because the QCQC initiative aims at a moving target, things may change. The initial stage of Massachusetts health reform implementation was an exciting period for policy makers and consumer advocates alike, guided by optimistic assumptions and best-guess estimates. The possibility of a funding shortfall was recognized, but felt to be resolvable. As this report is being written, however, the "elephant in the room" – a combination of higher-than-anticipated implementation costs and worsening economic conditions – is becoming ever more visible and the policy context is growing more strained. A number of difficult unresolved issues will be coming to a head over the next few months as the proposed state budget is finalized, noncompliance penalties begin to be felt by individuals and businesses, some important decisions are announced by state and federal agencies, the state-subsidized insurance plans go through their open-enrollment period, and the current state legislative session comes to an end. Meanwhile, important personnel changes are unfolding within HCFA and national election campaigns are underway. The outcomes of all these "cliff-hangers" will affect both the course of Massachusetts health reform and the consumer engagement strategies being used by HCFA, in ways unknown at this point. Thus the lessons learned so far through QCQC can be expected to expand and change as the initiative moves forward.

A second Interim Report will be forthcoming in spring of 2009, followed by a comprehensive Final Report in spring of 2010. The author welcomes comments and discussion at any time. She can be contacted at [carolyn.needleman@cox.net](mailto:carolyn.needleman@cox.net).

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<sup>3</sup> The latest data, available after Year 1 ended, show that "the share of low-income residents using emergency rooms for nonemergency care rose slightly" (see "The Massachusetts Model," editorial in *The New York Times*, June 16 2008). However, because of insufficient provider capacity to meet the needs of the newly insured, emergency room utilization is somewhat complicated as an indicator of health reform's effects. The same source notes that "many of the newly insured reported difficulty finding a primary care physician," leaving the ER as their only resource for health care even though they are now insured. The implications of physician shortage will be explored in next year's Interim Report.

## Acknowledgements

Evaluation of this multifaceted, unpredictable, fast-moving project has required an unusual amount of cooperation from staff members of the grantee organization (Health Care For All of Massachusetts) and the consumers working with them. The evaluator would like to thank all of the individuals who have supplied factual information and opinions during Year 1 of the project. They have been remarkably candid, generous with their time, and insightful about the project's successes and challenges.

Particular thanks go to the HCFA staff and board members who have made time available for interviews during site visits and/or have granted telephone interviews during Year 1. In alphabetical order, these include: Mehreen Butt, Lisa Fenichel, Lisa Kaplan Howe, Jean Leu, James Madden, John McDonough, Diana Ong, Fawn Phelps, Lucilia Prates, Marla Stein, Brian Rosman, Lindsey Tucker, Deborah Wachenheim, Camille Watson, and Lynn Wickwire. In addition to their professional work with HCFA, two of these individuals were among the first members of HCFA's Consumer Health Quality Council, as consumers personally affected by medical error. Many other consumers and consumer advocates participating in the project through the ACT!! Coalition and the Consumer Health Quality Council have shared time, stories, and ideas with the evaluator. While they are too numerous to list here individually, their contributions have been invaluable, and are very much appreciated.



## Part 1

# Introduction

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## Background of the QCQC Initiative

In April 2006, Massachusetts enacted a ground-breaking piece of legislation known as Chapter 58 of the Acts of 2006,<sup>4</sup> intended to achieve universal health coverage for Massachusetts residents and also to address issues of health care quality and cost. Like most ambitious laws, Chapter 58 left numerous issues to be resolved in the process of implementation. Consumer advocates who had worked to get the legislation passed, well aware that devils could be lurking in the details, were concerned that the voice of consumers should be heard loud and clear in decisions on the exact shape that Massachusetts health care reform would take as the plan went into effect and various provisions of Chapter 58 were phased in. They wanted to head off the possibility that, despite the new legislation's potential for improving health insurance coverage and quality of care, it might be implemented in ways that excluded meaningful participation by consumers themselves.

At the center of this concern was a Boston-based consumer advocacy organization called Health Care For All in Massachusetts (HCFA-MA, shortened to HCFA in this report). Working with a number of organizational partners and broad-based coalitions, HCFA has for decades played a leading role in Massachusetts health care reform efforts.<sup>5</sup> The organization's stated mission (*see Appendix #1*) is to create "a consumer-centered health care system that provides comprehensive, affordable, accessible, culturally competent, high quality care and consumer education for everyone, especially the most vulnerable." In the words of its current Executive Director, "Together, we bring consumer health advocacy to a new level – 21<sup>st</sup> century advocacy combining community organizing with legal, technology, policy advocacy, research, educational, and care management strategies. In contrast with the current fad – 'consumer-driven health care' – we are consumer-driven health care *reform*."<sup>6</sup>

Shortly after Chapter 58 was passed, HCFA sought funding to "establish a smart, focused consumer voice to influence both health access reform implementation and the rapidly expanding quality improvement/patient safety movement in Massachusetts."<sup>7</sup> The request struck a responsive chord within the Robert Wood Johnson Foundation (RWJF), which also has had a long-standing commitment to promoting effective consumer engagement on issues of coverage, access, and quality care. RWJF awarded an initial six-month planning grant to HCFA starting September 1, 2006, followed by a three-year grant of \$1.5 million to support the HCFA activities described in this report, with a start date of February 29, 2007. The project is called the "Massachusetts Quality Coverage and Quality Care Initiative" (QCQC).<sup>8</sup> A brief description of the QCQC initiative, taken from the RWJF website, appears in *Appendix #2*.

The QCQC initiative offers some unusual opportunities both for RWJF as the sponsor and for HCFA as the recipient organization. From the Foundation's point of view:

- **The project fits RWJF's commitment to making a timely, tangible, positive difference in helping to solve the nation's growing health care crisis**, in the spirit of Foundation President Risa Lavizzo-Mourey's public statement that "Now is the time to fix what's broken."<sup>9</sup> Because QCQC connects directly to a sweeping state law that affects large numbers of people, the project has the potential for significant impact.
- **QCQC serves as a vehicle for combining strategic interests in two of the Foundation's priority areas – health care coverage and health care quality/equality.** In recent years, interest has grown in learning more about possible complementarities and synergies between

<sup>4</sup> The full text of Chapter 58 is available at [www.mass.gov/legis/laws/seslaw06/sl060058.htm](http://www.mass.gov/legis/laws/seslaw06/sl060058.htm).

<sup>5</sup> In addition to its advocacy work, HCFA provides several kinds of direct service including a HelpLine for outreach, information, and referrals; a benefits counseling service called RealBenefits; and legal support for consumers through a partner organization, Health Law Advocates. It is closely allied with Community Catalyst, a consumer advocacy group that focuses on health care reform nationwide.

<sup>6</sup> Message from HCFA's Executive Director, available on HCFA's website.

<sup>7</sup> HCFA proposal to RWJF, 2006.

<sup>8</sup> RWJF ID # 58234. (On the Foundation's "active grants" list, the initiative is titled "Ensuring the consumer voice in coverage and quality in Massachusetts.")

<sup>9</sup> Robert Wood Johnson Foundation, Message from the President; Risa Lavizzo-Mourey, *Now is the Time to Fix What's Broken*, January 29 2007.

these two areas, particularly regarding their consumer engagement aspects. Because of Chapter 58's broad scope, health care reform in Massachusetts provides an excellent context for exploring these interconnections and helping the Foundation "learn how to coordinate its quality and coverage-related work better."<sup>10</sup>

- **In addition, QCQC can potentially yield lessons that will be helpful for other Foundation initiatives related to consumer engagement in health care coverage/quality reform efforts** – in particular, a three-year, multi-state RWJF initiative called "Consumer Voices for Coverage" launched in February 2008.<sup>11</sup>

The project matches HCFA's agenda as well. The issue of consumer engagement is not new for this organization, which has long advocated for a greater consumer role in health policy decision-making. However, the QCQC grant comes at an ideal time, providing a large increase in resources just as the implementation of Chapter 58 opens new windows of opportunity for strengthening consumer voice in health care policy. More specifically:

- **The grant has supported a major expansion of HCFA staff, providing the labor needed to manage the organization's stepped-up consumer advocacy efforts.** In 2006, prior to the RWJF grant, HCFA's full-time staff numbered about 12. Funds from RWJF and other sources now support more than 30 full-time staff, with additional part-time staff and interns bringing the organization's workforce up to approximately 38 FTEs.
- **The grant has enabled HCFA to undertake some new kinds of consumer engagement that complement its usual strategy of consumer advocacy through coalitions.**

In particular, a HCFA-supported Consumer Health Quality Council is breaking new ground in terms of direct consumer voice, and some pioneering consumer advocacy work is unfolding through HCFA's involvement with electronic health information systems (e-Health).

In HCFA's grant proposal, the deliverables planned for QCQC were described in very broad terms because the implementation details of the Massachusetts plan were (and still are) not yet fully worked out. The proposal set out the following broad objectives:

- › Enrollment of newly eligible individuals and families into appropriate coverage.
- › Educational materials about Chapter 58 implementation for the public and policy-makers in Massachusetts and nationally.
- › A Massachusetts' consumer-driven patient safety and improvement agenda.
- › Educational materials to teach consumers about quality improvement in Massachusetts.
- › The addition of a consumer voice in key Massachusetts quality councils and other fora.
- › Recommendations to ensure e-Health initiatives account for consumer interests.

The present report's purpose is to explain how these objectives have been interpreted and addressed by HCFA during the grant's first year, particularly in terms of their consumer engagement aspects.

<sup>10</sup> This goal is stated in the Robert Wood Johnson Foundation's letter of agreement to Health Care For All.

<sup>11</sup> A description of RWJF's Consumer Voices for Coverage Initiative appears on the Foundation's website. The QCQC initiative may also be relevant to health-consumer advocacy initiatives being funded by other institutions – for example, the David and Lucile Packard Foundation's eight-state Finish Line Project on children's coverage recently launched in coordination with RWJF's Consumer Voices for Coverage, and the fifteen-state program that Community Catalyst is undertaking to address underinsurance (unaffordable cost burdens for those who have insurance, but cannot meet the cost-sharing requirements).

## Four Important Caveats

Because the primary evaluation focus is on HCFA's efforts to *facilitate consumer engagement* in achieving quality coverage and quality care, this report does not attempt a comprehensive policy analysis of the Massachusetts health reform plan itself. Some aspects of Chapter 58's implementation are discussed as context, but only briefly, skipping over many important policy issues. For fuller background information, the reader may want to consult the growing body of reports discussing the Massachusetts plan's provisions, complex implementation details, results to date, and emerging challenges.<sup>12</sup>

Still, because HCFA's consumer engagement efforts are unavoidably affected by their political, organizational, and policy environment, the following caveats are important for understanding what has been attempted and achieved through the QCQC initiative so far.

### Caveat #1: "Massachusetts Exceptionalism"

Health reform in Massachusetts benefits from a number of factors that may not be present (at least, not in the same combination) in other states. Probably most important, as HCFA's leaders often emphasize, is *the advantage of time*. Consumer advocates in Massachusetts have been working on reform legislation since mid-1980, slowly developing alliances and building a history of negotiation and problem-solving among key stakeholder groups.<sup>13</sup> This shared history greatly smoothes the way for HCFA's coalitions. Also, Massachusetts is one of very few states able to approach health reform with *a publicly subsidized "uncompensated care pool"* (now called the "Health Safety Net Fund") already in place, used to help compensate hospitals for services they provide free to the uninsured. In theory, universal coverage should reduce the

need for this pool, allowing at least some of its funds to be redirected into Chapter 58's state-subsidized coverage plan, Commonwealth Care. The transition is proving difficult for safety-net hospitals,<sup>14</sup> but at least Massachusetts is not starting completely from scratch in terms of funding health reform, as states without a pre-existing safety net fund would be. Similarly, *relatively strong regulation of the insurance industry* has historically been part of the Massachusetts health policy scene, so again, while some very difficult challenges remain, the state has had a base to work from in negotiating premium levels and minimum benefit packages. Finally, during QCQC's first year, Massachusetts has enjoyed (perhaps briefly) an *unusual window of opportunity* for consumer-oriented health reform due to a rare convergence of public support, political will, and available policy tools – coupled with *extraordinarily experienced leadership* already in place within HCFA and its related consumer advocacy organizations.

Alignment of so many favorable conditions is rather unusual.<sup>15</sup> So the question arises: Is the Massachusetts experience too unique and exceptional to serve as a useful guide in other states where advocacy organizations are working on consumer-oriented health reform, but without these conditions?

The answer seems mixed. Massachusetts may indeed be something of a special case on the policy level; while much is being learned, HCFA's specific advocacy strategies and policy goals may not all transfer directly to other states. On the other hand, *the Massachusetts experience offers insights into the process of consumer engagement in health reform* that will be of interest in any advocacy effort seeking to include an effective consumer voice. In addition, *Chapter 58's broad*

<sup>12</sup> Two very useful comprehensive analyses are *Massachusetts Health Reform: What It Does; How It Was Done; Challenges Ahead* (Community Catalyst, April 2006) and *Revisiting Massachusetts Health Reform: 18 Months Later* (Community Catalyst, December 2007), both accessible through the Community Catalyst website. Current information on available insurance options, affordability schedules, timetables, penalties, and some quality/cost issues can be found on the website of the Massachusetts Connector Agency. In addition, HCFA's blog contains extensive discussion, both current and archived, of policy related to coverage and quality issues in Massachusetts' health reform.

<sup>13</sup> Fascinating background information can be found in John E. McDonough (2000), *Experiencing Politics: A Legislator's Stories of Government & Health Care*, Chapter 7 (Berkeley: University of California Press). See also John E. McDonough (January, 2007), *The Road to Massachusetts Health Reform (Chapter 58) and Beyond* and *HCFA Annual Report 2004, Health Care For All: 20 Years of Making History in Massachusetts* (both available through the HCFA website).

<sup>14</sup> Jeffrey Krasner, "Safety net hospitals strained by reform," *Boston Globe*, March 18 2008.

<sup>15</sup> In effect, Massachusetts is already well along in terms of building bridges among stakeholder groups as envisioned in RWJF's initiative "Aligning Forces for Quality."

*scope – linking issues of coverage, access, and affordability with issues of quality care and cost containment – provides useful insights into interrelations, tradeoffs, and synergies among various facets of health reform.* These lessons from the Massachusetts experience will remain relevant to other states' health reform efforts (and to health reform at the national level) even if circumstances in the other states are very different.

## Caveat #2: Health Care Cost Containment

Massachusetts has not escaped the economic pressures being felt by state governments nationwide. Throughout QCQC's Year 1, HCFA's leadership and staff have been conscious of what they termed the "PLFC" (the "Potential Looming Financial Crisis") expected to hit the Massachusetts health reform effort in spring of 2008. As this report is being written, health advocates and state policy makers are ruefully acknowledging that the expected crunch has now arrived. The Commonwealth faces a \$1.3 billion budget deficit, and the "PLFC" has become the "FC." Numerous spending priorities are competing for state funds just as an unfolding economic downturn threatens to shrink state revenues. At the same time, implementing Chapter 58 is turning out to be more costly than anticipated – paradoxically, in part because of the plan's success in enrolling more than the expected number of previously uninsured individuals. Estimates of the cost overrun vary widely, from a figure of \$400 million reported in the Boston Globe to HCFA's own calculation of about half that much if the costs attributable to Chapter 58 are separated from other factors that increase health care costs.<sup>16</sup> But whatever the exact figure, the state's health reform program is clearly going to be pressed for resources. Health reform in Massachusetts has entered what all concerned are calling its "Phase Two," in which a central focus is *cost containment*.

The situation is very much in flux politically. The Governor's proposed state budget, issued in February, supported full funding for health care reform. That proposal is now being

vigorously debated in the state legislature, along with various revenue-generating strategies such as a \$1 per pack increase in the existing cigarette tax. The situation is greatly complicated by uncertainty over pending actions by the federal Centers for Medicare & Medicaid Services (CMS). By June 30 2008, CMS must decide whether to approve Massachusetts' 1115 Medicaid waiver renewal request, a decision affecting \$385 million in federal funding to the Commonwealth. Also, regulations withdrawing federal support for certain Medicaid health care services were proposed or issued by CMS last year, and only temporarily delayed by Congressional action. If not reversed by Congress, these funding cuts are scheduled to go into effect this spring, reducing federal funding in Massachusetts by more than one billion dollars over the next five years.

Meanwhile, public debate is growing sharper concerning how the rising costs of Massachusetts' health reform should be apportioned among the "three legs of the stool" in Chapter 58's shared responsibility framework (individuals, employers, and government). In workplaces where insurance is offered to employees, regulations put in place during Governor Mitt Romney's administration defined a "fair and reasonable" premium contribution by employers at a level far below the national market average – a 33% employer contribution rate for full-time employees, as compared to 84% nationally.<sup>17</sup> With the government contribution already overspent, this low threshold for employer responsibility threatens to leave consumers "out front and out alone," bearing increased cost-sharing burdens that strain the concept of affordability and could undermine public support for individual mandates as an approach to health reform. As discussed later, HCFA and its organizational partners have been active and highly visible in introducing consumer voice into decision-making related to these issues.

Whatever the implications for Massachusetts' health reform on a policy level, *these deepening financial pressures are*

<sup>16</sup> See "Putting in Perspective Today's Globe Story," *A Healthy Blog*, January 24 2008.

<sup>17</sup> Alternatively, employers can comply by enrolling 25% of their employees in a group health plan – again, a low level compared to national patterns.

*bound to yield lessons about consumer engagement that are potentially applicable in other states and the nation as a whole.* How does consumer voice fare in the midst of a state financial crisis? Do consumer advocacy tactics change, and if so, with what results? Is zero-sum conflict among stakeholders now becoming unavoidable, or will the challenge instead stimulate innovative cost-containment strategies, collaboration and compromises?

### Caveat #3: Leadership Transition

In early February 2008, HCFA's Executive Director, John McDonough, publicly announced that he will be leaving the organization at the end of July 2008<sup>18</sup> – a development that, in the words of a senior HCFA staff member, “sent a quiver throughout the entire health advocacy community” because he has been such a prominent figure in Massachusetts' health reform. Recruitment for a replacement is currently underway. The change of leadership will require some organizational adaptations, as HCFA has relied heavily on Dr. McDonough for strategy, connections, tone-setting and “visioning.” In addition, several other HCFA staff members who have played important roles in QCQC will be leaving in the fall to pursue graduate studies or for other personal reasons. But turnover is the kind of challenge that advocacy organizations face fairly often. A number of steps are already being taken to make the departures and replacements as smooth as possible, and a large measure of continuity will likely be provided by the organization's recently completed Strategic Plan for 2007-2010. *How HCFA manages its personnel transitions during the next two years should yield insights into how a consumer-interest organization can best weather a change in top leadership and other staff turnover in the midst of a long-term advocacy campaign.*

### Caveat #4: Other Issues Waiting in the Wings

A host of additional thorny questions loom in the background. To list a few:

**The basic direction of health care reform.** As affordability issues become more acute, will the mandated coverage approach continue to enjoy its present political support in Massachusetts? Ironically, HCFA did not originally push for individual mandates, but – not wanting the perfect to be the enemy of the good – embraced the present shared responsibility model as a pragmatic necessity to get Chapter 58 passed. This spring's tax season is expected to bring the issue of non-compliance penalties to a head, potentially stiffening individual and business opposition to mandated coverage and deepening existing strains between advocates of the present Massachusetts health reform plan and advocates of different approaches such as a single-payer system or non-mandated (voluntary) participation.

**Scope and equal accessibility of covered benefits.** Will the plan be able to cover a full range of health needs equally for all state residents? At present, coverage for oral health is not included and the currently required coverage for prescription drugs is a target for reconsideration. Disparities in access to care continue to plague the system.

**Provider capacity.** As more individuals gain insurance coverage, will the healthcare system be able to meet the increased treatment needs? While there is a high concentration of health care resources in the Boston area, physician shortage is already acute in some other parts of Massachusetts, along with shortages of pharmacists and available hospital resources.

**Changing ideas about health and health care.** Recognition is growing that health depends on non-medical factors at least as much as on access to medical treatment through insurance.<sup>19</sup> How will the Massachusetts health reform plan intersect with aspects of disease prevention and health promotion that go beyond insurance coverage?

<sup>18</sup> This departure date has now been moved up to the end of May 2008.

<sup>19</sup> See Charles E. Rosenberg, *Our Present Complaint: American Medicine, Then and Now* (Johns Hopkins University Press, 2007); Shannon Brownlee, *Overtreated: Why Too Much Medicine is Making Us Sicker and Poorer* (Bloomsbury USA, 2007); and *Overcoming Obstacles to Health* (Report from the Robert Wood Johnson Foundation to the Commission to Build a Healthier America, 2008).

## The Special Nature of Grant-Funded Advocacy Initiatives

One final point needs to be mentioned by way of introduction. QCQC represents a special kind of grant – an “advocacy initiative” aimed at furthering broad system change in a dynamic political environment. This kind of initiative differs in fundamental ways from the demonstration projects often supported through philanthropic giving. For example:

- **Advocacy initiatives cannot specify all of their funded activities and anticipated outcomes in advance.** They necessarily operate within a framework of what might be called “constructive opportunism,” constantly adapting to new circumstances and opportunities. Thus, while their broad goals may remain steady, their specific grant-funded activities and objectives can be expected to change during the life of the grant, sometimes drastically.
- **Advocacy initiatives tend to sweep diverse activities into a broad overall effort in a blended way that makes it difficult (and possibly beside the point) to separate out exactly what constitutes “the funded program.”** For example, this report focuses on the three aspects of HCFA’s advocacy work described in HCFA’s proposal to RWJF, representing what the grant explicitly targeted: (1) consumer engagement in the expansion of quality affordable coverage through Chapter 58’s implementation; (2) consumer engagement in decision-making related to quality-of-care and patient safety; and (3) consumer engagement in the development of “e-Health” systems such as electronic medical records and computerized prescription orders. However, HCFA is simultaneously working on consumer engagement in other closely related areas such as reduction of health disparities, increased attention to oral health problems, improvements in children’s health and mental health services, and reform of cost-inflating relationships between physicians and pharmaceutical companies. Supportive interconnections exist among all of these activities, and there is a certain artificiality in saying that some of them “belong” in QCQC and others do not.
- **Advocacy initiatives rely heavily on complementarities among grants from different funding sources.** For example, HCFA’s work being directly funded through QCQC is closely intertwined with related work not funded by RWJF, such as the HCFA HelpLine. Thus the success of the QCQC initiative depends not only on its primary funding from RWJF but also on ancillary support from multiple other sources.
- Finally, **many uncontrolled forces are at work in an advocacy initiative’s external environment, shaping what is possible in terms of policy impact.** In the case of good policy outcomes, factors outside the initiative may deserve at least part of the credit. If the initiative fails to have the desired impact, external circumstances may be the reason why. Thus an advocacy initiative cannot be judged solely by its effect on policy. It might be considered successful if it improves the *process* of consumer advocacy, even if the immediate policy impact is disappointing.

The most useful way to think about a general-support advocacy initiative like QCQC may be to view it not as a stand-alone project, but more holistically – as one part of a larger effort with many different funders and lots of parts, all moving fast, whose overlaps and fuzzy boundaries are not so important because all the pieces interact synergistically with the common goal of making a positive difference. This kind of initiative does not offer the right conditions for field experiments aimed at measuring the effectiveness of specific intervention approaches. However, it is perfect for qualitative exploration of system-change strategies in a real-world context; clarification of issues and needs related to a broad goal such as consumer engagement in health reform; and generation of new ideas and lessons that may ultimately prove very useful in “fixing what is broken” in U.S. health care. These themes and some other issues related to advocacy funding will be revisited in the present report’s Part 5 (Implications for Program Sponsors).

## Evaluation Methodology

Because advocacy initiatives evolve in unpredictable ways, their evaluation differs from assessment of a clear-cut demonstration project. To stay flexible enough to keep up with quick changes, the research approach is likely to be descriptive, mainly qualitative, and process-oriented.<sup>20</sup> That has been the case for the present evaluation.

### Data Collection and Analysis

The present evaluation of QCQC started May 1, 2007 and will run for three years. After start-up discussions with RWJF project officers and an initial month of gathering and digesting background information on the Massachusetts health reform effort, the evaluator visited HCFA's office in Boston and spent several days sitting in on coalition and staff meetings and talking with the organization's Executive Director, key staff, and some consumer participants. This first visit laid important groundwork, giving the evaluator opportunities to:

- › Get acquainted and establish a productive climate for evaluation.
- › Understand how HCFA and its participating consumers are interpreting the potentials and challenges of the QCQC initiative.
- › Learn more about the specific roles played by various HCFA staff in promoting consumer advocacy, both through QCQC directly and more broadly.
- › Brainstorm with a wide range of participants on what would be fruitful and practical as focal points and methods of data collection for the evaluation – in particular, how best to put some boundaries around what would be considered QCQC's core activities.

Based on these discussions and with further input from RWJF project officers, it was decided that the evaluation would be most useful if it centered on qualitative description and interpretation of HCFA's evolving consumer advocacy activities in three areas – Chapter 58 implementation, quality of care (especially patient safety), and e-Health – with an emphasis on lessons being learned. While apparent policy impact would be reported, the primary orientation of the evaluation would be formative, aimed at understanding the meaning and implications of QCQC's evolving consumer engagement activities and strategies rather than assessing whether some pre-set outcome goals were being met.

During the next few months, three data collection routines were developed that will continue throughout the three-year evaluation period:

- **Ongoing review of electronic and print commentary** relevant to HCFA, Massachusetts health reform, and health reform issues more generally.<sup>21</sup> Sources being checked and analyzed on a more-or-less daily basis include HCFA's "A Healthy Blog" plus several other relevant blogs; HCFA's web-based newsletters, reports, alerts, and announcements; newspapers and key journals such as the Boston Globe, the New York Times and Health Affairs; Massachusetts state government documents and announcements; and information services that monitor and supply links to research and national reporting on health care policy and health reform, such as the RWJF News Digests, the Kaiser Daily Health Policy Report, and Medical News Today.
- **Occasional site visits** to observe HCFA-sponsored consumer advocacy activities in action. These visits, typically lasting about 2 days, also provide opportunities

<sup>20</sup> Fuller discussion of "advocacy evaluation" is beyond the scope of this report, but some useful materials on this kind of research can be found through the website of the Harvard Family Research Project (HFRP), a research and evaluation organization at the Harvard Graduate School of Education; see especially the Spring 2007 issue of HFRP's web-based periodical on emerging evaluation strategies and issues, *The Evaluation Exchange* (Vol XIII, No.1: special issue on "Advocacy and Policy Change"). The approach known as community-based participatory research (CBPR) is also highly relevant; see Minkler M, Blackwell AG, Thompson M and Tamir H (August 2003), "Community-Based Participatory Research: Implications for Public Health Funding," *American Journal of Public Health*, 93 (8): 1210-1213. An additional resource is the Alliance for Justice's "Tips for Evaluating Advocacy," excerpted from the Alliance's publication *Investing in Change: A Funder's Guide to Supporting Advocacy*; see Appendix #5 of this report.

<sup>21</sup> Internet addresses for these sources and other websites mentioned in this report are listed on p. v.



for informal discussions with HCFA leadership and staff, participating consumers, issue experts serving as advisors to HCFA, state legislators and officials, and representatives of various stakeholder groups with interests in health reform. Focal points for the six site visits carried out in Year 1 have included HCFA-supported consumer testimony at public hearings related to proposed quality-care legislation; a HCFA legislative briefing session on consumer concerns in Chapter 58's implementation; planning meetings of HCFA's ACT!! Coalition, Consumer Health Quality Council, and Expert Advisory Committee for the HCFA Quality Initiative; a public meeting of the state's Health Care Quality and Cost Council; and HCFA's annual conference held in March 2008, which included public presentations by state officials responding to consumer concerns raised by HCFA and others. In addition, the evaluator has remotely attended some key HCFA strategy meetings via speaker phone.

- **Ongoing telephone interviews** including regular monthly discussions with eight HCFA staff members who play key roles in QCQC; discussions as needed with HCFA leadership and additional staff; and occasional discussions with consumers and consumer representatives who work with HCFA. These telephone interviews roughly follow the guide that appears in *Appendix #3*, but are intentionally kept flexible, exploratory, and conversational in tone. They typically last about an hour.

For analysis, information from all of the above sources is first converted to narrative text – abstracted notes from electronic and print sources; field notes from the site visits; and content summaries of the telephone interviews. The resulting body of text material is then processed following established methods for ethnographic social science research.<sup>22</sup> That is, as the materials accumulate, they are read repeatedly and “open-coded” thickly with marginal notes. Descriptive reports and tentative interpretative themes are developed from the coded texts and continuously amended as new information comes

in – a process called “constant comparison.” As information gaps and questions crop up, they get explored further through the ongoing data collection. Gradually an interpretive framework begins to emerge that remains fairly constant and seems to fit the QCQC experience even as new data come in – a point of “data saturation” – and this framework becomes the outline for reporting findings in a document such as the present Interim Report.

Unfortunately for neatness and closure in presenting findings, the timing of the annual Interim Reports does not necessarily coincide with logical end-points for analysis. As mentioned earlier, this Year 1 report is being written at a time when a number of dramatic political developments are unfolding week-to-week with potential to force changes in HCFA's consumer engagement approaches. Caught between summing up the past year and anticipating the fast-approaching future, the present report simply tries to convey what has been learned up to this point (March of 2008) in the midst of changing circumstances. The evaluation's Final Report, due two years from now, will be better positioned to say what lessons from the QCQC initiative prove most useful over time.

### This Report's Format for Presenting Preliminary Findings

The three components of QCQC – quality coverage, quality care, and e-Health – are interrelated, but each one presents a different set of opportunities for consumer voice and involves somewhat different consumer engagement goals, strategies, and challenges. Each could easily be the subject of a long report in its own right. HCFA staff themselves, determined to keep up with fast-paced developments that cross-cut these three areas (plus several more), periodically shake their heads and say, “We're constantly struck with just how complicated this all is!”

To avoid obscuring central points in a sea of interconnections, Parts 2, 3, and 4 of the present report first describe the three

<sup>22</sup> See Michael Quinn Patton (2002), *Qualitative Research & Evaluation Methods, Third Edition*, Thousand Oaks, CA: Sage Publications; Anselm Strauss and Juliet Corbin (1998), *Basics of Qualitative Research, Second Edition*, Thousand Oaks, CA: Sage Publications; Matthew B. Miles and A. Michael Huberman (1994), *Qualitative Data Analysis, An Expanded Sourcebook, Second Edition*, Thousand Oaks, CA: Sage Publications.

areas separately, using a common format to discuss five aspects of HCFA's consumer engagement work in each area:

- > The *organizational strategies* being used to encourage consumer voice through work directly funded by QCQC.
- > Some *related programs* that are not funded through QCQC but contribute to the initiative's goals in important ways.
- > Year 1's *activities and outcomes* (summarized with selected examples; all three areas have been so energetic that a complete review of all activities is not feasible).

> Some *lessons learned* during Year 1.

> Some *challenges ahead*.

Part 5 then considers interconnections and synergies among the three areas; discusses implications for program sponsors based on Year 1's experience; and briefly summarizes QCQC's Year 1 "bottom line."

With this introduction as context, we now turn to the actual work of the QCQC initiative during its first official year of operation. As the next sections describe, three very different approaches to consumer voice are being supported through QCQC:

On **coverage issues** (Part 2) HCFA staffs a coalition of stakeholder organizations well accustomed to working together, operating as a well-oiled machine to put a sharp focus on consumer input and connect it quickly with strategic administrative and legislative opportunities for influencing health reform implementation.

On **quality-of-care and patient safety issues** (Part 3), HCFA is assisting people personally impacted by medical error to form a Consumer Health Quality Council, which has developed an action agenda, legislative proposals, and a variety of dramatic ways to present consumer needs to policy makers and providers.

And in **e-Health** (Part 4), where the electronic record systems being developed are still largely hypothetical and consumer interests lack clear definition, HCFA is staking out a place at the table for consumers in the policy debates that seem certain to become sharper within the next few years.

## Part 2

# Consumer Engagement in Quality Affordable Coverage

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## Strengthening Consumer Voice Through Coalitions

Chapter 58, aimed at achieving quality affordable health coverage for all Massachusetts residents, sets out bold principles and goals based on a “shared responsibility” framework. Its central features include an *individual mandate* requiring all uninsured state residents to obtain health insurance coverage deemed affordable at their income level; *state subsidies* to make coverage accessible for low-income families; an *exemption and appeal* process for hardship cases; *employers’ responsibility* either to offer their workers health insurance that meets specified standards, or to pay state penalties; a *linkage between expanded coverage and health care quality concerns*; and negotiation with insurance and provider groups on various strategies for *cost containment*. Through its Connector agency, the state is charged with defining a package of benefits that qualifies as “*minimum creditable coverage*” (MCC).

Many details were left as questions to be answered during the law’s planned two-to-three-year implementation phase. What health plans would be available to state residents, and what would be considered “affordable” at different income levels? What exactly would the required minimum creditable benefit package include? Penalties for noncompliance with the individual mandate were fairly low in the law’s first year, but were scheduled to rise sharply after that point; what would that second-year schedule of penalties look like? What kinds of employer health programs would qualify, and what level of “fair share” payments would be assessed for employers who did not offer adequate health insurance to their workers? Would the state’s major health plans cooperate in holding down the cost of premiums and co-pays? Most challenging in the short run, could the new law’s requirements be clearly defined and effectively communicated to all of the individual state

residents and employers affected by it, in time for them to either avoid penalties by complying or apply for exemption?

Chapter 58 officially became effective on July 1 2007, but so many implementation details remained undecided at that point that the state’s deadline for individual and employer compliance was rolled back to December 31 2007. Both before and after these deadlines, various stakeholder groups have worked energetically with relevant state agencies and elected officials to hammer out implementation details, with HCFA playing a central role in terms of consumer advocacy. *At each key point of implementation, HCFA has sought ways of bringing consumer voice into the agenda setting and decision making on Massachusetts’ expansion of quality affordable coverage.*

*HCFA’s strategy for consumer engagement on coverage issues is representational, following what the organization’s staff call a “grass-tops” approach* in which prominent organizations speaking for different stakeholder interests (heavily weighted toward consumers) join together in coalitions sponsored and staffed by HCFA. The centerpiece of the coverage effort<sup>23</sup> is a coalition called *Affordable Care Today*, which pre-dates the present RWJF initiative and was an important actor in earlier campaigns to get health reform legislation passed in Massachusetts. The coalition is generally known by its acronym ACT!!<sup>24</sup> Its membership numbers 74 organizations representing a very diverse collection of stakeholders – consumers, patients, community organizations, religious organizations, labor unions, doctors, hospitals, health plans, and community health centers. *Appendix #4* provides a list of current coalition members.

<sup>23</sup> On specific issues, additional coalitions in which HCFA plays a key role may also come into play – for example, the Disparities Action Network (DAN); the Children’s Health Advocacy Coalition (CHAC); and a new Massachusetts Prescription Reform Coalition.

<sup>24</sup> The coalition’s acronym “ACT” used to be followed by a single exclamation point. After the passage of Chapter 58, a second exclamation point was added to indicate a new phase of advocacy related to the law’s implementation. This has led to an in-house joke that HCFA’s advocacy work is now in “Act Two.”

## How the ACT!! Coalition Works

ACT!! carries out much of its work through meetings in which individuals from the participating organizations (typically senior officers) represent the interests of their respective constituencies, presenting their memberships' concerns about Chapter 58 implementation and when necessary carrying specific issues and ideas back to their members for further discussion. While rank-and-file members of the participating organizations are not generally present in person at ACT!! meetings, they can play a more direct role if they wish. They receive information and can give input through HCFA's active electronic communication system (described later), and sometimes become directly involved in advocacy on specific issues through community surveys, letter-writing campaigns, and attendance at public hearings.

ACT!! receives extensive background support from HCFA. A full-time HCFA staff member with the job title of *Health Reform Coalition Coordinator* (Lindsey Tucker) facilitates the coalition's meetings, stays in close touch with individual coalition members by e-mail and telephone, organizes strategy planning, posts internet-accessible information on ACT!! activities and action alerts (see *Appendix #6 for typical examples*), and manages logistics for ACT!! turnout at events such as public hearings on proposed legislation and open meetings of state agencies. The coalition gets regular input from full-time HCFA policy analysts responsible for keeping up with the intricacies of Chapter 58's public and private insurance offerings (Lisa Kaplan Howe and Diana Ong); HCFA's Executive Director (John McDonough) and Research Director (Brian Rosman); the HCFA Policy Director (Fawn Phelps); the HCFA Government Affairs Director (Mehreen Butt); and HCFA's Communications Manager (Jean Leu). All this support work would have been impossible for HCFA to supply without the staff expansion made possible by RWJF's funding.

Working closely with the Executive Director and others on HCFA's policy team, the Health Reform Coordinator also synchronizes the coalition's work with HCFA's lobbying efforts (not funded by QCQC) directed at state agencies and

elected officials. Current legal opinion favors the idea that IRS limits on use of foundation grants for lobbying purposes are more flexible than commonly thought.<sup>25</sup> Still, to be on the safe side, HCFA staff keep detailed activity logs to document the separation.

The organizations participating in ACT!! have their own broad agendas and frequently pursue independent advocacy action related to health reform policy, but the coalition gives them a common forum to coordinate their work and to discuss how their respective constituencies feel about various aspects of the health care reform implementation plans. This representational approach to consumer engagement provides focused, timely input and feedback from a wide range of consumers, as well as from key provider groups and other institutional stakeholders – important advantages in a policy context where the issues are complicated, events are moving fast and unpredictably, and strategic opportunities to inject the consumer voice into decision-making come and go quickly.

To provide structure and maintain momentum, each month HCFA holds a 90 minute *ACT!! Steering Committee* meeting where members discuss strategies and action plans related to Chapter 58's implementation – what new issues are emerging; whether particular issues call for administrative versus legislative advocacy; what content should go into legislative proposals supported by the coalition; how to prepare for upcoming public hearings; when and whether targeted community surveys or letter-writing campaigns might be useful; and what concerns the coalition representatives are hearing from their respective constituencies. Officials from relevant state agencies occasionally attend ACT!! Steering Committee meetings by invitation to describe their agencies' work, discuss particular points of policy, meet the coalition members, and generally gain exposure to the coalition as a voice in state-level agenda setting. Discussion at the Steering Committee meetings tends to be crisp and efficient, with a businesslike tone, reflecting the fact that the coalition members are not newcomers to advocacy work. They are familiar with each other and have the background information,

<sup>25</sup> See *Appendix #5* for materials from the Alliance for Justice concerning IRS limits on advocacy grants from non-profit institutions.

policy experience, and common understandings needed for quick, sharp focusing on specific implementation issues.

Alternating with the monthly ACT!! Steering Committee meetings, HCFA staff meet monthly with the *ACT!! Executive Committee*, a subgroup made up of about a third of the ACT!! Steering Committee members. This smaller gathering allows for additional in-depth discussion of advocacy strategies, which can then be raised at the next meeting of the ACT!! Steering Committee. The ACT!! Executive Committee is on call for any decision-making requiring quick turnaround.

In between these regularly scheduled meetings, ad-hoc *ACT!! Workgroups* convene as needed to develop background information and strategies on specific issues to be presented and discussed at the Executive and Steering Committee meetings. In “emergency” situations, HCFA staff and relevant ACT!! workgroups sometimes organize quick ad-hoc conference calls to share information and plan responses. Membership on the Workgroups is deliberately kept open and flexible; any HCFA staff member or ACT!! coalition member expressing interest in a Workgroup issue can volunteer to participate. During Year 1, ACT!! Workgroups have been formed to deal with Affordability and Individual Mandates, Public Programs (Commonwealth Care, MassHealth, and the Free Care Pool/ Health Safety Net), Private Insurance, Outreach, Legislative Advocacy, and Communications.

ACT!! intentionally includes diverse stakeholders whose interests do not always coincide, and may in fact sometimes be in tension.<sup>26</sup> However, the participating organizations have worked together on health care reform long enough – in some cases for decades – to have developed some useful conflict-resolving mechanisms. Where potential interest conflicts might arise, the coalition tends to “bracket” the contentious issue and to concentrate instead on areas where stakeholder interests overlap, so as to avoid bogging down and deflecting

effort from common concerns. If any coalition members feel after discussion that their constituencies would not support some specific consumer advocacy action or position being planned by the majority of ACT!! participants, they can simply decline to sign on to that particular effort without withdrawing from the coalition itself. During Year 1, these two “safety valves” have proved helpful for maintaining the focus on problem-solving and keeping the coalition together despite occasional internal disagreements.

The linkage between the coalition and HCFA’s other advocacy activities is strong and two-way. On the one hand, HCFA’s research and policy staff contribute briefing information to inform the coalition’s strategy discussions. Because they closely monitor developments in health reform policy, they can also alert ACT!! members whenever strategic opportunities arise to inject consumer voice into the state’s deliberations through turnout at public hearings, formal requests to legislators and state agencies, letters to the editor, or a call-in campaign. They also can supply logistical support and materials such as talking points and information packets.

In the other direction, ACT!! meetings bring to the surface a wide range of consumer issues, including not only obvious concerns but also problems that might otherwise be missed.<sup>27</sup> Recommendations emerging from the coalition’s research and discussions greatly strengthen the many formal and informal lobbying activities being carried out continuously by HCFA and the other organizations in the coalition. The fact that HCFA and its partner organizations can accurately claim to be receiving broad, regular input from consumers and other stakeholders through ACT!! gives their own lobbying efforts a higher level of credibility and groundedness. When they meet with state officials and legislators, they are representing their respective organizations rather than ACT!!,<sup>28</sup> but their common membership in the coalition communicates a united front of broad-based consumer support.

<sup>26</sup> Some examples: The coalition includes a large hospital association that represents hospital administrators, unions that represent hospital workers, and community organizations that represent the interests of hospital patients — a potentially conflicting combination. Some ACT!! members strongly favor higher cigarette taxes for both public health and revenue reasons, while other members represent constituencies with high smoking rates and do not favor such taxes. Putting controls on pharmaceutical companies’ gift-giving to physicians and hospitals seems like a badly needed reform to some ACT!! members, but hits close to home for others (which has led to the creation of a separate coalition to work on prescription drug costs, discussed later in this report).

<sup>27</sup> For example, the ACT!! representative from the Artists’ Foundation called attention to the fact that the Connector’s website, a major information resource for those trying to comply with the individual mandate, was initially set up in a way that could not be used by individuals with intermittent, fluctuating incomes – a common situation for artists and many other occupational categories.

<sup>28</sup> Although an “ACT!! position” is sometimes presented to policy-makers, the coalition functions primarily as a forum for information sharing and strategy development rather than as a lobbying organization in its own right.

## Related Programs That Support QCQC'S Coverage Goals

A number of other HCFA activities, not all of them funded by RWJF, contribute to the effectiveness of ACT!! and HCFA's consumer advocacy in general. Four in particular – the HelpLine, the HCFA blog and newsletters, the Communications Campaign, and the Massachusetts Prescription Reform coalition – are so critical for the consumer engagement goals of QCQC that they need mention in this report. At this point they have been used most heavily to support Chapter 58 implementation, but they also contribute to QCQC's quality care component.

### The HCFA HelpLine

HCFA operates a telephone HelpLine available to take calls from 9:00 a.m. to 6:30 p.m., with language capacity in English, Spanish, and Portuguese. This service connects with the QCQC initiative in several ways:

- **The HelpLine functions as a very active enrollment center for the Commonwealth's new insurance plans.** Callers are able to get information quickly, and they can sign up without needing to appear in person at an enrollment office. Especially during the first few months of Chapter 58 implementation, when state residents were just learning about the plan's requirements and the state's Connector website and enrollment centers were not yet in place, HCFA's HelpLine (along with HCFA's other outreach activities) played a central role in the entire enrollment process.
- **The HelpLine functions as a wide-open, unstructured "ear to the ground" that frequently brings to light unexpected problems that consumers are encountering with Chapter 58's implementation.** This new information can be incorporated into the consumer advocacy work of ACT!! and HCFA more generally. During Year 1, most

HelpLine calls have related to coverage issues as callers try to meet the sign-up deadlines set by Chapter 58. HCFA expects quality-of-care to become an increasing focus for the HelpLine as health reform moves forward.

- **HelpLine logs provide insight and statistics on how consumers are being helped by health care reform, as well as a source of positive "stories"** – personal accounts of how the coverage available through Massachusetts' health reform has changed people's life for the better. These personal accounts are proving extremely useful for presentations to policy-makers, and also for the Communication Campaign discussed below.

Ironically, the HelpLine's very usefulness has created something of a problem. During Year 1, the volume of calls escalated from about 350 per month to the present level of over 2000 per month, with large surges around critical deadlines. Prior to the effective date of Chapter 58, call volume reached 4000 per month. Even with a voicemail call-back system, it has been hard for HCFA staff to keep up with these numbers. At one "crunch point" just prior to the date when penalties would start for noncompliance with the individual mandate, requests for help came in so fast that the backlog far outstripped the response capacity of the HelpLine staff (4 full time workers including the Helpline Manager, plus 5 part time interns). Because of its non-hierarchical norms, HCFA was able to handle the situation by having most of the organization's staff, from top to bottom, temporarily drop all other work and answer HelpLine calls so as to aid callers trying to make the deadline – a good solution, but not a sustainable one for the long term. At the moment, the HelpLine is rather precariously funded out of overhead from grants other than QCQC. Yet it represents an essential support for the QCQC initiative's goals.

## The HCFA Blog and Newsletters

The HCFA blog, which predates RWJF funding, provides a steady stream of current information on HCFA's work, relevant news items, reports on state activity, and general commentary related to health reform – all designed, in the words of the blog's banner, to be “Interesting. Informative. Insightful.” Entries are contributed frequently, sometimes several a day, by the Executive Director, Research Director, and other members of HCFA's core staff. The blog is archived back to April 2005 and elaborately cross-indexed in ways that make searching easy, with embedded click-on links to relevant news articles and reports, and a “blogroll” of other blogs dealing with Massachusetts health reform.

The HCFA blog attracts heavy usage. It represents the only place on the internet where one can easily find comprehensive and timely information about progress on Massachusetts' health reform, and keep up with relevant state and national commentary. It has become the “go-to” information source not only for consumers and consumer advocates, but also for state policy makers.<sup>29</sup>

While not funded out of QCQC, the blog is closely intertwined with QCQC's goals, putting real substance behind the concept of “empowering” consumers. For example:

- **It is accessible to a large consumer audience that goes beyond the rank-and-file members of organizations represented in the ACT!! coalition.** This expands the base of consumer engagement and reinforces the coalition's advocacy efforts.
- **It provides consumers with an easy way to get accurate and comprehensive background information on specific health reform topics, so they can better define their interests and concerns.** Browsing through the blog archives provides a good brief history of key issues and easy

access to a variety of expert analyses, along with HCFA's editorial perspective.

- **It provides consumers with timely information about formal opportunities for citizen input into health-reform decision making, so they can better focus their own advocacy efforts.** For example, information about the time and place of a public hearing is often buried in some easily missed place such as the back pages of a newspaper. The blog rescues this kind of “public secret”<sup>30</sup> from the shadows, and puts the information where consumers can find it in time to exercise their democratic rights.<sup>31</sup>
- **It furthers the goals of transparency and citizen participation by presenting various perspectives and inviting responses.** Blog postings include a variety of opinions, and the public comments received in response run the gamut from very sophisticated policy discussion to emotional gut reactions.<sup>32</sup> By allowing different viewpoints and maintaining the blog as a receptive forum for information-sharing and debate, HCFA convincingly promotes open dialog and free speech.

In addition to the blog, HCFA staff prepare periodic (more-or-less monthly) electronic newsletters on specific health reform areas such as quality care, health disparities, and oral health, as well as a general newsletter for HCFA as a whole. These newsletters, available on the HCFA website, provide up-to-date summaries of recent consumer advocacy activities and upcoming events in each topic area, making it easier for consumers to stay informed.

## ACT!!'s Communication Campaign

As HCFA is acutely aware, the tone of the “narrative” that mass media uses to portray health reform has a profound effect on public opinion and the political environment for advocacy. Thus the HCFA Communications Coordinator has been a

<sup>29</sup> HCFA staff like to tell about the time they were given an important state report prior to its official release. They mentioned it on the HCFA blog, and almost instantly got requests for further information from other state agencies and legislative staff – an indication of how closely policy makers were monitoring the blog.

<sup>30</sup> For a discussion of how “administrative guerrillas” can further consumer advocacy by unveiling “public secrets” (as well as other strategies), see Martin Needleman and Carolyn Needleman, *Guerrillas in the Bureaucracy: The Community Planning Experiment in the United States* (John Wiley & Sons, 1974).

<sup>31</sup> See *Appendix #6* for a typical example of an “action alert” issued on the HCFA blog to “friends of health care reform” who might want to send a letter or email message to their elected representatives and government officials.

<sup>32</sup> The public responses are not always sympathetic to HCFA's policy positions. In fact, now that the blog has become so prominent, it is regularly visited by a small but persistent group of single-payer advocates who condemn HCFA's pragmatic support for the shared-responsibility model of health reform as a “sell-out.”



central support for all of the organization's work, managing public information and relations with the press.

Unfortunately, around January 2008, the tone of media coverage on health reform took a very gloomy turn. Chapter 58's remarkable success in expanding coverage began to be eclipsed by alarmed commentary about health reform's cost-related challenges. Both sides of this story are needed for informed public discussion, but increasingly, only the negative side was being emphasized by the press.

Recognizing the danger that this kind of spin poses for advocacy efforts, HCFA decided to reinforce the ongoing communications effort with a special "Communications Campaign" organized through ACT!! Like HCFA, many of the coalition's larger members have sophisticated (in some cases professional) staff working on communications for their own organizations. ACT!! has been able to link HCFA's communications staff and these other communication specialists together into a "rapid response" network that can respond quickly to inaccurate or negative media coverage on health reform. The network monitors national and state coverage, and also a variety of local daily newspapers, radio stations, and TV channels, with various coalition members taking responsibility for specific outlets and regions of the state. If negative coverage appears (or is known to be planned), someone from the network can quickly contact the author or prepare a response to correct facts if needed and offer alternative interpretations.

The Communications Campaign also works in proactive ways, making sure that op-ed pieces on the achievements of health reform appear periodically and that celebratory events such as the health reform law's second anniversary in April receive appropriate media coverage. Stories showing how health reform has helped real people in major ways (gleaned from the HelpLine and from HCFA's Outreach/Enrollment efforts) are collected, cleared with the individuals involved, and made

available to the media as much as possible. Here is one such story, taken from HCFA's "A Healthy Blog:"

*Here's a message we got at HCFA's Helpline:*

*"I read the article in the Boston Globe by Alice Dembner. I know about the new law and I need help! I am a victim of identity theft/fraud and I have been trying to get health insurance since January, 2007. I have applied to the MassHealth and I get no answers. I live alone, own my house and I am trying to save it from foreclosure. My name is in debt of over \$400,000 and I reached out to the state since Jan. 2007 and I cannot get help. I had to close my business therefore I have no income, nothing. My problem is I cannot afford my medications for high blood pressure/migraine and acid reflux because I have no insurance and cannot get any. What I don't understand is that I got a letter stating that I have to have health insurance, it's the law, but I can't get it. I know the person that did this me and he is living high and mighty on my money while I am struggling to save my house, get food, and the everyday necessities to live.*

*Can you help me? Thank you for at least reading this."*

HCFA's Helpline Manager Kate Bicego describes what happened from there:

I received the letter above forwarded from our friends at GBIO.<sup>33</sup> They hoped that we could help this woman. After a short telephone conversation with her, I learned that she had already submitted an application to MassHealth/Commonwealth Care in January. As is so often the case, she had no clue that she had been already been determined eligible for Commonwealth Care. All that had to happen for her to have comprehensive health, vision and dental coverage was for her to enroll into a plan. I described the enrollment process to her step-by-step. She just called me back to say, "I just enrolled into Network Health. I'm without words and that doesn't ever happen. Thank you so much for your help!"

## A New Coalition on Prescription Drugs

Early in Chapter 58's implementation, after difficult negotiations, the Connector Board voted to require prescription drug coverage as part of the "Minimum Creditable Coverage" (MCC) benefit package. While this move seemed certain to involve added costs, ACT!! strongly

<sup>33</sup> GBIO, the Greater Boston Interfaith Organization, is a key member of the ACT!! Coalition and the ACT!! Executive Committee.

supported it on the grounds that medications play an indispensable role in medical care and that improved access to prescribed drugs yields better health outcomes and lower long-term healthcare costs. The requirement becomes effective on January 1, 2009, but since policies are generally in effect for one year, the deadline actually cuts in earlier for individuals and businesses renewing their insurance policies anytime after February 1, 2008. If the renewed policies do not meet the MCC standards, non-complying individuals will be subject to penalties for tax year 2008.

Complaints from employers (particularly small business interests), coupled with the rapidly rising cost of drugs, have recently begun to raise second thoughts about this requirement within the Connector Board. ACT!! continues to defend prescription drug coverage as an essential part of the MCC standards, but also recognizes that the cost may pose genuine problems with insurance affordability, the stability of health care reform, and the Commonwealth's budget.

In light of this dilemma, HCFA has decided to attack the rising cost of prescription drugs at one of its roots: artificial inflation of drug prices stemming from inappropriate relationships between providers and the sales representatives of drug manufacturers. In January of 2008, HCFA launched a new coalition called Massachusetts Prescription Reform – including health insurers as well as consumer and advocacy groups such as HCFA, AARP, and MassPIRG – to advocate for an end to pharmaceutical marketers' gift-giving and special relationships with doctors and hospitals. The new coalition strongly supports cost-control legislation recently released by the president of the Senate, which contains provisions that HCFA has been advocating for some time, prohibiting pharmaceutical gift-giving and creating an educational outreach program to provide doctors with an unbiased source of information about drugs. This attack on "big pharma" is not a direct part of QCQC. However, it complements the work of ACT!! by aiming to lower the cost of prescription drugs, easing the way for policies that make medications more accessible and affordable for consumers.



Boston Globe, March 21 2008.

*Consumers working with Health Care For All's ACT!! Coalition attend a meeting of the state panel that oversees Massachusetts' subsidized health insurance program.*

## Coverage, Year 1: Activities and Outcomes

During Year 1, the ACT!! coalition has added a critical dimension of coordination, credibility, and person-power to consumer advocacy efforts, complementing the direct lobbying of HCFA and ACT!!'s constituent groups as they make the case for consumer interests in two major policy arenas: *administrative decision-making* and *legislation*.

### Administrative Strategies

Administrative rules and regulations have certain advantages over legislative action as a focal point for consumer influence, since this kind of decision-making operates with already-established mandates and a relatively fast time schedule – in fact, with pressing deadlines. Thus the most immediate target for consumer advocacy related to Chapter 58 has been the state's administrative machinery, consisting of the Governor and key members of his administration; newly created entities such as the Commonwealth Health Insurance Connector and the Massachusetts Health Care Quality and Cost Council; and operating agencies such as the Department of Insurance, Department of Revenue, and Department of Public Health. The Connector sits at the core of health reform's administrative decision-making, charged with responsibility for determining allowable insurance premium limits, co-pays, and benefit requirements; setting compliance deadlines and penalty schedules; publicizing the state's health reform plan; setting up systems for outreach and enrollment; and a host of additional implementation details.

The following examples illustrate how HCFA and the ACT!! coalition have approached consumer advocacy in the arena of administrative decision-making.

#### Example: Initial Definitions of Affordability

One crucial piece of administrative advocacy unfolded well before Chapter 58's effective date of July 1 2007. An essential

prerequisite for launching the new law was determining what would count as "affordable" health insurance for individuals at different income levels, in effect defining the amounts that individuals would need to spend on premiums in order to avoid a penalty for non-compliance with the individual mandate requirement. The initial affordability schedule proposed by the Connector in spring 2007 was met with howls from consumer advocates, who viewed the expected expenditures as wildly unrealistic for low-income state residents. ACT!! quickly launched into a flurry of activity through its Affordability Workgroup, centered around a community survey carried out by one of the coalition's largest members, the Greater Boston Interfaith Organization. GBIO's survey showed that families' discretionary income at various income levels was much lower than the Connector's initial plan had assumed. This piece of hard evidence received wide publicity. It became the focus of action campaigns by HCFA and numerous other organizations participating in ACT!!, which appear to have had a strong impact on decision-makers. In what HCFA and other ACT!! members regard as a major victory,<sup>34</sup> the state's initial affordability schedule was revised downward to reflect more realistic premium levels for low-income individuals.

#### Example: Simplifying and Equalizing the Individual Penalty Schedule

Similar efforts by ACT!! surrounded the state's schedule of penalties related to the individual mandate. In Chapter 58's first year, the penalty for non-compliance was fairly low – loss of the personal state tax exemption, amounting to \$219. However, starting January 1, 2008, the annual penalty was to be calculated differently, at up to one-half the premiums that would have been considered affordable for the non-complying individual's level of income, age, and geographic location – a very sharp increase. Despite much publicity, many state

<sup>34</sup> They recognize that such victories do not stay won without ongoing advocacy. As discussed below, Chapter 58 requires periodic updates of the affordability schedule, and each update opens a new occasion for consumer voice. Moreover, the affordability schedule was approved with a lifetime cap on benefits, which ACT!! members had vigorously opposed and will continue to question.

residents were not yet aware that they would be incurring higher penalties starting January 1, 2008. Worse yet, the fact that the penalties were pegged to diverse health plans meant they would vary widely for individuals in different categories, falling disproportionately hard on the elderly and introducing a level of complexity and unevenness (involving dozens of different penalty amounts) that was hard to justify or even explain. HCFA and ACT!! understood the need for some kind of penalty increase as an incentive to make the individual mandate work, but feared the penalty schedule being planned would seem so unwieldy and unfair that it might jeopardize the entire health reform effort.

Following internal HCFA discussions and a number of ACT!! working group strategy sessions reflecting consumer input, it was decided to argue not for dollar figures, but rather for guiding “principles of fairness” – i.e., the penalty structure should:

- › Be simple, clear, accessible, and arrived at through a transparent and participatory process.
- › Be equitable, and should not vary by age, geographic location, or occupation.
- › Be finalized prior to the January 1 deadline, and made public via a robust and aggressive public education campaign.
- › Take into account the varying monthly affordability situation of an individual with fluctuating income over the course of the year.

This became HCFA’s own lobbying position with the Secretary of Administration and Finance, and ACT!!’s participating organizations also encouraged their constituencies to support these four principles in an active letter-writing campaign. While discussions continued down to the wire, the state did in fact revise the penalty schedule

shortly before January 1<sup>st</sup>, setting the penalty for all non-complying individuals at one-half of the *lowest-cost* plan being offered. This fixed the maximum penalty at \$912, much lower than it would have been under the earlier formula. It also greatly simplified the structure of penalties, avoided disparities based on age and location, and made the plan much easier to explain to the public.

As this report is being written, the Commonwealth’s deepening financial difficulties are putting considerable strain on some of health reform’s early administrative agreements and understandings concerning allowable increases in insurance premiums and co-pays for consumers. Chapter 58’s “shared responsibility” framework itself is growing contentious, as individuals are being asked to bear more of the cost burden while the payments made by employers lag far behind what policy-makers initially anticipated. As these strains increase, HCFA’s approach to consumer advocacy is becoming more complex, as the following example shows.

#### Example: Clashes over Cost-Sharing

The Connector Board is required by law periodically to update certain Chapter 58 implementation measures, such as new contract agreements with the four large health insurance plans participating in the state-subsidized coverage program, Commonwealth Care. In spring 2008, much to the distress of consumer advocates, the Board’s proposals included a number of unwelcome changes in these contracts, including premium increases of up to 14% and much larger co-pays (in some cases double the previous amount). In discussions with HCFA staff prior to the Board’s scheduled public meeting to vote on these proposals, Connector officials explained they felt their hands were forced not only by health reform’s escalating costs but also by the threat of “crowd out” – state-subsidized plans displacing people’s current private coverage. HCFA and other ACT!! members took the position that such concerns should not be allowed to push costs for low-income individuals past the point of realistic affordability. They also saw great unfairness in placing additional cost burdens on individual

consumers (falling disproportionately on the sickest and poorest) when employers have not yet fully shouldered their projected contribution in Chapter 58's "shared responsibility" framework. Connector Board members were well aware their vote on these proposals would be controversial – so much so that the public Board meeting scheduled for late February was postponed at the last minute, to give more time for hearing from stakeholders and possibly making modifications.

When the Connector Board finally convened to vote in March, the coalition was ready. In the days preceding the public meeting, several call-in telephone strategy sessions were held by the ACT!! Affordability/Public Programs Working Group, and it was decided to work through the coalition's member organizations to encourage a large turnout of consumers in the meeting audience. According to the plan, the consumers would be supplied with signs personalized with stories contributed from the HCFA HelpLine or ACT!!'s member organizations, depicting Massachusetts residents who had been helped by the insurance coverage made possible through Chapter 58. Consumer attendees would also hand-deliver packets of information (prepared by HCFA staff) to each of the Connector Board members just prior to the meeting, describing the impact that the proposed cost-sharing increases would have on consumers, based on community surveys by ACT!! member organizations. The intent was to be respectful, but also to make a consumer presence felt and to dramatize consumer issues in the press conferences that would follow the meeting. Since no one knew quite what to expect, the action plan also included a hasty assembling of ACT!! members in the back of the room immediately after the Connector session ended, to discuss what to do next. If the results of the Connector vote turned out to be too discrepant with ACT!!'s core position, one possibility under consideration was a coordinated "walk" over to the Governor's office – in effect, a multi-organization demonstration to express consumer opposition.

On the day of the public meeting, over 200 members from various coalition organizations attended, more than could fit in the room. They wore tee-shirts emblazoned with their own organizational logos and stickers showing their affiliation with ACT!! The planned signs and information packets were ready, but as it turned out, they were not used. The Connector's cost-sharing proposals had been adjusted somewhat downward at the last minute, apparently in response to a small meeting that representatives of HCFA and other ACT!! members had held with Connector Board members the day before. In place of the earlier 14% increase in premiums, the Board now proposed a 10% increase; also, some of the proposed co-pay increases were rolled back a bit. These changes and a few others showed enough "movement" by the Connector that ACT!! members agreed no escalation of advocacy tactics was necessary, at least for the moment.

In terms of *policy* results, HCFA and other ACT!! members feel the recent compromise outcomes are not really satisfactory as long as employers are not being asked to bear more of the shared sacrifices. The debate, and the advocacy efforts, will continue and probably intensify – especially if it begins to seem that disproportionate costs to consumers are fueling a public backlash to the individual mandate.

At the same time, in terms of *process* results, HCFA and ACT!! members describe the whole episode as being extremely good for consumer voice. In the pre-meeting negotiations, the Connector Board listened receptively to ACT!!'s consumer concerns and did in fact make modifications in response. In addition, the consumer presence at the public meeting could hardly be missed. As a HCFA staff member put it, "Through ACT!!, consumers are being seen as a force to be reckoned with, and it's a force they [administrative officials] value."

## Legislative Strategies

ACT!! also works on the legislative front to fill what the coalition sees as consumer needs unmet by Chapter 58. This is recognized as a slower and more uncertain advocacy path, since in a typical Massachusetts legislative session, over 600 proposals are introduced and most fail to make it out of committee. Common outcomes are for a bill to be reintroduced several times before it sees the light of day, or for a few specific provisions to be picked up and folded in with related legislative proposals. Thus ACT!! approaches legislation with the idea that it may result in at least a partial victory, at some future point if not immediately. In the meantime, as the following example illustrates, the advocacy process itself is worthwhile because it raises the visibility of consumer issues.

### Example: Using the Legislative Process

As Chapter 58 went into effect, the ACT!! coalition undertook to shore up some aspects of the law that seemed weak in terms of consumer interests, developing a legislative proposal titled “An Act Strengthening Health Reform” (see *Appendix #7*).<sup>35</sup> The bill addresses issues of affordability and access through a number of adjustments to Chapter 58 including:

- > Raising the minimum employer coverage to require 50% employer contribution and 50% employee participation.
- > Redefining “affordability” for the individual mandate to include premium and out of pocket costs.

During the early summer of 2007, ACT!! Steering Committee meetings served as a forum for discussing and fine-tuning the proposal to reflect the concerns of consumers represented by coalition organizations. HCFA and other ACT!! members have worked to increase the number of legislative sponsors.

They also gave testimony at a public hearing on the bill in July 2007, with a strong turnout of rank-and-file members of ACT!! organizations in the audience to show public support. Besides demonstrating broad consumer support and explaining the need for the bill, the public hearing provided a focal point for extensive press coverage of consumer concerns. While the bill did not make it out of committee in Year 1, its existence was well noted by policy-makers.

At this writing, the ACT!! bill has been attached to a landmark cost-containment bill recently passed by the Senate (now working its way through the House). The attachment in effect retires the ACT!! proposal for the present legislative session, but its key provisions are likely to reappear in some form next session. Meanwhile, it appears to have had indirect effects. Three important floor amendments to the cost-containment legislation might have had different outcomes, if not for the consumer voice embodied in ACT!!’s bill.

An amendment to weaken the minimum creditable benefit package by stripping out drug coverage was roundly defeated; an amendment to strengthen consumer privacy protections in electronic health records was adopted; and an amendment to weaken the ban on pharmaceutical industry gifts to providers was not only beaten back, but was replaced with amended language that strengthened the provision.

HCFA also sponsors “lobby days” on various consumer issues,<sup>36</sup> on the assumption that when consumer advocates coordinate their lobbying efforts on the same day, legislators are more likely to pay attention and the press is more likely to cover the consumer issues. Lobby days are publicized through the HCFA blog and webpage and also through e-mail alerts sent out to organizations participating in ACT!!. While not funded through QCQC, the lobby days clearly complement HCFA’s other consumer engagement activities.

<sup>35</sup> The complete bill is included in *Appendix #7* in order to show the level of detail needed to translate broadly defined consumer issues into the sharply focused language of legislation.

<sup>36</sup> For example, HCFA-sponsored lobby days have been held during the past year to promote consumer interests related to children’s mental health and oral health. Health reform did not have a HCFA-sponsored lobby day this year, but a number of ACT!! member organizations focused their own lobby days on health reform.

## Coverage, Year 1: Some Lessons Learned

What can be learned from HCFA's Year 1 consumer engagement work related to coverage? Some preliminary lessons – thought-provoking, even if not all entirely new – include the following:

- 1 Where the advocacy target is a rapidly moving policy implementation effort, coalitions are a particularly effective tool for consumer input.** Coalitions offer a way for large organizations to coordinate their members' input efficiently – a distinct advantage for dealing with the active politics surrounding policy implementation, where fast action is often called for and the issues can be complicated enough to require considerable background information. By representing large numbers of consumers and linking the consumer input with that of other stakeholder groups, coalitions lend breadth of perspective, credibility, and political clout to the consumer voice.
- 2 In addition to its own collective actions and presentations to decision-makers, a coalition like ACT!! can work in tandem with independent lobbying activities by its organizational members.** The consumer voice developed through the ACT!! coalition was amplified with good results when it also reached the ears of policy-makers in smaller, non-public meetings by way of a few individual advocates from the constituent organizations. In effect, independent lobbying by member organizations' representatives served as extra "transmission wires" for consumer voice, with the coalition hovering in the background to generate added energy and credibility for the message itself. This approach also takes some of the pressure off the coalition to reach complete consensus and speak with a single voice on all issues.
- 3 A great deal of "invisible work" is needed to keep coalitions on track.** Coalitions are high maintenance and need significant behind-the-scenes tending, especially given that the interests of coalition members do not always coincide. Strategies for maximizing a diverse coalition's smooth operation include: bracketing contentious issues and concentrating on areas of interest overlap; openness and transparency in managing the coalition's work, so that no members feel disregarded or excluded; timely and appropriate background research by staff; skilled facilitation of meetings; and pre- and post-meeting discussions with coalition members who have special concerns. All of this is extremely time-consuming and needs to be planned for when allocating staff resources.
- 4 Conscious use of conceptual frameworks to guide strategy can be a practical and effective advocacy tool.** This approach may not be right for every advocacy organization, but it has worked well for HCFA. Probably having something to do with the Executive Director's penchant for theory, concepts have often guided HCFA's strategy choices during Year 1, making their way into the work of ACT!! They are introduced in a light-handed way, not for their own sake but as tools for cutting through complexity and confusion, and have become almost second nature for staff in strategy discussions. *Appendix #8* summarizes a few theoretical ideas that have been particularly useful and may be of interest to others.
- 5 Maintaining an informational blog requires a significant time commitment, but appears to be well worth the effort in terms of effective consumer advocacy.** HCFA's "Healthy Blog" has become a widely used tool for transparency and public education. It helps empower consumers by disseminating information, alerting the

public to opportunities for consumer voice, and correcting misinformation. In addition to promoting consumer engagement related to the three QCQC areas (coverage, quality of care and e-Health), the blog also supports consumer voice on other issues such as health disparities, oral health, and children's mental health.

**6 In addition to more structured consumer engagement activities, it is wise to have some mechanism that serves as an open-ended “ear to the ground.”** In HCFA's case, this function is served by the HelpLine, which is widely advertised and open to all callers. The HelpLine has often brought to light some consumer needs or problems that might otherwise have gone unrecognized and unattended in HCFA's work related to coverage.

**7 It is worthwhile to invest in skilled professional resources to manage relations with the media.** For better or worse, media “narratives” have a strong impact on consumer advocacy efforts. Especially in the latter part of Year 1, HCFA's coverage work benefited greatly from having a full-time staff member with strong expertise in communications who could help plan and coordinate press releases, TV coverage, and letter campaigns; cultivate appropriate media relationships; and organize a quick-response communications network to counterbalance negative or erroneous press reports.

**8 The organizational climate of the advocacy workplace matters enormously in maintaining staff morale when the work is geared to fast-moving, intense political events.** This can hardly be emphasized enough. As is common in advocacy organizations, HCFA staff work long hours, sometimes 60 hours a week, frequently under considerable pressure. If the organization felt a need to drive employees hard because of the importance of the cause, the result might well be staff exhaustion and burnout. But fortunately, HCFA's stated mission includes a commitment to a “work environment that is enjoyable, respectful, safe, inclusive, family-friendly, work/life balanced, and supportive for all staff.” The organization pays attention to quality-of-work in many large and small ways, including a striking absence of status hierarchy and a great deal of personal affirmation; flexible hours; concern for skill development; plus lots of jokes and friendly conversations, celebration of personal events, and appreciative gestures such as an extra day off after an especially demanding public event. This results in staff members who exude commitment, high motivation, and joy in their work (even though they still think they are probably working too many hours). HCFA staff frequently remark: “I love working here!” “I learn so much.” “I like the people I work with.” It's also worth noting that, as HCFA recruits for the Executive Director position being filled this summer, one of the qualifications listed in the job description is “sense of humor.”



## Coverage, Year 1: Upcoming Challenges

Year 1 has overall been quite successful in terms of QCQC's goals for strengthening consumer voice related to coverage issues. However, at least three major challenges for consumer engagement are shaping up in the next year or so. How HCFA deals with these challenges (and others that may arise in Year 2) will be central themes in next year's Interim Report.

### **Challenge #1: Increasing cost pressures on Massachusetts' health reform**

Cost pressures seem likely to increase due to implementation cost overruns, a worsening economy, and possible large cuts in federal funding. The tax increases being considered (e.g., a higher tax on cigarettes) cannot by themselves close the gap entirely. Thus, despite strong advocacy to the contrary, consumers may in the end be asked to bear higher cost burdens. Alternatively, or in addition, other interest groups will come under pressure to contribute more.

One question is: How this will affect ACT!!'s advocacy approach? So far, the coalition has served well as a mechanism for fairly non-controversial "inside the system," consensus-based advocacy strategies intended to inform, focus and empower the consumer voice being expressed and help it reach the ears of relatively sympathetic policy makers. At this point, the expectation is that these strategies will continue and ACT!! will work cooperatively with policy makers to find practical methods of cost containment. However, if consumer interests seem to be losing out badly as policy debates grow sharper, the coalition could face internal pressure to move advocacy into more militant territory. Some of ACT!!'s participating organizations (perhaps including HCFA itself) may want to "up the ante" of consumer advocacy activities, adding demonstrations of various kinds to the milder expressions of consumer voice used so far.

More assertive and confrontational advocacy is not a negative development in itself, but it would probably change the dynamics of the QCQC initiative. For example, strains could develop within the coalition, because some of ACT!!'s members represent provider groups with organizational interests different from those of health care consumers when it comes to apportioning cost burdens. So far, the coalition's internal diversity has been a strength, and minor policy disagreements among member organizations have been handled amicably. Will that continue to be the case, when policy issues start to hit close to home? If serious internal conflicts do start to develop, will HCFA find effective ways of working around them? If so, these could be very useful lessons for health reform advocacy efforts in other states, many of which are in the same financial bind as Massachusetts.

An additional complexity is the idea of "consumer voice" itself. Consumers are all potential patients who need access to health care, but in addition they are taxpayers who may not support additional tax increases to fund health reform's rising costs, and they are also members of economically strained families who may feel they can't pay for health insurance even if it's being called "affordable." So far, HCFA has been able to assume that state residents generally favor Massachusetts' health reform and want it to succeed; public opinion polls support this assumption. But if large numbers of Massachusetts residents were to change their minds and withdraw support for the plan's individual coverage mandate, QCQC's consumer engagement goal itself might need some reconceptualization. This spring's tax season will provide an important test of public support, as the Commonwealth's individual residents and businesses file the new insurance declaration forms now required with their state tax returns, and the penalties for non-compliance become clearer.

**Challenge #2: The tone of media coverage**

As discussed above, media coverage has tended to feature – even exaggerate – the problems of Massachusetts’ health reform, while underreporting its achievements. If unbalanced press coverage continues, the result could be a negative public mindset and policy momentum that would make QCQC’s consumer engagement goals harder to reach, as well as jeopardizing the policy goals of health reform itself.

As discussed above, HCFA has already put in place some very active machinery aimed at changing the tone of the public narrative. The HCFA Communications Campaign is likely to be needed more than ever in the coming year, and some important lessons may be learned about how best to balance negative “spin” related to health reform’s struggles.

**Challenge #3: Leadership transition within HCFA**

The impact of the impending leadership change within HCFA is a large unknown. The present Executive Director, John

McDonough, has been a strong, tone-setting presence in the organization for the past five years, and much will depend on the specific qualifications of his successor. Recruitment is now underway, with the actual transition expected in August.<sup>37</sup>

HCFA staff were initially a bit shaken when the announcement was made in January, but have adapted well. Some promising strategies for easing the transition are already apparent – sufficient lead time allows for careful recruitment and getting used to the idea; normalization of the change keeps it from seeming like a catastrophe (“Administrators tend to stay about five years, so it’s to be expected”); announcing the decision in an open, sensitive and widely distributed way had the effect that no one felt left out; and continuing attention to organizational morale is being given through acknowledgement of the emotions involved and an open door to any staff member who wants to talk about it. Numerous long-term planning sessions are being held to help key staff move ahead with confidence and minimum disruption to QCQC and HCFA’s other activities.

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<sup>37</sup> This timing has just been changed. Due to demands of Dr. McDonough’s new position as Senator Edward M. Kennedy’s senior advisor on national health reform, he will be leaving HCFA at the end of May. The change is requiring acceleration of the transition planning and has reportedly been a little unsettling for some junior staff at HCFA, although more experienced senior staff do not regard it as a major problem.

## Part 3

# Consumer Engagement in Quality Care and Patient Safety

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## Supporting Direct Consumer Voice

In contrast to the well-established coalition strategies being used for consumer advocacy in coverage issues, *the QCQC initiative's quality care component breaks new ground – bringing consumers who have been personally affected by healthcare quality failures directly into policy discussions.* This is truly a new direction, since the whole issue of medical error and patient safety has tended to be a discussion among experts. Consumers have historically been slow to engage with quality concerns in an organized way, due in part to a sense of powerlessness in the face of large health care systems. HCFA is using the QCQC grant to try changing this situation. The goal is to help consumers use their own experience to make the human impact of medical error easier for policy makers to understand and harder to ignore, ultimately bringing about quality-of-care improvements.

HCFA's primary consumer engagement mechanism for QCQC's quality component is the *Consumer Health Quality Council*, termed "the Council" in this report, supported by a HCFA *Quality Coordinator* (Deb Wachenheim) and a HCFA *Quality Organizer* (James Madden) who staff the Council and also engage in complementary public education and advocacy activities.<sup>38</sup> The work of HCFA's *Communications Coordinator* (Jean Leu) is partially funded through QCQC and serves the quality component as well as the initiative's coverage aspects.



Supplied by Health Care for All.

*A Typical Meeting of Health Care For All's Consumer Health Quality Council*

<sup>38</sup> The work of HCFA's *e-Health Coordinator*, also considered part of the quality initiative funded through QCQC, is distinct and independent enough to require discussion in a separate section (Part 4) of this report.

## How the Consumer Health Quality Council Works

When the centerpiece of QCQC's quality component – the Consumer Health Quality Council – was first launched in November 2006, no one knew quite what to expect. Starting with just a few individuals, HCFA planned to bring together a group of people who had been affected by serious medical errors or quality-of-care failures, either personally or through a relative or close friend. HCFA staff, along with an Advisory Committee made up of outside experts, would assist this Council in developing a consumer quality agenda and bringing that agenda to policy-makers' attention in ways that could result in real change. Beyond that, little was specified.

A little over a year later, the Council has grown into a solidly established organization with 45 members and a well developed set of policy proposals, some of which have already made their way into pending legislation. Some extremely effective educational resources have been developed, with more underway. Individual Council members have furnished powerful testimony at public hearings; raised public consciousness through TV, radio, and print media interviews; and held persuasive meetings with their state legislators. Based on the progress made so far, HCFA and the Council are laying groundwork for expansion of the quality initiative through regional councils and chapters aimed at special populations. There have been growing pains along the way and some unresolved issues remain, but the overall picture is one of remarkable achievement within a very short period.

To understand how so much was accomplished in Year 1, it's important to have an accurate picture of the Council's consumers. The possibility of poor quality health care touches everyone, from top to bottom of the income and education scale, regardless of race, location, or insurance status.<sup>39</sup> Anyone could suffer a life-changing “never event”<sup>40</sup> in a hospital. Anyone could lose a child or spouse or parent due to a preventable medical error. Because this risk applies so broadly, HCFA has been able to find and recruit victims of medical error who

are also unusually capable, resilient, and talented individuals. The initial consumer members included a long-time HCFA staff member and a member of HCFA's own Board. Among the present membership, more than half have college degrees and 14 have graduate degrees and/or professional credentials. When they joined the Council, they were hardly helpless. In fact, most of them had already demonstrated strong capacities for individual advocacy on quality issues. What they needed and wanted was organizational support and some policy entry points to make their voices heard in ways more likely to result in system change.

There are consumers advocating for attention to quality issues elsewhere in the country, but they tend to be lone voices. What makes this Council distinctive, in the eyes of its consumer members as well as the HCFA staff, is that it provides *group support* and puts the *resources and experience of a large advocacy organization* behind the effort, so that individual consumer members become more confident, empowered, and able to target their efforts strategically.

### Recruitment and Screening

Building the Council's membership has required empathetic and very labor-intensive recruitment and screening work by HCFA's staff. After initially recruiting a small nucleus of appropriate members from within HCFA itself, calls were put out through various organizational partners, inviting volunteers who had been seriously harmed or had lost someone close through quality failures such as misdiagnosis, botched surgery, hospital-acquired infections, or major medication errors. Responses came back from people who did not actually fit this definition, including lobbyists and advocates representing various mental health and disease-group organizations. Responses also came back from people who did fit the definition, but who were still so angry and in pain about their experience that they were not ready to link their personal tragedy to policy change; what they needed was

<sup>39</sup> Asch SM, Kerr EA, Keesey J, et al (2006). “Who is at greatest risk for receiving poor quality health care?” *New England Journal of Medicine*, 345(11): 1147-1156.

<sup>40</sup> This term, developed by the National Quality Forum, refers to events that should never happen in a hospital such as wrong-site or wrong-person surgery, serious medication errors, or leaving a foreign object inside a surgery patient.

a support group and/or legal assistance. Fortunately, responses also came back from consumers who did fit the definition and were ready to work for system change; they wanted to use their experience to make sure that what happened to them or their loved ones would not keep on happening for other patients. Sorting out these categories required numerous contacts and long interviews with prospective members, carried out by HCFA's Quality Organizer. Every consumer who had suffered harm was passionate and emotionally vulnerable, and needed to be screened with sensitivity – not saying “You aren't what we want” but rather “Is this Council a good match with what you're feeling right now?” In some cases, the prospective member might attend a few meetings before deciding. If the fit was not good, the person was not simply dropped, but rather was referred to service organizations that might help such as Medically Induced Trauma Support Services (MITSS) or Health Law Advocates. They also were added to the HCFA quality e-mail list to receive monthly newsletters and other updates and alerts. HCFA's careful screening process has been time-consuming and sometimes stressful for all concerned, but appears to have been essential for building the Council's membership in a way conducive to its goal of policy change.

The Council's current membership of 45 consumers is diverse in terms of age, education, professions, and medical experiences – more or less accidentally, since the primary emphasis in recruitment has been aimed not at proportional representation but rather at getting people who were in the right place emotionally to pursue system change. In terms of race and ethnicity, the current membership is predominantly white but does include 3 African Americans, 3 Asians or South Asians, and two members who strongly self-identify as Portuguese. One membership characteristic that is still very unbalanced is gender (the group contains only six males), which probably reflects the fact that women use health care more than men do, are more likely to seek help, and have more involvement in caretaking. Simple logistics have also shaped the current membership. For example, the meetings are set for evenings to accommodate consumers who work;

this makes them less accessible to the elderly. They are conducted in English, which makes them less accessible to those with limited English proficiency. For this reason, some of the Council's consumers see a need for possibly setting up additional chapters for special populations next year.

The idea occasionally comes up in discussion that people who have not personally suffered from medical errors might still be committed and interested in health quality advocacy, so maybe they should be allowed to join the Council. That idea has been rejected by Council members so far, on the grounds that it would dilute the group's identity and erode the feeling of safety and support that members get from knowing the meeting room is filled with people who understand from the inside what the experience of poor quality care is like.

### Organizational Process

In terms of process, the Council has needed to feel its way slowly. HCFA staff were (and still are) firmly committed to the idea that consumers should run the Council. However, they also recognized that special support would be needed at first to get things started. The fledgling Council began as a small group of volunteers with a loosely defined set of goals, holding meetings and adding new members without yet being quite sure of the group's direction. For about the first year, HCFA staff were relied on heavily to manage all the meeting logistics, set up meeting agendas, facilitate the meetings, do the research and follow-up work, do the recruitment and screening, organize speakers and workshops, etc. The HCFA staff went to great lengths trying not to over-control, while still giving the necessary support – a delicate and not always comfortable balance. As they put it, they initially served as an “incubator” during the Council's infancy.

During Year 1 the Council has settled into a pattern of monthly meetings with average attendance of 10 to 20 consumers, not always the same individuals. In terms of content, the meetings serve multiple functions (described in more detail later) including:

- › Organizational development work such as creating a mission statement and bylaws.
- › Work on projects such as development of a consumer quality agenda, legislative proposals, and various educational resources.
- › Guest speakers, allowing opportunities for consumer members to have direct conversations with prominent advocates and policy makers and to learn more about provider systems and health policy issues.
- › Preparation for events such as giving testimony at public hearings.
- › Training sessions in subjects such as legislative process and messaging, some provided by HCFA staff and some by consumer members who have special expertise.

While the meetings are work sessions and a lot gets done, they also have an undertone of community building and personal support, giving them a feel very different from the efficient, task-focused meetings of the ACT!! coalition described in Part 2. As a consumer member who was recently elected Council President explains, “There’s so much emotion here, so close to the surface.” All of the Council members, by definition, have been through experiences that were personally devastating, and on various levels they are still grieving. Even the Council’s most sophisticated members occasionally verge on tears when they discuss what happened, and they speak of their Council work in deeply emotional terms (for example, “I do this because, as my father was dying, I vowed to him that his death would not be in vain”). Because of these ever-present raw nerves, empathetic attention needs to be given to Council members as they speak. If they delay the meeting agenda by needing time to focus their thoughts and feelings, they have to be moved along very gently. A few missteps occurred before this need for extreme sensitivity was fully recognized. It’s an important lesson learned.

Because of the group’s newness, its Year 1 work began with definitional issues, discussing basic questions such as: What do we want our group identity to be? Exactly what went wrong in the health care system that allowed horrible things to happen to us and people we love? What concrete changes should we push for, to prevent such things from continuing to happen? What skills do we already have for advocacy, what new skills do we need to learn, what advocacy strategies are open to us?

Early in the year, after much discussion, the Council reached consensus on the following mission statement:

*The Consumer Health Quality Council empowers those impacted by health care quality issues to have a voice in our health care system, to engage fellow consumers to be active partners in their health care, and to advocate for high quality, safe, and accessible health care for all Massachusetts residents.*

Later in the year, with strong encouragement from HCFA staff, the Council developed by-laws that lay out consensus criteria for membership and norms for attendance and participation in Council meetings. The by-laws also set out procedures for electing officers from among the membership (a President, Vice President, and Recorder, elected in December 2007) who can take on some of the meeting facilitation tasks previously done by HCFA staff, moving the consumers themselves into fuller control over the Council’s organizational process. HCFA staff welcome these changes, but are well aware that they do bring with them some unpredictability. As one staff member commented, “Democracy can be SCARY!”

Reflecting their own growing sense of the Council as a genuinely consumer-directed organization, the consumer members have recently decided to establish a mentorship system in which new members, as they join, will each be taken under the wing of an “old” member who will acquaint them with the Council’s history, goals, and procedures. This is intended to provide an added measure of continuity and stability as the Council accumulates shared experience. It also has the feel of new members being inducted into something important, special, and valued.

### The Consumer Council's Advisory Committee

As part of the QCQC initiative, the Consumer Health Quality Council has been supported by an Advisory Committee made up of 13 recognized experts on issues of quality care and patient safety, who can serve as resources both for the Council and for HCFA more generally. A list of Advisory Committee members is attached in *Appendix #9*.<sup>41</sup> During Year 1 this Committee met quarterly with HCFA's staff to discuss policy issues and strategy, and also held two joint meetings with the consumer members of the Council.

The first of the joint meetings, held in June 2007, was seen by HCFA staff as an "ice-breaker" in which the consumer members and expert advisors could get to know each other and begin to define productive ways of working together. HCFA staff planned the agenda around brief self-introductions by each participant and some informational presentations, followed by small group brainstorming with each group including some consumer members and some expert advisors. The meeting plan also provided plenty of opportunities for unstructured informal conversation, plus a well-catered meal. The highlight of the afternoon was a group priority-rating of possible ways the consumers and experts could work together. Ideas on this, growing out of the small group discussions, had been written on newsprint and taped to the walls. Everyone in attendance was given a supply of colorful "smiley face" stickers and asked to visit all the newsprint lists, putting stickers on the ideas they liked best. This method worked well in that it gave a quick take on the group's priorities, put everyone on an equal footing, created a sense of collective participation, and (because of the stickers) had a certain silliness to it that appealed to everyone's sense of humor. The ideas that got the most votes – i.e., the most smiley faces – became a base for future planning.

The good news from the first joint meeting is that it did indeed leave the consumers and experts feeling more connected with each other. However, a number of the expert

advisors had not been able to attend, and the consumers' discussions with those who did attend were still at a beginning stage. Wanting to increase interaction and the opportunities for conversation, HCFA's staff followed up on the joint meeting by inviting individual members of the Advisory Committee to attend regular monthly Council meetings and talk more about their professional work and how it could fit with increased consumer voice. This format allowed for informal questions and answers and appears to have been empowering for Council members as well as mutually informative. As a follow-up step, it has been a very effective way to link the Consumer Council comfortably with the Advisory Committee.

The second joint meeting of consumers and expert advisors, held in January 2008, reflected this growing sense of connection and empowerment. Again, it was primarily a work session focused on ways that consumer voice can best be brought to bear on issues of quality and patient safety. As of the end of Year 1, the Council's consumers and its Advisory Committee experts seem to be thinking of each other as known resources and allies. The experts have learned more about what the consumers value and want, and the consumers have a better understanding of how various policy and service systems work and might be influenced.

Advocacy goals and priorities have occasionally been seen differently by the Council's consumers and some of the expert advisors, particularly over the scope of public reporting, the wisdom of setting the goal for hospital-acquired infections at zero, and the importance of apologies for medical mistakes. As discussed below, experts have sometimes counseled going slower and making more compromises in order to improve a measure's political chances. However, when there are differences, HCFA has supported the consumer viewpoint. The principle guiding QCQC's quality component has been that the Council's consumers themselves control what their "voice" expresses. HCFA is supporting them with information, advice, and logistical assistance, but not telling them what to say.

<sup>41</sup> It's worth noting that, according to HCFA staff, most members of the Council's expert Advisory Committee – and also many of the legislators who work with the Council – have been personally touched in some way by healthcare quality problems, usually through a relative ("Here's what happened to my dad..."). This shared experience further underscores that everyone who uses medical services is potentially at risk for medical error.



## Related Programs That Support QCQC'S Quality Care Goals

HCFA's work on quality and patient safety also benefits from some HCFA activities and programs not directly funded by RWJF, such as the blog and HelpLine discussed in Part 2. In terms of external links, close connections exist with various statewide and national organizations working on quality issues such as the Massachusetts Coalition for the Prevention of Medical Errors, the Betsy Lehman Center for Patient Safety and Medical Error Reduction, Blue Cross Blue Shield of Massachusetts, and Consumers' Union; many of these partners are represented on the Council's Advisory

Committee. Also, HCFA's current Executive Director serves on the board of a related initiative called the "Partnership for Health Care Excellence," started in 2007 with funding from Blue Cross Blue Shield of Massachusetts, that aims to use a carefully crafted series of print and TV ads to raise public awareness concerning ways that consumers can reduce patient safety risks; for example, some of the ads model how to be a "good patient" by assertively asking questions and requesting that health providers wash their hands before starting a medical examination.

## Quality Care, Year 1: Activities and Outcomes

### 1. Organizational Growth and Capacity Building

The Council's own organizational growth should be counted as a major positive outcome in Year 1. Starting from scratch, the group has by now acquired a sizeable membership, a strong sense of cohesion and momentum, a solid set of internal procedures, and comfortable working relationships with HCFA staff and with the expert Advisory Committee. As volunteers, the Council's consumers will continue to need and benefit from the support of HCFA's paid staff – but the Council's "infancy" is clearly over. The Council's individual consumer members have also built skills during the year, becoming more knowledgeable about how healthcare systems and political systems work, and about various strategies for system change. At the end of Year 1, they are visibly more confident and at ease with public speaking, giving testimony, working with the press, initiating conversations with their political representatives, and taking initiative in organizing advocacy efforts.

### 2. A Consumer Agenda for Improving Healthcare Quality and Patient Safety

One of the tasks the Council undertook early in Year 1 was to craft a consumer agenda for improving healthcare quality and patient safety. Based on their own collective experience, and reflecting some concerns often underplayed in expert discussions of health quality problems, the consumer members put together a list of goals to guide their advocacy efforts. These goals are essentially the same as the provisions in the Council's proposed legislation, described below.

### 3. Legislative Proposals

A high point for the Council this year has been proposing an omnibus consumer health quality bill called "An Act

Promoting Healthcare Transparency and Consumer/ Provider Partnerships" (*see Appendix #10*). The bill was filed in the Massachusetts legislature on January 10 2007 and quickly attracted 47 legislative sponsors. It included the following six provisions, based on the Council's consumer agenda.

- › Require hospitals to *reduce rates of hospital-acquired infections to zero*, or as close to zero as feasible . . . and, through the Department of Public Health, to disclose and *publicly report infection rates*.
- › Require medical facilities, through the Department of Public Health, to *publicly report so-called never events*,<sup>42</sup> *identify problem areas, and develop quality improvement initiatives*.
- › Require physicians or designated health care representatives to *notify patients of adverse medical events* and potential adverse medical events that occur during their care.
- › Allow physicians and healthcare providers to acknowledge a medical error by offering an *apology* to a patient without fear of the apology being used in a lawsuit.
- › Require hospitals to establish and convene "*Patient and Family Councils*" through which consumers would have a voice in improving hospitals' quality of care.
- › Require hospitals to establish *Rapid Response Teams* which patients and families can activate when immediate medical attention is needed.

<sup>42</sup> Related to this provision, HCFA and the consumer Council have also pushed for prohibiting hospitals from charging patients for costs arising from "never events."

Some of these provisions might have read differently – or have been missing entirely – if they had been presented by expert advocates without consumer input. For example, setting a goal of zero for hospital-based infections is viewed as unrealistic and unnecessarily confrontational by many health policy experts. However, the Council’s consumers felt strongly that a zero infection rate needed to be stated in the legislation as a “stretch goal,” and their wishes prevailed. Similarly, the idea of physicians apologizing for their medical mistakes has often been seen by experts (with some notable exceptions<sup>43</sup>) as something that poses complicated liability issues without doing much actual good for the patient. The Council’s consumers feel differently and very strongly about this issue. Based on their personal experience, they see apologies as essential to mental health for victims of medical error. Many of them had encountered a defensive “wall of silence”<sup>44</sup> after suffering preventable harm, and had felt trapped in a state of rage and frustration for years, deprived of the closure that could have been provided by an acknowledgement of error and an apology from medical providers. The last two items – Patient and Family Councils and Rapid Response Teams – also reflect the consumers’ direct experience of what they lacked in their own time of need and urgently want to put in place for other patients.

The omnibus bill was favorably reported out of the legislature’s Public Health Committee on February 19 2008 with five of the six provisions intact<sup>45</sup> – a significant step forward, since most legislative proposals in Massachusetts die in their initial committee. This positioned the bill for further review through several other committees. Having been thoroughly briefed on legislative process, the Council’s consumer members knew that the legislature’s long-drawn-out redrafting process would probably bring more compromises, and were prepared for the possibility of “half a loaf.” As they said, “Whatever happens this time around, we have at least started a conversation.”

As things are turning out, the conversation they started has apparently had an effect. Some of the Council’s health care

quality priorities have been incorporated into a major piece of legislation introduced March 12 2008 by the Senate President – a landmark health care cost-containment bill, informally being called “Health Reform Phase II,” expected to be passed into law this session. In addition to its many important cost-containment provisions, this bill *prohibits payments for never events; requires reporting of never events; requires reporting of hospital-acquired infections to the Department of Public Health; and sets up Patient and Family Councils in hospitals* to ensure that consumers have a voice in hospital policies. Including these provisions in a bill aimed primarily at cost-containment reinforces the idea that quality care saves money as well as lives – an important part of the message that the Council has tried to convey.

The Council’s own omnibus quality bill is “attached” to the cost-containment legislation, essentially retiring any of its provisions that were not explicitly mentioned; they would need to be re-introduced next session. Thus the victory is a partial one. The Council’s consumers do not view this outcome as a setback, however; instead, they feel encouraged. Without the training on legislative process they received through QCQC, they might not have recognized a partial victory as the significant progress that it actually does represent.

#### 4. Administrative Advocacy

Just as for coverage issues, the QCQC initiative works on quality care issues through both legislative and administrative routes. A good example of the administrative strategy involves public reporting of hospital acquired infections (HAIs), a top priority of HCFA’s Consumer Health Quality Council. The issue can be addressed through existing regulatory powers as well as legislation, and a vigorous debate has been underway all year centering on proposed regulations to be issued through the Department of Public Health (DPH). Input from the Council has been an ongoing part of this debate, with HCFA and the consumers pushing hard for full public reporting and

<sup>43</sup> The *Sorry Works! Coalition*, a rapidly growing national organization, is a good source of information on this issue.

<sup>44</sup> See Rosemary Gibson and Janardan Prasad Singh (2003), *Wall of Silence* (Washington, DC: LifeLine Press).

<sup>45</sup> The one provision that was dropped dealt with mandatory disclosure of adverse events.

a goal of zero HAIs but also recognizing that time might be needed to realize these goals.

The new regulations, approved by the State Public Health Council in February 2008, will assist DPH in monitoring and surveillance of HAIs, create greater consumer transparency, and provide data to achieve the goal of eliminating HAIs by 2012. Healthcare facilities will report data through CDC's National HealthCare Safety Network, and some data will be made public on a website to be created in conjunction with the state's Health Care Quality and Cost Council. Although the final wording reflects a compromise, it is much stronger than it probably would have been without the consumer pressure. Before the final vote, the State Public Health Commissioner publicly thanked Public Health Council member Lucilia Prates (also President of the Consumer Health Quality Council) for her commitment to the issue – a recognition of the consumer role in developing the regulations.

At a public hearing in December, as the regulations were being drafted, the consumer Council offered a number of recommendations through prepared written testimony and also through personal testimony by a consumer Council member. The recommendations included (1) creation of an advisory group including consumer members to monitor implementation, and (2) some alternative ways of disseminating HAI data, because the planned website would be inaccessible for some consumers. Both suggestions were accepted. The final regulations create a Technical Advisory Group with three or four consumer representatives including a HCFA staff member (Deb Wachenheim), and DPH has made a commitment to look at other modes of communication including materials in languages besides English. While the consumers did not get agreement to everything they recommended, these two changes were big victories. They build an ongoing consumer presence into the HAI reporting machinery and will help the new regulations connect in a more meaningful way with the realities of consumers' lives.

## 5. Three Innovative Tools for Public Education and Advocacy

The Council has produced some innovative education and advocacy tools<sup>46</sup> that are getting very good response in Massachusetts and could potentially serve as models for similar efforts elsewhere. They include:

- **The Story Bank Project** – a compilation of personal stories written by Council members describing their own experiences with poor quality care, the deficiencies in the health care system that led to the problem, and what consumers can do about the situation. The stories are shocking, but not self-pitying; the Council put a lot of thought into ways of making them focused, informative, and linked to practical action steps for improving the system. They appear on a Health Quality “Stories of Harm” webpage linked to the HCFA homepage, and each month one story is featured in HCFA's Quality Newsletter. In addition to web-based public education, they provide a ready resource for public hearings and for responding to journalists who request personal stories volunteered by consumers to illustrate problems with poor quality care.
- **The Video Storytelling Project** – With the technical assistance of students from Boston University's School of Public Health, some of the Council members have produced a series of short digital videos presenting their stories, showing the systemic problems involved, and explaining the life-long impact on themselves and their families. In January 2008, three of these videotaped stories were posted on the HCFA website and also on youtube.com. They included Ginny's horrifying story of how medical treatment for a broken ankle led to a lingering hospital-acquired infection that required 28 agonizing surgeries over a five-year period, involving live bone and muscle transplants and eventually the amputation of her leg, with the surgery causing respiratory failure three separate times; Lisa's maddening experience of a misdiagnosis that cost her years of painful, expensive,

<sup>46</sup> Accessible through the HCFA website.

but completely ineffective treatment before she was finally diagnosed correctly and treated appropriately (and incredibly enough, her experience was followed by a similar misdiagnosis for her daughter); and Linda's wrenching account of how a preventable mistake by hospital staff led to her mother's death. These three stories were also featured at an event at the State House (described further below) to raise awareness of legislators and their aides. The reaction to the videos has been extraordinary. Viewer ratings on youtube.com are at the highest possible level, five stars. Although released only a few months ago, they have had over 6000 online viewings so far, and 20 blogs and news sites have posted entries and links to them. They have already begun to spread on their own as a tool for others interested in patient safety; HCFA staff have heard reports of them being used in professional training and by hospital administrators in other states and in fact, as far away as the Philippines. Three students from Boston University's School of Public Health are currently working with Council members on a distribution plan to help the videos reach a widening circle of providers, decision-makers, and consumers.

- **The Consumer Resource Guide** – Work is getting underway on a consumer-oriented resource guide, compiling information about supports available to people experiencing problems with poor quality care. In addition to the “official” services, Council members want to include less-well-known supports that they found helpful in their own experience, often only after a long and frustrating search.

## 6. Consumer Testimony at Public Events and Legislative Hearings

Among the Council's most dramatic activities in Year 1 have been individual consumer members' personal testimony before large, policy-relevant audiences. In March 2007, the Council held a briefing on healthcare quality at the Massachusetts State House, coinciding with Patient Safety Awareness Week and attended by 75-100 legislators and staff, consumers and

advocates. An overview of the Council's initial 6-part quality agenda was presented by a panel that included an expert from the Council's Advisory Committee, the House and Senate co-sponsors of the Council's legislative proposal, and consumer Council members. Two of the Council's consumers told stories of their experiences with the health care system and discussed how those experiences had led to their involvement in advocacy for quality improvement. HCFA staff note that “many in the audience had little to no knowledge of these issues and this event educated all in attendance.”

Another climactic moment occurred in September 2007, when a group of Council members testified at a day-long public hearing covering the Council's own omnibus quality bill along with some 20 other bills related in some way to healthcare quality. The consumer witnesses knew there would be a large audience, but they say they felt confident because of the group support, the Council's training sessions on legislative process, and the preparation they had done. They had each written their own testimony, discussed it with HCFA staff, shared it in advance with other Council members at a group dinner, and practiced repeatedly to make sure they could deliver it within the strict time limit of three minutes. On the day of the hearing, the schedule ran late and the Council members were kept waiting for several hours – not easy, considering that the day was hot and some of them were on crutches or in a wheelchair – but they managed this with aplomb. When their turn to speak finally came, their testimony was a show-stopper. It signaled a definite change of pace from the expert witnesses' facts and figures that had so far dominated the hearing. The room grew hushed as the Council members each told their personal story of poor quality care, carefully stressing not only their own pain and loss but also the huge preventable costs to the health care system. The legislators in attendance stopped all doodling and side-bar conversations and gave rapt attention, nodding their heads, in some cases visibly shocked by what they were hearing. The testimony clearly had a strong impact in terms of information and education, and helped build momentum for favorable legislative action on quality-care issues.

A different group of Council members gave similar testimony in January 2008, at a special event held at the State House to debut the storytelling videos described above. The high-visibility event got good press coverage and, again, helped to educate and build momentum for legislation on quality care improvements. With the consumer Council's newly elected Vice President running the meeting, the videos were shown for an audience of over 75 people – legislators and their staff, journalists, consumers, and health advocates. The three consumers featured in the stories then spoke; their physical presence and personal comments gave the videos even greater impact. They were followed by other speakers including the two lead legislative sponsors of the Council's omnibus quality bill and a prominent member of the Massachusetts Health Care Quality and Cost Council (Jim Conway, Senior Vice-President at the Institute for Healthcare Improvement). In a moving moment that helped to further “put a human face” on the problem of poor quality care, Dr. Conway publicly apologized on behalf of the Massachusetts healthcare community to each of the three consumers who were featured in the videos. After the meeting, one of them thanked him for being the first person ever to apologize to her for what she had gone through.

Consumer testimony has had an impact on administrative as well as legislative decision-making. As discussed above, the Council's prepared testimony at a public hearing of the Public Health Council in December, presented compellingly by a consumer member, directly resulted in two important additions to the State Department of Public Health's new regulations on hospital acquired infections. The Council has also submitted comments to the Health Care Quality and Cost Council on its goals and steps to achieve them.

## 7. Participation on Policy Fora and Conferences

One of the QCQC initiative's goals is to strengthen consumer voice within administrative agencies, official policy fora, and policy-related conferences. Initially, HCFA had hoped that a cadre of Council members, after some training, could fill

some of the often vacant consumer positions on the state's professional licensing boards. As it has turned out, this plan did not work well for structural reasons; the licensing boards meet during working hours and demand considerable time – not a problem for salaried professionals who are serving on the boards as part of their paid employment, but more than the Council members can manage as volunteers. However, other opportunities have emerged, both for the Council's consumer members and for HCFA's quality-initiative staff. In April 2007, Lucilia Prates (a consumer member and currently the Council's elected President) was appointed by Massachusetts Governor Deval Patrick to serve on the state's *Public Health Council* – an important position, since this body promulgates rules and regulations, holds public hearings, approves certain appointments, and approves Determination of Need applications. Deborah Wachenheim, HCFA's Consumer Health Quality Coordinator, has been serving for most of the year<sup>47</sup> on the Advisory Board for the state's *Health Care Quality and Cost Council* – again, an important position since it allows her to inject consumer concerns into a hot spot of current negotiations over what health reform compromises should (or should not) be considered in the name of cost containment. She also serves on the board of the *Massachusetts Coalition for the Prevention of Medical Errors*.

Quality issues have been heavily featured at *HCFA's Annual Policy and Organizing Conferences* in March 2007 and March 2008 – well attended events that gathered together Massachusetts policy-makers, health advocates, and health consumers. Council consumer members, Advisory Committee members, and HCFA's quality-initiative staff have also been active as presenters and/or workshop facilitators at a number of national conferences, including the *Annual Conference of Families USA* in January 2007; the *National Patient Safety Foundation Annual Congress* in May 2007; a *conference of Consumers Union* in January 2008; and the *Annual Conference of Families USA* in January 2008. At this last annual meeting of Families USA, HCFA coordinated a session on “advocating for quality care” that featured

<sup>47</sup> Her service was temporarily interrupted by maternity leave, but other HCFA staff have substituted for her.

HCFA's own quality initiative plus other advocacy efforts elsewhere, along with a panel of nationally known speakers. This session was the conference's first-ever workshop on consumers and quality, and drew an audience of over 100 people. HCFA also helped to bring Don Berwick, CEO of the Institute for Healthcare Improvement, to the Families USA annual meeting as a plenary speaker. Further linking HCFA's quality initiative with national-level work on quality issues, Deb Wachenheim, HCFA's Consumer Health Quality Coordinator, has been appointed to the Consumer Advisory Panel of the *National Committee on Quality Assurance*.

## 8. Media Coverage

The work of the HCFA's Quality Initiative and the activities of the Council's consumer members have received strong media coverage during Year 1, including:

- > 35 stories in print news
- > four radio news stories
- > three television spots including a feature on a popular regional TV news magazine (the Chronicle) and a story on Spanish-language Univision news.

This coverage has generally emphasized personal stories of the Council's consumer members, often told by them in their own words, to illustrate the problem of poor quality health care in Massachusetts and nationwide.

In addition, the Council has been able to make some sophisticated strategic links between media exposure and advocacy efforts in terms of timing. For example, through speakers and conferences, the consumer Council had learned about the Hospital Standardized Mortality Ratio (HSMR), a quality measure currently used to rate hospitals in Massachusetts and around the world. The Institute for Healthcare Improvement has these numbers and shares them with hospitals upon request. However, the public does not

have access to this information and hospitals with high rates may or may not know it, and may or may not work to improve their numbers. The Council felt strongly that this kind of information should be in the hands of consumers so they can make informed decisions about where they and their loved ones should go for care. In December 2008, an advocacy letter jointly signed by the Council's consumer president and by the Executive Director of HCFA was sent to two key state administrators (the Commissioner for the Department of Public Health and the Executive Director for the Board of Registration in Medicine) asking (1) that they move toward public reporting for hospital mortality rates using the HSMR or some other measure<sup>48</sup> and (2) that the data be used by the state to require quality improvements where needed. With the help of HCFA's Communications Coordinator, the letter was timed to coincide with a news article<sup>49</sup> planned to appear in the Boston Globe the same day, featuring the fact that Massachusetts hospitals have widely varying mortality rates and a few have rates much higher than the national average. The combination of the letter and the news article was stronger than either one would have been alone. This kind of coordinated action would have been much more difficult without the web of interconnections and supports built through the QCQC initiative. The advocacy has led to the Massachusetts Department of Public Health and the Massachusetts Board of Registration taking concrete steps to investigate mortality measures and move toward public reporting.

## 9. Laying Groundwork for Regional Councils

While HCFA's consumer engagement efforts on quality issues have centered on the Consumer Health Quality Council located in Boston, the intention was always to spread a wider geographic net by creating regional councils. Some members of the present Council travel long distances to attend the meetings in Boston, and regional councils would relieve them of that burden. Also, some parts of the state – notably, western Massachusetts and Cape Cod – have healthcare issues

<sup>48</sup> The Council acknowledged the complexity of constructing a useful mortality measure, and did not attempt to recommend a specific choice. Their role, as they saw it, was to urge authorities to move quickly in selecting the most appropriate measure based on expert opinion, and then report the resulting data publicly in a format that consumers could use to make informed choices.

<sup>49</sup> Liz Kowalczyk, "Mass patient death rate a concern," *Boston Globe*, December 6 2007.

somewhat different from those in Boston and might benefit from more locally focused consumer advocacy. Ideally, HCFA and the present Council members would like to see five to seven regional consumer councils modeled after the present Council, loosely linked in a network that could support both united and separate advocacy activities.

At the same time, everyone acknowledges that this is not something to rush into. The present Council has been successful in part because of the enormous commitment and effort put into it, both by the consumer members and by HCFA staff. Moving too fast into adding more councils might prove counterproductive by straining HCFA staff resources past their capacity, particularly in terms of available time for HCFA's Consumer Health Quality Organizer, who during Year 1 has played a key role both in staffing the Council and traveling around the state to lay groundwork for future regional councils. In developing regional councils, it's unlikely that HCFA could manage the same amount of time-consuming recruitment screening and one-on-one discussion with consumer members that went into building the Council in Boston; local consumer members would need to assume these tasks from the start. There is also some concern that coordination for a network of semi-independent consumer councils could turn out to be a considerable challenge.

The compromise has been to move ahead slowly, concentrating on the geographic areas where leadership capacity is already apparent among consumers interested in forming a separate chapter. In such areas, the first step has been for the HCFA Consumer Health Quality Organizer to help organize small community meetings to get the ball rolling, followed by a larger HCFA-sponsored community forum if the situation looks promising. So far, two areas have had a community forum. The first is the *MetroWest Region*, where consumers, providers, and advocates met in August 2007. A consumer Council member talked about how poor quality care has affected her life and why she is pressing for quality improvements; John McDonough discussed HCFA's quality initiative, and a representative from an area medical center

talked about that facility's efforts to improve care. The second is the *Southeast Massachusetts Region*, where HCFA and the Falmouth Democratic Town Committee together organized a Falmouth community forum on health care quality in January 2008, attended by more than fifty individuals with a speakers' panel that included John McDonough, local healthcare advocates, and consumers. Again, a consumer member of the present Council is taking the lead in the local organizing.

It seems likely that these two regions will develop their own consumer councils during Year 2. In addition, the present Council has expressed strong interest in developing some chapters aimed at special populations such as the elderly and consumers with low English proficiency, probably in the Boston area. It's possible that the organizational machinery so carefully developed by the present Council – its mission statement, bylaws, and election procedures – will be transferable to any new chapters. On the other hand, the new chapters may prefer to create their own.

## 10. Individual Advocacy by Consumer Council Members

Finally, a number of consumer members say that, as a result of their work on the Council, they feel much more empowered to engage in individual advocacy for improvements in healthcare quality. One member described at a Council meeting how she arranged an individual meeting with her elected representative, something she had never done before. He had originally intended to grant her only a few minutes, but grew so engrossed in her story that they talked for an hour. At the end of the discussion, he said he now understood the issue's importance and would work to support quality reforms. HCFA staff say this was very inspiring to the rest of the Council members, who now feel that perhaps they could do the same. Other consumer members report that they have more confidence now about being interviewed by reporters and appearing on TV – again, things they had generally not done before.



## Quality Care, Year 1: Some Lessons Learned

Some preliminary lessons can be drawn from the HCFA quality initiative's first year experience:

- 1 The partnership concept behind the Consumer Health Quality Council worked well and is worth replicating – i.e., in advocacy work, direct consumer voice is exceptionally valuable but it gains from being organized and supported.** The Council is made up of very capable consumers with powerful stories to tell, but prior to this initiative they were each acting alone or as individual families. Their advocacy abilities and opportunities have been greatly increased by a year of organization building, skill development, and staff support from an experienced, well-networked, well-resourced organization like HCFA. This is evident at public hearings, where the testimony from Council members tends to be confident, crisp, focused and well-informed, in contrast to testimony from unaffiliated consumers whose individual presentations often wander and miss the policy target.
- 2 HCFA's time investment in organizing the Council, supporting its work, and laying groundwork for regional expansion has been much greater than anticipated in the RWJF grant.** During Year 1, the staff resources budgeted for the quality initiative were strained to the limit (fortunately eased somewhat by the participation of interns from Boston University's School of Public Health, recruited by a consumer member who received her MPH degree from BU). Just as for QCQC's coverage component, a great deal of the necessary staff support in the quality component has been for various kinds of "invisible work" that are hard to put your finger on – pre-work and follow-up for meetings, networking, phone calling, gathering background information, contacting prospective members, traveling around the state, etc. In planning staff resources for an effort such as this one, allowance needs to be made for covering not only the explicit tasks but also the invisible work. Even if the consumers themselves eventually take on some of the procedural work of running Council meetings, HCFA staff will still continue to be needed for large amounts of this kind of back-up.
- 3 Not everything can be maximized at once, so a sequence should be planned.** For example, in order to get the Council up and running, attention to diversity in the membership has been deferred until later; while there is some diversity, it's so far there by chance. Also, because building a strong central Council was the first concern, the planned move into regional councils has had to proceed slowly; moving too quickly into creating new chapters might have proven counterproductive, given limited staff resources. In this initiative's Year 1, it seems to have worked well to consciously sort out primary and secondary priorities, and not try to do them all at once.
- 4 Because group facilitator skills are so critically important in this kind of effort, it may be helpful to supply some training in these skills.** As mentioned earlier, the consumer members' emotions tend to be close to the surface, which makes staff sensitivity and good interpersonal skills not just nice, but essential. In addition (in contrast to a well-established coalition such as ACT!!), it is not predictable in advance who will be attending each Council meeting. Not all of the "regular" consumer members attend every time, and every meeting generally has some new consumer members attending who lack familiarity with the group's purpose, history, and current work. This creates a real challenge for the person trying to lead the meeting. Some of HCFA's staff went to

workshops on leadership and group facilitator skills, and found the training helpful; there's some thought that the newly elected consumer leaders might be offered the same training opportunities, at HCFA expense.

**5 For raising awareness about poor quality medical care, personal stories have been a remarkably effective advocacy tool.**

While this might seem obvious, HCFA staff say that paid consultants from marketing firms that specialize in framing messages have sometimes advised against using personal stories to advocate for system change. The argument is that personal stories can backfire, creating sympathy for the individual but deflecting attention from the system failure. In the case of medical errors, however, that did not seem to happen. These stories are ones that all audiences can see potentially happening to themselves or their loved ones, and they also tap into common apprehensions about being helpless in a hospital. Also, as HCFA staff point out, legislators (frequently the target for the stories) are accustomed to hearing and responding to personal stories from their constituents. It's how they think. In any case, the tremendous impact that personal stories have had in the quality initiative's Year 1 is evident and undeniable.

**6 It is essential to spend time recognizing the group's advocacy victories, affirming the work of individual members, expressing mutual support, and celebrating collective accomplishments.**

The consumer members are volunteering their time, rewarded mainly by the satisfaction they get from feeling that their efforts are important,

valued, and effective. The tone of the organization makes a difference in whether they look back on the year with pride, or not. Because the HCFA staff and the Council's consumer leaders have wisely devoted sufficient time to recognition ceremonies and celebrations, the group has ended Year 1 with high morale and a sense of momentum.

**7 True consumer control can bring uncomfortable moments; this is to be expected, and not necessarily undesirable.**

During most of Year 1, as the Council was taking shape, issues of control did not come up much. The consumers were in a learning mode, grateful for HCFA's assistance and for the frequent assurances that "This is **your** Council." Now that they are feeling greater actual ownership, the group's center of gravity is beginning to shift slightly. They have their own consumer leadership now and are beginning to formulate plans independently, develop their own agendas and call meetings on their own, making the partnership a little less predictable. HCFA's commitment to consumer self-determination has been strong and unwavering, and enormous good will and affection exists between HCFA staff and the consumers, so this shift toward greater assertiveness probably will not pose problems. It is in fact a sign of growth, and HCFA staff view it as indicative of successful movement toward QCQC's consumer-voice goals. But in terms of lessons being learned, anyone seeking to build a consumer Council should expect that the process may not always be calm and comfortable. Almost by definition, a group of genuinely empowered consumers will not always be easy to work with.

## Quality Care, Year 1: Upcoming Challenges

While all aspects of QCQC potentially could be affected by the state's growing financial troubles, this factor is not listed here as an upcoming challenge for the quality initiative. If anything, quality reforms may receive extra attention if funds run short, because improvements in the quality of care tend to be seen as cost-saving measures. Several different issues seem more likely present themselves as special challenges for the quality initiative in the year ahead.

### Challenge #1: Policy Changes at the State and Federal Level

Next year will bring changes at the state and federal level in policies related to pay-for-performance and also non-payment for medical costs arising from specified adverse events. In principle, these changes should promote quality improvement. But hospitals and health-care providers will be working to adapt in ways not yet known, and incentives may be inadvertently created that work against quality improvement. It seems likely that new kinds of quality issues arising from these policy changes will come up for the consumer Council to monitor, and perhaps to address with legislative and administrative advocacy.

### Challenge #2: HCFA Staff Turnover

Dr. McDonough's departure as HCFA's Executive Director will probably not affect the quality initiative directly. While he has been a highly effective and valued speaker both at Council meetings and at regional community meetings, the direct HCFA leadership on quality issues has come from others – Deborah Wachenheim as the Consumer Health Quality Coordinator; Mehreen Butt as the Government Affairs Coordinator and substitute for many of Deb's duties during her maternity leave; and James Madden as the Consumer Health Quality Organizer. It's this last position where staff turnover will be felt, and felt acutely. Mr. Madden is leaving HCFA as of July 2008 to pursue graduate study. In the eyes of the consumers, he has been a central figure in the Council's formation and he is very well liked. Now the Council will be getting a new person to work with, and that person's characteristics and skills are bound to have an effect on the Council's work. Fortunately, a good level of continuity will be provided by the other HCFA quality-initiative staff.

### Challenge #3: Broadening the Scope of Quality Care Advocacy

So far, the Council has concentrated primarily on issues of patient safety and prevention of medical error, and the recruitment of consumer members has matched this emphasis. These issues are important, urgent, and dramatic enough to be a wise choice of focus for initial organizing. But there are also other dimensions of health care quality – for example, the adequacy of health reform's required "minimum creditable coverage" benefit package. If the MCC package is watered down to cut costs, is that not a quality issue? If disparities exist, is that not related to quality of care? HCFA's Information Technology work discussed in the next section (Part 5) is officially part of the quality initiative, but has not so far been linked very closely to the Council's work. Should it be?

The Institute of Medicine's 2001 report on *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century* lists six aims for quality care: it should be "safe, effective, patient-centered, timely, efficient, and equitable." Given the Council's present focus, will it be motivated and able to address issues such as efficiency and equity? If it chooses to keep its focus on patient safety, perhaps some of the developing regional chapters might focus on something else. For example, Cape Cod has an acute shortage of providers, and patients in that region need to travel long distances or wait a long time for appointments; a regional council in Massachusetts' Southeast Region might therefore choose to focus on the "timeliness" aspects of quality.

There are tradeoffs here. For the Council to try covering everything relevant to quality might dilute the impact of consumer voice, which has so far been very effective on issues of patient safety. On the other hand, focusing sharply on patient safety might leave out other important quality concerns. Having different emphases in different regional Councils could turn out to add strength, or it could prove too difficult to coordinate. Setting workable boundaries on exactly what "quality care issues" need consumer advocacy is something to be considered carefully, as QCQC moves forward.

## Part 4

# Consumer Engagement in e-Health

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## Making a Place for Consumer Voice

Within its quality component, the QCQC initiative includes a special effort related to “e-Health,” a catchall term that covers a variety of emerging ideas for applying information technology (IT) in health care in order to reduce costs, increase efficiency, and improve the quality of care. E-Health poses special considerations for consumer advocacy, and for that reason is being discussed separately from other quality concerns in this evaluation report.

Some examples of e-Health include:

- **EMR/EHR – Electronic medical/health records**, when interconnected, can allow multiple authorized providers to access a patient’s medical record, potentially reducing duplication and increasing coordination of care.
- **CPOE – Computerized physician/provider order entry** is a system that potentially improves the legibility and appropriateness of prescriptions and diagnostic tests, and reduces related errors.
- **e-Prescribing** – E-prescribing is an electronic method of generating prescriptions through an automated data-entry process using e-prescribing software and a transmission network that links to participating pharmacies.
- **PHRs – Electronic personal health records** can be accessed both by authorized providers and proxies and by the individual patient, potentially improving transparency, accuracy, patient/provider communication, chronic disease self management, and disease prevention.
- **RHIOs – Regional health information organizations** link networks of hospitals, physicians, and/or other health care providers and facilities, potentially improving coordination of care for larger patient populations and portability of electronic health records for patients who change location or providers.
- **Data management tools** such as **digital imaging systems** that reduce hospital data storage costs.
- **Online services** – for example, **electronic alerts to physicians and patients** when patients are due for screenings, at risk for drug interactions, or in need of other care; and **online health care quality and cost comparisons** that enhance transparency and enable consumers to make more informed care choices.

The whole area of IT in health care has attracted enormous interest among policy makers. Demonstration projects are proliferating around the nation and e-Health development is moving ahead full-steam, fueled by increasingly urgent concerns about cost containment – but so far, without much of an active consumer presence or voice. This is unfortunate and a bit ominous, since e-Health has potential to affect consumer interests greatly, both negatively in terms of concerns about privacy, access and control, and positively in terms of improvements in quality of care, transparency and patient safety. From the consumer perspective, this technology could be a blessing if designed and implemented well, and a nightmare if designed and implemented badly.

Efforts to involve consumers directly in the development of e-Health systems have historically been limited and fairly unsuccessful. The reason is not simply that the area is technical and complex, although those are real issues for developing the consumer voice in relation to e-Health. The underlying problem is that the e-Health systems under development are in a beginning stage and still largely hypothetical. Best guesses and general statements about consumer interests are always possible, but until these systems are actually put in place and more experience with them accumulates, it is difficult for anyone –experts or consumers themselves – to define in detail what the relevant consumer needs and concerns actually are. The situation contrasts sharply with the patient safety issues discussed earlier in Part 3, where the consumer members

of HCFA's Consumer Health Quality Council feel well-informed about the human consequences of medical error, can illustrate system problems with dramatic and passionately felt stories based on personal experience, and are prepared to offer specific proposals for system reform.

This consumer unfamiliarity with e-Health has required a *third kind of consumer engagement effort for the QCQC initiative*. In contrast to the representative form of consumer voice working through organizations in HCFA's ACT!! coalition and the direct form of consumer voice taking shape through the Consumer Health Quality Council, *consumer interests in QCQC's e-Health component are so far being raised and explored through a single HCFA staff member serving as a Consumer Advocate on e-Health issues*. In addition to keeping HCFA apprised of consumer-related issues in the nation's rapidly moving e-Health scene and serving as HCFA's primary spokesperson on the subject, *the Consumer Advocate's job is to ensure that e-Health activities in Massachusetts do not move ahead without a connection to the consumer advocacy arena, and that ways of including the consumer voice more directly are expanded whenever possible*.

That being said, it is important to note that the *e-Health Consumer Network* – a loosely defined group organized by HCFA's Consumer Advocate and consisting of consumer advocates, consumers, providers, health educators, health privacy lawyers, and others involved or interested in e-Health – has grown significantly over the past two years (from about 20 people to over 160). Many of its members have become enthusiastic and regular participants in HCFA's e-Health meetings. Particularly ardent supporters include advocates for adults or parents of children with mental health problems, AIDS Action advocates and members, Easter Seals advocates, providers from health centers serving low-income patients, and staff from state agencies interested in health quality improvement.

QCQC's e-Health component should be thought of as developmental – an effort to lay groundwork in anticipation that, as e-Health itself becomes more established, the need for consumer engagement will emerge more clearly, consumer issues will be more sharply defined, and the opportunities for consumer voice will grow. In the meantime, HCFA's e-Health activities through QCQC are aimed at *keeping consumer interests from being overlooked and making a place for consumers to be heard*.

## How the e-Health Consumer Advocate Role Works

HCFA's e-Health Consumer Advocate position appears to be something of a first. About mid-way through Year 1, the staff member occupying this position (Lisa Fenichel) attended a conference of health-related consumer advocacy groups in New York City and described the e-Health work being done at HCFA. The other participants at the conference were extremely interested, saying that they had not heard of such a position before and were just now realizing the need for it.

Because the role is so new and loosely defined, the e-Health Consumer Advocate is in a sense constructing her own job description as she goes along. She consults regularly with others at HCFA, especially with other staff working on quality issues and with the current Executive Director, and with others in the national arena working on e-Health issues from a consumer perspective, but her work is essentially independent and self-directed, taking advantage of opportunities as they arise and building a community of interest.

## Related Programs That Support QCQC'S e-Health Goals

The e-Health component of QCQC does not involve setting up or managing electronic systems. Instead, it aims to *infuse the consumer perspective* into proposed and already ongoing external initiatives that are separately funded and related to the use of information technology in healthcare.

One particular external initiative interconnects so closely with QCQC that a brief description is needed here. In 2004, Blue Cross Blue Shield of Massachusetts launched a \$50 million demonstration project to develop electronic medical record systems in three Massachusetts communities: North Adams, Newburyport, and Brockton. The project is overseen by a nonprofit organization called the *Massachusetts eHealth Collaborative* (MAeHC), which has pursued its goal with great energy (as a look at the MAeHC website and blog will attest). As HCFA staff describe it, “this project is one of the first in the nation to focus on e-Health connectivity from the ground up, from wiring individual providers’ offices to interconnecting providers in the community with one another and the local hospitals.”

The MAeHC pilots were originally envisioned as a three-year effort scheduled to end June 30, 2008, a timeline that has turned out to be over-optimistic. While steady progress has been made in all three sites, the process has been slowed by the complexity of technical and confidentiality issues, resistance by some providers, and disagreements over how the expenses would be divided between medical practices and health plans (currently, doctors would incur most of the costs and health plans would enjoy most of the savings).<sup>50</sup> As of March 2008, only one of the three pilot communities has been able to “go live” – that is, to be interconnected with active links among

different physicians and between physicians and hospitals. Fortunately, rather than terminating the effort with the systems only partly finished, Blue Cross Blue Shield has extended the timeline to carry the grants through December 2008.

The pilot programs have also demonstrated the magnitude of the up-front investment to put EMR systems in place. MAeHC’s CEO, Micky Tripathi, estimates that scaling up the project to cover the entire state may require \$500 million over five years. Still, policy-makers in Massachusetts (and elsewhere) believe that e-Health will eventually deliver on its promise of containing rising medical costs, and the momentum behind the idea remains strong. A proposal currently pending in the state legislature (the Senate President’s cost containment bill, discussed in Parts 2 and 3) includes provisions that would require Massachusetts medical providers to set up electronic medical record systems and interconnect them statewide within the next few years. If this legislation passes, whatever insights come out of the MAeHC pilot projects will be put to immediate use (although there may be some surprises when extrapolating from small pilot programs to larger networks).

Basically, the HCFA Consumer Advocate’s work with MAeHC has helped these pilot projects do double duty, shedding light not only on what’s needed to set up the technology and encourage provider participation but also on what’s needed to build a meaningful consumer voice into the process. Without QCQC, this timely opportunity to learn more about consumer engagement in e-Health would likely have been missed.

<sup>50</sup> Jeffrey Krasner, “Massachusetts seeks more use of electronic medical records,” *Boston Globe*, December 5 2007.

## E-Health, Year 1: Activities and Outcomes

During Year 1, the e-Health Consumer Advocate's work has had six main focal points:

### 1 Participation in ongoing e-Health initiatives in Massachusetts, monitoring their development and advocating for the inclusion of consumer voice and attention to consumer interests.

Foremost among these is the *MAeHC initiative* described above. The Consumer Advocate has worked with MAeHC's community-based pilot projects in three major ways, all of which have had a positive impact:

- › Encouraging the *creation and use of local consumer councils* in the three pilot sites. By design, the MAeHC pilot projects primarily emphasized working out technical bugs in the planned electronic medical record systems (EMRs) and securing acceptance and participation from providers. The Blue Cross Blue Shield grant did provide for local consumer councils in the three communities, but these councils might have remained fairly weak if not for the boost they got from QCQC. At least partly because of the Consumer Advocate's work, HCEA reports that "after much delay, the third – and final – consumer council was convened this past February, and the consumer councils have been taking an active role."
- › Working with the project's Privacy and Security Committees and Consumer Councils to push for *clarity and openness in their consumer documents*, resulting in greater transparency all around, making sure that there is balance in the descriptions (e.g., benefits AND risks) and that the process and the forms for opting in and out of the health summary are clear and simple. Rather than being constructed by experts alone, many of these documents have now had the benefit of consumer review.
- › Arranging for consumer/advocate review and feedback on the project's *patient portals* – i.e., secure, web-based "windows" that consumers can use to access their own health information. Patient portals were not included in the project's initial electronic architecture, but are now in active development in two of the three community sites. The Consumer Advocate has facilitated discussions that bring staff of the technical firm constructing the patient portal in Newburyport (Welogic) into direct contact with consumers and advocates for populations for whom such a portal could have a significant positive impact. By convening these stakeholders to discuss the portal, they all get the opportunity to discuss and comment on what they would like to see included and ways of making the portal more useful and user-friendly.

In addition to the MAeHC projects, the Consumer Advocate participates in a federal-state project called *HISPC (Health Information Security and Privacy Collaborative)*, managed by the *Massachusetts Health Data Consortium (MHDC)*. This project is assessing how the state's privacy and security laws and business practices affect the prospects for establishing a statewide electronic health information network. Its second phase, just now starting, will focus on *patient consent management* in an electronic environment. The Consumer Advocate will be a member of the Education and Consumer Engagement Collaborative Workgroup in this next phase. The Consumer Advocate has also been invited to work with a new group recently started by the *Massachusetts AIDS Action Committee*, focusing on *health privacy and data security*.



## 2 Legislative testimony on the need for inclusion of consumer voice and attention to consumer interests in pending legislation that deals with e-Health.

As mentioned earlier, the cost containment bill currently pending in the Massachusetts legislature would mandate *statewide establishment of EMR systems* by 2015. The HCFA Consumer Advocate has provided oral and written testimony to support an active consumer voice as these plans move forward – robust privacy and security policies, meaningful consent, patient portals, availability of electronic copies for consumers, and consumer representation on all decision-making and advisory e-Health boards.

## 3 Linking with national organizations working on consumer engagement in e-Health.

The Consumer Advocate works nationally as well as within Massachusetts. As summarized in HFCA's own Year 1 report to RWJF, she is “part of both the *Markle Foundation's Workgroup on Consumer Access to Health Information*, which is developing a privacy and security framework for networked personal health information (which subsumes the many forms of a personal health record, including the patient portal), and the *National Partnership for Women and Families' Consumer Partnership for e-Health*, which works on health information technology initiatives and policies at the federal level. She has also been involved in a consumer information project around e-Health with some members of that partnership. In addition, [she] participates in meetings of the *Health Privacy Project* (now a part of the Center for Democracy and Technology) around engaging consumers in e-Health.”

## 4 Organizing local and statewide events that bring together consumers and experts to discuss various consumer issues in e-Health.

For example, a second series of “*eHealth Consumer Network Lunches*” has been held during the past year, allowing consumers to hear presentations by prominent speakers and talk informally with them afterwards. The first

lunch featured a demonstration of the patient portal given by Sumit Nagpal, the CEO of Wellogic (the company that is building the health information interchange in two of the MAeHC pilot communities). Because this talk generated so much interest and enthusiasm, the conversation about patient portals has been continued with a series of follow-up meetings, two held already and more planned. At the second lunch, David Ahern, National Program Director of the Health e-Technologies Initiative funded by RWJF, presented a talk on “Consumer Perspectives on Personal Health Records and Their Potential for Enhancing Patient-Provider Communication,” describing research that he and some colleagues have conducted on consumer input in design of the personal health record. A third lunch, held in April 2008, focused on a new development in the e-Health world. Sherri Dorfman, CEO of Stepping Stone Partners, gave a talk on “Patient Empowerment: Methods, Models, and Motivations,” describing how a fictional patient needing to lose weight could use the interactive web for healthcare (now known as Health 2.0), to compare and choose among four different approaches.

In addition, each year an *Annual e-Health Summit* is sponsored by HCFA, bringing together a wide range of experts and consumers interested in e-Health. The Second Annual e-Health Summit, held in the summer of 2007, focused on “Phase II: e-Health in Mass., En Mass: Where We Are, Where We're Going, and How Best to Get There,” featuring presentations by representatives from the MAeHC; a nurse manager from a community health center in New Hampshire with a mostly low-income patient population, discussing that center's transition from paper records to EMRs; and the director of the Health Privacy Project in Washington, DC, providing a national context for the discussion. The Third Annual e-Health Summit, scheduled for June 27, 2008, asks “Are We There Yet?” As described by HCFA, it will be “taking stock of the MAeHC pilot project in its final months, with presentations from all three communities.”

### 5 Public presentations discussing the consumer perspective on e-Health at conferences and in articles.

The Consumer Advocate makes sure that e-Health is included in the program of *HCFA's Annual Policy and Organizing Meetings*, which attract a large audience of consumers, consumer advocates, providers, and policy makers. In the 2007 meeting, a representative of the Massachusetts Health Data Consortium (MDHC) spoke on "The E-Convenient Truth: How and Why Consumer Trust is Needed for Electronic Health Information Exchange," and in the 2008 meeting, a consultant to MDHC spoke about "Behavioral Health & eTechnology: the Search for eTrust."

In addition, the Consumer Advocate has served as a presenter, panelist, and moderator at a number of other conferences, including *two annual HealthMart events* sponsored by the MDHC where she discussed "The Integration of Behavioral Health and Physical Health Information" in 2007 and "Healthcare Technology: The Patients' View" in 2008. *Materials from her webpages* have been distributed at events such as a meeting in New York

City of the United Hospital Foundation and the annual meeting of the Professional/Parent Advocacy League. She has also been *interviewed for and quoted in the July/August 2008 issue of the magazine Patient Safety and Quality Healthcare*, in an article titled, "EHRs, PHRs, and ePrescribing: How Do the Pieces Fit Together?," by Heinold, Allen, and Stone.

### 6 Ongoing electronic updates and reports.

As groundwork for expanded consumer voice in e-Health, the Consumer Advocate is actively building the *e-Health Consumer Network* (an e-mail list of interested consumers and advocates, many of whom participate in HCFA's e-Health meetings, as noted above). She reports regularly to this network through weekly and monthly HCFA e-mails and newsletters, the monthly quality e-newsletters, the quarterly Board reports, and the HCFA blog. These activities help demystify the field of e-Health and connect consumers with what has in the past tended to be an arcane, expert-dominated arena. They also help keep the consumer advocacy community generally "in the loop" regarding e-Health.

## E-Health, Year 1: Some Lessons Learned

### 1 Including consumers in the e-Health planning process potentially makes a slow process even slower.

All new computer systems seem to take more time and have higher start-up costs than anybody initially thinks. The resulting deadline pressures can create unacknowledged passive resistance to the added complication of including consumer input – something that consumer advocates need to anticipate so they can craft persuasive arguments for the importance of taking the necessary extra time.

### 2 Consumers want more information about e-Health, but aren't well prepared for detailed advocacy as long as the systems are still hypothetical.

Specific consumer-generated proposals for protecting consumer interests will probably be forthcoming, but only after the systems are up and running and more experience accumulates. Although many surveys (by the Markle Foundation and other organizations) show that consumers have strong opinions about electronic health records and interoperability, at present there are few personal stories for consumers to tell about e-Health, either positive or negative. Many of the consumer issues are “invisible” ones that the patient doesn't see – for example, the loss of data that often occurs in cumbersome and fragmented paper record systems, which may negatively affect treatment and require duplication of medical tests. Accordingly, QCQC's consumer engagement effort has so far emphasized ways of promoting practical, interesting, interactive consumer education about e-Health, laying the groundwork for an informed consumer voice in the future.

### 3 Even if consumers themselves are not yet pushing for a direct, active voice in e-Health, it is critically important to have some form of consumer advocacy involved as e-Health develops.

Consumers are just beginning to connect with e-Health's potential benefits and possible problems. Meanwhile, because policy-makers hope that e-Health will be a solution for rising medical costs, the whole area is moving ahead like a runaway freight train. If consumer interests are not made a special emphasis, they are likely to be neglected in this rapid development – and later, if serious consumer concerns emerge after the systems are set up, it will be hard to establish consumer “e-trust” and hard to put things right. Thus, even though a direct consumer voice in this area is mostly in the future, the Consumer Advocate approach is an important strategy for making sure there will be a place at the table for consumers when the time comes and that consumer interests receive attention in the meantime.

Although advocacy has been done on behalf of consumers without much direct input from them during Year 1 (for one important exception, see above regarding the e-Health Consumer Network), HCFA's Consumer Advocate has been able to head off some potential problems for consumers in the MAeHC pilot programs. For example, she has been able to bring more clarity to the confusing intricacies of the “opt-in, opt-out” choices. Through her work, proposed consent forms and prototype patient portal displays have gotten at least an informal level of consumer review and consumer interests in privacy and transparency have been addressed, while more permanent organizational machinery for consumer input takes shape.

### 4 It isn't easy being a pioneer.

As a lone individual working on increasing consumer voice in e-Health, the Consumer Advocate has sometimes found the role a bit lonely. She is not isolated in a literal sense, since she has regular contact with relevant experts nationally and technical professionals in Massachusetts,

gets good support from colleagues at HCFA and from interested consumers, and can report to and call upon HCFA management as needed. But still, much of her work is done away from HCFA headquarters, most of the advocacy issues she deals with are fairly new and very complex, and she lacks people to talk with on a daily basis about “granular-level” task details related to consumer engagement. This has not been a problem in terms of effective work, but more contact and closer ties with other e-Health consumer advocates (especially in-state) would give her welcome peer support. One great benefit of working on current legislation related to e-Health is that it has brought the Consumer Advocate into more contact with the AIDS Action Committee and the ACLU of Massachusetts, with their intersecting concerns about patient privacy and healthcare quality. The problem is, though, aside from this kind of specific focus, there are not many local organizations working on e-Health issues from the consumer perspective. Hopefully, this will change.

**5 While privacy of electronic records is an obvious and significant concern, many consumers are interested in e-Health primarily for its positive potential to improve quality of care, promote transparency, empower the patient, and facilitate public reporting by hospitals.**

The quality benefits of e-Health seem to be uppermost for many consumers. Even the advocate for the AIDS Action Committee, an organization with serious privacy concerns, is open to the idea of thoughtfully implemented e-Health systems because they hold promise to empower patients and improve quality of care through better coordinated treatment.

**6 The consumer voice may need to be cultivated separately for different issues.**

For example, the consumers recruited to the Consumer Health Quality Council specifically to work on patient safety issues are not necessarily going to be appropriate for contributing a consumer perspective to e-Health – or vice versa. The Consumer Health Quality Council has offered to serve as a focus group for e-Health and welcomes knowing more about QCQC’s e-Health component, but already has its “advocacy plate” more than full. It seems likely that the CHQC and the growing e-Health Consumer Network will tap different consumer populations, coordinating their work but not overlapping directly in terms of membership.

**7 Consumer interest in e-Health is certain to grow.**

QCQC’s Year 1 experience suggests that once consumers become aware of e-Health’s potential benefits and threats, they are very interested in learning more and developing an active consumer voice in this technology. For most people, e-Health is not yet a burning issue, but as more e-Health systems become operative, consumers will want to engage with this new technology. This will go much more smoothly if a place for consumers has been built in from the start.

## E-Health, Year 1: Upcoming Challenges

At least five challenges can be expected for QCQC's e-Health consumer advocacy in the coming year:

### **Challenge #1: How will the consumer voice fare in the midst of power struggles among other stakeholders?**

While they have some common interests in e-Health, major healthcare stakeholders – hospitals, insurers, and medical providers – also have some seriously divergent interests at stake with enormous financial implications. In particular, the distribution of system expenses is currently in heavy negotiation. As these power players' competing interests are fought out, the still-fledgling consumer voice being built through QCQC may not yet be strong enough to compel a hearing. It could get lost in the shuffle, even though consumer concerns such as “e-trust” will be critical to e-Health's ultimate success.

### **Challenge #2: e-Health experimentation in Massachusetts could lose some of its momentum.**

Blue Cross Blue Shield's funding for the three MAeHC community pilot projects will expire in December 2008, possibly before the e-Health systems being developed through them are fully operative and self-sustaining. Pending state legislation (the previously described cost-containment bill) could potentially solve this problem and also extend e-Health more broadly; the bill mandates statewide adoption of electronic medical records by 2015 and calls for \$25 million per year in public money to support EMR adoption. However, this legislation has not yet passed.

On a more positive note, in February 2008, Blue Cross Blue Shield of Massachusetts announced a plan revising the threshold for participating in its quality and incentive

program, which has so far paid out \$104 million in extra payments to 64 hospitals that have implemented improvements in quality or technology. Starting in 2012, participating hospitals will be required to install and use computerized physician order entry systems in order to receive the incentive payments. The announcement follows release of a shocking study<sup>51</sup> of six Massachusetts community hospitals showing that one in every ten patients admitted suffered serious and avoidable medication mistakes, including severe allergic reactions or dangerous drug interactions – mistakes that could largely be prevented by CPOE systems. While noting that up-front costs are high (roughly \$2.5 million), the researchers recommend that CPOE be adopted in every hospital in the state. Help may become available from state government, possibly through an existing Essential Community Provider Trust Fund which typically has about \$40 million per year.

### **Challenge #3: In the short run, the net savings from e-Health may be smaller than anticipated.**

In the long run, e-Health may turn out to be the cost containment solution that everyone is hoping for, but the up-front development and implementation costs could turn out to be larger than anticipated, and/or the immediate savings may be smaller.

### **Challenge #4: In the enthusiasm for e-Health as a cost-containment measure, its potential to improve the quality of care may or may not get adequately developed.**

Some aspects of e-Health are weighted heavily toward efficiency of treatment, data-storage and billing, hopefully saving time and lowering costs for hospitals, medical providers, and health plans. Other aspects speak more directly

<sup>51</sup> See Patricia Wen, “Insurer urges computerized prescriptions at hospitals,” *Boston Globe*, February 15, 2008. The study was carried out by Dr. David Bates of Brigham and Women's Hospital.

to quality of care. Most e-Health systems have the potential to accomplish cost savings and quality improvements simultaneously. However, the combination will not happen automatically. Exactly what kind of emphasis will be put on the quality end of things is a matter for negotiation, and a big reason why a consumer voice in e-Health is so important.

Consumer input is particularly needed to focus attention on health disparities. An estimated 60 million adult Americans do not use computers, and could find themselves left behind by a system that assumes computer literacy. As noted in a 2007 Issue Brief from the Massachusetts Health Policy Forum,<sup>52</sup> “health care disparities can be exacerbated by disparities in HIT [health information technology] adoption among providers, and members of vulnerable populations may not reap the benefits of interconnected health information exchange.”

**Challenge #5: In the push to implement e-Health as quickly as possible, technological decisions might dictate system policies, leaving important consumer concerns out of the mix.**

The rush to implement electronic health records before policies are carefully and clearly developed – especially the policies so important to consumers around privacy, security, transparency, consent, access, control, audits, and remedies and sanctions for breaches – could have a severe and negative impact on their ultimate adoption and usefulness.

A guide provided by the organization Connecting for Health, titled “The Common Framework: Overview and Principles,” emphasizes the “necessity of addressing critical policy and technical questions in parallel and considering both from the outset.” This document goes on to say:

If we are to share health information in a way that is trusted and effective, the policies that establish who has access to health information, what uses of information are acceptable, the extent to which patients can give or withhold access to their information, and the design of privacy and security safeguards must all be crafted in parallel with the design and deployment of the technology. And the technology choices themselves must incorporate policy objectives that protect patients and our society’s values.<sup>53</sup>

<sup>52</sup> Massachusetts Health Policy Forum Issue Brief No. 34 (2007) prepared by Susan Feinman Houghton and Michael T. Doonan, titled “*Health Information Technology in Massachusetts: A Public/Private Partnership? What Should the State’s Role Be in Facilitating Health IT Adoption?*” The forum is a collaboration of the Massachusetts Health Policy Forum and the Massachusetts Health Data Consortium.

<sup>53</sup> Connecting for Health, *The Common Framework: Overview and Principles*, p.2. Available at <http://www.connectingforhealth.org/commonframework/#guide>

## Part 5

# Implications for Program Sponsors

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## The Longer View

One of the values of formative evaluation is that it can yield ideas and insights useful to funders for planning and managing related initiatives in the future – an especially important point for the Robert Wood Johnson Foundation’s Quality Coverage and Quality Care Initiative (QCQC), because additional health reform advocacy initiatives are already underway or taking shape. Earlier sections of this Interim Report have offered lessons related to specific activities used by the QCQC initiative’s grantee organization, Health Care For All (HCFA), to strengthen the consumer voice in quality coverage and quality care during Year 1. The present section, Part 5,

summarizes some thoughts about what the QCQC initiative’s Year 1 experience means for program sponsors.

Some of these ideas, while not exactly new, are important to note because they reinforce lessons learned through previous Foundation initiatives. Others, less familiar, are offered here as food for thought. Judging from Year 1’s experience, the list of implications for program sponsors is certain to be refined and expanded during the QCQC project’s remaining two years.

## Interconnections and Synergies

The QCQC initiative represents only a part (albeit a pivotal one) of a huge, long-term effort to improve multiple aspects of U.S. health and health care simultaneously, in multiple states and ultimately on a national scale, with ideas and funding coming from multiple independent sources. Since so many elements of this overall effort turn out to be interrelated in the field, concepts of *context*, *synergy*, and *coordination* are becoming more and more important.

The added value of synergy has been very evident in the QCQC initiative. The project’s three separate advocacy targets – expanding affordable quality coverage, improving quality of care and patient safety, and developing e-Health systems responsive to consumer needs – have been presented separately in this report for the sake of clarity. However, they have not been separate in terms of their actual operation. While each area has its own specific issues, advocacy concerns and distinct ways of involving consumers, *the three different*

*focal points have each benefited greatly by being combined in one grant.* For example:

- **Because of the combination, HCFA has been better able to take advantage of various explicit and/or potential links among the three areas in Massachusetts’ health reform legislation and its implementation machinery.** Expanded coverage was the first priority in Massachusetts’ health reform, but from the start, Chapter 58 contained provisions related to healthcare quality as well as coverage. By working on several fronts simultaneously, HCFA has been able to highlight these interconnections, defining consumer interests broadly so as (in the words of HCFA’s blog) “not to trade off affordability or quality to obtain access.” Policy-makers themselves are increasingly working in terms of linkage, seeing quality improvements and e-Health systems as ways to reduce health reform’s overall cost burden and thereby keep the plan’s initial coverage



goals viable. HCFA has supported this more integrated perspective by offering plans for reducing costs<sup>54</sup> that tie various consumer interests together and balance the pressures bearing down on policy makers.

- **By working on coverage, quality, and e-Health at the same time, QCQC staff in all three areas are able to utilize the same strong advocacy resources at HCFA,** tapping into the organization’s relevant relationships and networks, diverse staff skills, accumulated policy experience, up-to-date research, communications support, grant management and development support, etc. Both through formal strategy sessions and informal staff interactions, the organizational culture at HCFA encourages sharing and blending these resources rather than keeping each issue area independent as a separate “silo.” The resulting cross-communications and idea exchanges have tended to spark creativity, solve problems and seize emerging opportunities quickly, keep staff morale high, and use organizational resources more efficiently.
- **In terms of public visibility and political clout, HCFA’s position as a consumer advocacy organization has been further strengthened by working on all three areas simultaneously.** As HCFA becomes known as the “go-to” organization in one area, the momentum spills over and the overall effort commands increasing attention and respect in the other areas as well. Conversely, if setbacks are suffered in one area, ongoing activities in the others keep HCFA’s reputation and effectiveness as a consumer advocacy organization from being diminished.

Of course, *complexity does not automatically result in positive synergy*. There are some possible problems with packaging different health reform issues together in a single consumer advocacy funding initiative:

- **Interconnecting different facets of health care reform requires an extremely experienced, well-staffed and politically savvy advocacy organization.** Each of the three areas included in QCQC is sufficiently complicated that it could well be the exclusive focus of a funding initiative, if a grantee organization has less extensive experience. Thus HCFA’s success in integrating coverage and quality issues, plus e-Health, may not be easy to replicate.
- **Having multiple advocacy goals necessarily involves competition for certain organizational resources** – in particular, attention of top management in terms of strategy-setting and consultation, and the focus of overall organizational effort if critical opportunities for policy influence occur at the same time in different issue areas. HCFA did not experience this as a problem in Year 1, but may need to rely on greater decentralization and division of labor in future years if the three separate areas each grow more active and internally complex.

<sup>54</sup> See HCFA’s document “A Consumer-Driven Health Care Cost Control Agenda for Massachusetts: 17 Legislative Proposals,” March 2007, researched and written by Norbert Goldfield, Marcia Hams, John McDonough, Michael Miller, and Brian Rosman.

## Five Familiar Ideas, Confirmed and Reinforced

Certain general lessons from QCQC's Year 1 experience echo the conclusions of other evaluations, but are worth noting here because of their importance.

- **Legislation is just a starting point for consumer advocacy in health care reform.** A central conclusion of Community Catalyst's evaluation of Massachusetts' health reform after 18 months of operation was that "campaigns do not end with enactment [of legislation]; implementation is just as important."<sup>55</sup> The present evaluation confirms this idea and further reinforces the need for *continuous monitoring and followup by consumer advocates* after the passage of a law, possibly over many years. In complex legislation like health reform, many details affecting consumers will necessarily be left to the implementation stage, and new issues will arise that were never anticipated. Without ongoing consumer advocacy, the original intent of legislation could easily be undermined. Thus health reform policy should be thought of not only in terms of the goals laid out in the original legislation, but also in terms of what ultimately comes out of the implementation process – the de facto policy that operates in the real world after all the elaborations, adaptations, and compromises have taken effect.
- **Consumer advocacy and system change initiatives require sustained support.** Many evaluations dealing with health policy have reached this conclusion. While milestones may be apparent sooner, making real headway on system-change goals seems to require at least three years, and considerably longer if advocacy networks and organizational infrastructure must be built from scratch. Thus, for advocacy initiatives aimed at system change (as opposed to bounded demonstration projects that test the effectiveness of specific interventions), donors need to plan for *relatively long funding periods and possibly renewal grants* that build on initial results. In particular, projects that involve new computer systems and software are likely to be "front loaded" – that is, they require large up-front investments of time, effort, and financial support before their value can be assessed – and this reality needs to be taken into account when funding and evaluating such projects.
- **In consumer advocacy and system change efforts, certain factors seem to favor grantees' success.** On this point, the present evaluation again echoes the findings of others:
  - › The grantee organization needs to have a *pre-existing advocacy network*, or the capacity to build one quickly. This seems essential; policy advocacy is not a task for a single organization acting alone.
  - › The policy context needs to offer a realistic "*window of opportunity*" for reform. If political will is lacking or public resources are too strained, the advocacy efforts may simply hit a brick wall even if the advocacy approach is a good one.
  - › The project needs a *strong champion* who can drive the effort, energize the staff, and make sure that critical skill sets are available within the grantee organization or through consultants.
- **Especially in the short run, some of the most important outcomes of an advocacy initiative are indirect ones,** as this and other evaluations confirm. Indirect outcomes include:
  - › **Learning lessons**, especially if immediate results get blocked by the external policy context; and
  - › **Capacity building** (important even for well-established advocacy organizations) in skills and experience, networks, relationships with decision-makers, and the advocacy organization's public visibility. If the external policy context becomes unfavorable, the initiative's original goals may be hard to achieve but it could still be useful to aim at capacity building, so as to be ready when context changes.
- **Personal stories are a powerful way to capture attention and illustrate a system problem.** The present evaluation once again confirms the value of this approach for working with legislators and state administrators. Stories are also a useful vehicle for public education and for working with the press, especially when coordinated by project staff with expertise in communications.

<sup>55</sup> Community Catalyst, "Revisiting Massachusetts Health Reform: 18 Months Later," December 2007, p. 2.

## Nine Less Familiar Ideas, as Food for Thought

QCQC's Year 1 experience has also yielded some less familiar lessons that could be useful for related Foundation initiatives:

- **There are different types of consumer engagement, each with its own strengths and limitations.** Although they can of course be used in combination, each type fits a different advocacy situation. At least four different approaches are being used concurrently by HCFA:
  - *Representative consumer participation*, as in ACT!!, where engagement is channeled through a coalition of organizations representing consumers. This approach has the advantage of efficiency. It allows rapid action suited to the pace of policy implementation after a law has been passed, where timing may be critical and delay could mean missing opportunities for influence.
  - *Direct consumer participation*, as, for example, in HCFA's Consumer Health Quality Council. This approach is less efficient and can take unpredictable turns, but has the advantage of authenticity, credibility, drama, and moral force. Direct consumer voice may be especially appropriate where the advocacy goal is to put a human face on a problem that has not yet received adequate policy attention, making policy makers and the public more aware and informed about the need for action.
  - *A consumer advocate* may be most appropriate in areas like e-Health, where the service is still largely hypothetical, consumers as yet have little experience with it, and not much pressure for "voice" has been evident from consumers. Once e-Health becomes more established, consumers may become more directly involved – but in the meantime, the advocate can protect consumer interests and build organizational machinery for including consumer voice when the time comes.
- *Open-ended, self-initiated consumer input* through publicly accessible mechanisms (for example, HCFA's HelpLine and blog) opens the door to surprises and allows unanticipated consumer concerns to be heard.
 

*Recommendation: Program sponsors should define "consumer voice" broadly, so grantees can choose consumer engagement approaches that match the external context.*
- **Because advocacy initiatives involve "constructive opportunism" (that is, they must adapt to unforeseen circumstances and opportunities as they arise), the design needs to be flexible.** If economic, political, or policy circumstances change drastically during the funding period, the original project plan may need quick revision.
 

*Recommendation: Program sponsors should be prepared to work supportively with their advocacy grantees if significant revisions are needed in the original project designs and strategies during a grant period.*
- **Conceptual models can be very helpful, if applied with a light touch.** For example, QCQC's effective strategizing was greatly aided by three particular theoretical models: Brian Frederking's contrast of the political conversation versus the political game; John Kingdon's ideas about "windows of opportunity"; and Deborah Stone's ideas on "discourse theory." Much of HCFA's advocacy work is implicitly guided by the principles of negotiation laid out in *Getting to Yes*, by Fisher and Ury from the Harvard Negotiation Project. HCFA's conscious matching of different advocacy strategies to different policy contexts owes much to theorists who have written on this subject, such as Jack Rothman and Roland Warren. See *Appendix #8* for relevant references and brief summaries of some of these ideas.

*Recommendation: It would probably be counterproductive to impose conceptual models on grantees in a rigid way. However, if grantees are receptive and interested, it might be useful to bring some relevant theoretical ideas about advocacy practice to their attention through workshops or other technical assistance.*

- **Major system change is a balancing act** in which short-term and long-term goals can lead in opposite directions and various worthy but conflicting objectives need to be reconciled. As a HCFA spokesperson put it, “There is an urgent need in Massachusetts [not only to achieve quality affordable coverage and quality care, but also] to control healthcare costs, to sustain healthcare reform, and to avoid croaking the overall economy.”<sup>56</sup>

*Recommendation: Advocacy initiatives should be designed and managed with the big picture in mind. The need for balance is easy to lose sight of in the push to achieve immediate gains in health care access, so program sponsors should assist grantees to avoid developing blind spots.*

- **Information technology is not only a target for consumer advocacy, but also a very useful tool for the advocacy effort itself.** In carrying out work for QCQC, HCFA has made excellent use of the internet’s communication capacities. The scale and complexity of the effort would simply not be possible without *A Healthy Blog* to organize information and provide convenient electronic links to other resources; *e-mail networks* that allow quick and efficient action alerts and calendar reminders; and the *electronic newsletters* that offer updated information on each of the various advocacy focal points along with a searchable archive of past newsletter issues. As the public face of the organization, the *HCFA webpage* is inviting, easy to navigate, and professional in appearance. It connects conveniently with HCFA’s consumer services and numerous other resources including *specialized*

*webpages for ACT!! and the Consumer Health Quality Council* (both with their own attractive logos and well-designed formats) and a *link to the e-Health Consumer Network*. In terms of graphics, a wide audience has tapped into the Consumer Health Quality Council’s storytelling videos not only through the webpage but also through *youtube.com*. These varied electronic communication media not only spread information efficiently, but also create a sense of momentum and buzz, and a feeling that the organization is up-to-date on new technology. The fact that the different electronic media overlap a bit is a plus, since periodic e-mails remind the audience to check the blog and newsletters, the blog puts other information in perspective, and a message missed in one place may be noticed in some other format.

*Recommendation: Because electronic media are so extraordinarily useful and efficient, program sponsors should encourage grantees engaged in advocacy initiatives to make maximum use of such technology. Technical assistance for this should be built into a grant initiative if necessary.*

- **Communication and idea sharing within broader advocacy networks has a large multiplier effect.** The QCQC initiative is closely related to several other RWJF initiatives and also to the work of various national consumer advocacy networks such as Community Catalyst, Families USA, Consumers Union, and the National Partnership for Women and Families. Some links have already developed through conference presentations, consultations, mutual exchange of staff as invited speakers, and informal collegial friendships. These connections are felt by all parties to be tremendously useful, and could potentially move toward even more explicit and regular collaboration.

*Recommendation: RWJF should increase even further its present efforts to promote (1) grantee interaction with national advocacy organizations and (2) idea-sharing*

<sup>56</sup> Jeffrey Krasner, “Mass group links drug costs, marketing,” *Boston Globe*, January 17 2008.

*among grantees with related goals. Ways of doing this might include:*

- › Additional encouragement and increased travel funding for grantee staff to participate in conferences and/or to visit each other's field sites.
- › Support for a web-based resource clearinghouse where grantees could share model legislation, public education tools, etc., related to health coverage, quality care, and e-Health.
- › Supplying grantees with relevant contact lists and making introductions to get informal contacts started among grantees and with outside experts.
- › Proactively acquainting grantees with Foundation web resources they might not know about, such as relevant webinars and news alerts.
- › Providing a technical assistance consultant (sort of a TA ombudsman) to act as a liaison among the various Foundation initiatives related to health reform and consumer voice, poking around to discover ways that grantees in different projects and/or project sites might be able to help each other.
- › Consolidating the lessons being learned about consumer voice in health reform through various RWJF initiatives, perhaps as part of the Foundation's Synthesis Project.
- **The QCQC work being directly funded by RWJF is closely intertwined with complementary work being funded by other donors.** To review a few previously discussed examples, while the HCFA HelpLine is critically important to QCQC's coverage goals, it is not funded by RWJF; its support comes, rather precariously, from overhead related to grants from the Boston Foundation and other donors. In the quality care arena, the advocacy work of QCQC's Consumer Health Quality Council benefits

indirectly from a quality-of-care public education effort sponsored by a local coalition called the Partnership for Health Care Excellence, funded primarily by a \$1 million grant from Blue Cross Blue Shield of Massachusetts. Much of the work being done by QCQC's e-Health Consumer Advocate is harnessed to three community-based e-Health pilot projects established not through RWJF's QCQC grant, but rather through a \$50 million grant from Blue Cross Blue Shield of Massachusetts, awarded not to HCFA but to another nonprofit organization (the Massachusetts e-Health Collaborative). Basically, QCQC is embedded in a sea of related projects with a variety of different sponsors. As a stand-alone project without these interconnections, the RWJF initiative might not have been able to reach its present level of success.

*Recommendation: Especially in the case of very large social change efforts, program sponsors could take advantage of synergistic effects on a higher level by consciously coordinating their own funding with projects being funded by other donors. Foundations already sometimes engage in collaborative funding efforts or plan complementary grants with other funding sources. This direction should be encouraged for health reform advocacy initiatives.*

- **A reality of current health reform advocacy is that the cost containment problem may lead to very tough politics** if powerful stakeholders such as business groups, insurers, and the pharmaceutical industry see their financial interests threatened. In turn, this could lead some health reform advocates into more militant territory in terms of advocacy tactics, raising questions if they are operating with foundation funding. A great deal of confusion exists about exactly what kinds of advocacy activity can be funded by nonprofit program sponsors without violating IRS requirements for tax exemption. The Alliance for Justice (a coalition formed to examine this problem) points out that the tendency has been for both sponsors and grantees to err on the side of caution, with the result that some

perfectly permissible activities are considered taboo and unnecessarily avoided. For example, the Alliance's analysis of IRS policy and recent IRS court cases shows that direct lobbying activities by grantees can be supported by foundation grants with no problem, as long as they meet certain criteria. The Alliance has produced a number of informational resources on the subject (*see Appendix #5*), including an exhaustive reference book for foundations that details exactly how a grant's letter of agreement should be worded for maximum flexibility and what type of nonprofit registration by grantees is most advantageous. Program sponsors need to be well informed about these boundaries, so they can stand behind their grantees and put them more at ease, especially if the politics of health reform start to turn ugly.

*Recommendation: Program sponsors should be proactive in dispelling entrenched but erroneous beliefs that make everyone excessively cautious about the permissible boundaries in funded advocacy initiatives. Sponsors could, for example, hold grantee workshops on advocacy issues early in a funding period; provide technical assistance supported by legal expertise for grantees with*

*specific questions about advocacy limits; and make sure that advice on the subject from all foundation personnel is consistent and up to date.*

- **System transparency has two dimensions – public reporting and consumers' ability to make meaningful use of the information. The first dimension by itself, without the second, will not accomplish true transparency.** While better public reporting is essential and represents a logical immediate goal for consumer empowerment, it should not become an end in itself. Just as advocacy for passing health reform legislation needs to be continued into the implementation process, advocacy for greater system transparency needs to be reinforced with additional advocacy effort to help consumers access and use the information in ways that actually make a difference.

*Recommendation: Grants aimed at increasing transparency (public reporting and disclosure) in healthcare systems should include support for strengthening consumers' ability to access, understand, and make use of the information.*

## Preliminary Conclusions: The QCQC Initiative's First-Year Bottom Line

As detailed in this report, at the end of Year 1 HCFA can show substantial progress on all of the project objectives explicitly stated for QCQC.<sup>57</sup> The year has seen remarkable success in monitoring the implementation of Chapter 58; enrolling eligible individuals and families into appropriate coverage; educating the public and policy makers about both Chapter 58 implementation and the need for improvements in quality of care; developing a sophisticated consumer-driven patient safety and quality improvement agenda; encouraging administrative and legislative actions to address consumer concerns about coverage and quality issues; introducing a strong consumer voice into key Massachusetts quality councils and other fora; and ensuring that e-Health initiatives take consumer interests into account.

Year 1's most impressive results, however, go beyond these originally stated objectives. The QCQC initiative seems to have had two important kinds of long-term impact on policy makers.

**First, QCQC has succeeded in heightening awareness among Massachusetts decision makers, both inside and outside of government, about the magnitude and nature of the interconnected problems that consumers actually experience in terms of quality, coverage, and affordability of health care.**

Of course, the fact that consumers have healthcare problems is not exactly new information for policy makers in a state that has been working toward health reform for over two decades. But the consumer engagement activities that HCFA has nurtured through the ACT!! coalition, the Consumer Health Quality Council and the work of the e-Health Consumer Advocate have added a level of detail, groundedness and credibility that was previously missing. Through QCQC,

*decision makers have gotten a reality check* on the current situation. For example, the Connector Board's initial assumptions about insurance affordability were challenged by detailed household budgets supplied by consumers; subsequently, changes were made in the affordability schedule. Legislators' complacency about medical errors was shaken by videotapes and live testimony at public hearings from real people who had suffered horrific breakdowns in the quality of care; subsequently, aspects of the consumers' quality agenda have been incorporated into a pending legislative bill with powerful sponsors. E-Health technical experts were persistently reminded that consumers will need to trust electronic medical records in order for e-Health to work; subsequently, the technical expert designing EMR systems for some of the e-Health pilot projects has met repeatedly with consumers to learn more about their concerns. Without the consumer input provided through the QCQC initiative, Massachusetts' coverage and quality reforms would in all probability still be guided mainly by untested assumptions about consumer interests, rather than by what consumers say themselves.

**Second, on a more general level, QCQC has succeeded in increasing decision makers' overall respect for and receptivity to consumer voice in policy discussions of health reform and quality improvement.**

Throughout Year 1, the contributions made by consumers working through QCQC have been noticeably sophisticated. Their strategies have been carefully considered in advance. Their legislative testimony and media interviews have been detailed, well informed, constructive, and focused. Their educational products, such as the Consumer Health Quality Council's videos, are not only compelling but also technically well executed. Their behavior at public events has been

<sup>57</sup> The project objectives are listed on page 4 of this report.

determined but always polite, even at tension-filled events such as the Connector Board's April meeting on allowable increases in health plans' premiums and co-pays.

As a result, key policy makers seem to be increasingly viewing consumer input in a somewhat new light – not only as a symbolically important process, but also as a source of genuinely useful ideas and information that needs to be taken seriously for planning purposes. This viewpoint has been evident<sup>58</sup> in the demeanor of state officials at this spring's various public hearings and in their attendance and presentations at HCFA's annual policy and organizing conference and other recent public events. A general mindset more receptive to consumer voice seems to be taking hold, in ways that auger well for the future.

This promising development is a direct consequence of *QCQC's partnership between concerned consumers and an experienced consumer advocacy organization*. The consumers working with HCFA have strong feelings and many relevant skills, and they could have exerted some kind of presence

on their own. But both they and HCFA's staff are quick to acknowledge that without the resources and technical assistance of HCFA, the consumers would not have been able to make such an organized, targeted, well-prepared policy contribution. Their voices might have been raised, but would have been much less likely to be really heard.

Thus QCQC ends Year 1 on a high note, with the hoped-for "smart, focused consumer voice" taking shape effectively and some early signs emerging that the initiative is already having real impact on policy decisions. At the same time, economic storm clouds are gathering and political events at both the state and national level could drastically alter the initiative's policy environment. The challenges described in this report loom ominously not only over QCQC but over the entire Massachusetts health reform effort. The evaluation's second Interim Report, forthcoming in spring of 2009, will examine how HCFA deals with these challenges during Year 2 of the RWJF funding period and what the QCQC initiative is able to accomplish in what may be a rapidly changing policy context.

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<sup>58</sup> Based on the impressions of HCFA staff and consumers, plus direct observation by the evaluator.



## Attachment Section

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# Health Care For All: Mission Statement

## *Who we are, what we believe in*

HCFA seeks to create a consumer-centered health care system that provides comprehensive, affordable, accessible, culturally competent, high quality care and consumer education for everyone, especially the most vulnerable. We work to achieve this as leaders in public policy, advocacy, education and service to consumers in Massachusetts.

## **Core Values**

We bring social justice values into the health care system. Our methods and philosophy can be applied to other social inequities as well. Our social change philosophy is best expressed by our Core Values, adopted by our Board of Directors in 2007:

- **Collaboration and Community:** We value community building and collaboration among our staff, board of directors, partners, and consumers as our source of strength and as our key to positive change.
- **Consumer Voice:** We supply strategies and tools to empower the consumer voice in the work of improving the health care system for everyone.
- **Diversity:** We value acceptance of and respect for each individual and community and strive to achieve representation of the communities we serve in our staff, board and coalitions.
- **Education and Awareness:** We value educating consumers about their rights and options in the health care system so they can access the resources they need.
- **Equity:** We believe health care should be a basic human right for everyone.
- **Inclusiveness:** We value participation from our directors, staff, outside partners, and communities in our work.
- **Quality of Work Life:** We value a work environment that is enjoyable, respectful, safe, inclusive, family-friendly, work/life balanced, and supportive for all staff.
- **Transparency:** To build trust among all stakeholders, we believe everyone should have fair and equitable access to information and processes about all aspects of the health system, including our own work.

# The Robert Wood Johnson Foundation's Website Description Of The "Massachusetts Quality Coverage And Quality Care Initiative"

*Ensuring the consumer voice in coverage and quality in Massachusetts*

**Grant Details:**

\$1,500,000, (awarded on Jan 31, 2007, starting Feb 15, 2007 ending Feb 14, 2010) ID# 58234

**Grantee:**

Health Care for All Inc.  
30 Winter Street, #1010  
Boston, MA 02108-4720  
(617) 350-7279

**Summary:**

Coverage and quality are interconnected problems in health care policy, and yet health care policy improvement efforts often pursue quality or coverage but rarely both together, as though they were isolated problems. In April 2006, Massachusetts passed landmark health reform legislation (Chapter 58 of the Acts of 2006) aimed at achieving near universal coverage which importantly recognizes the complementary role that quality plays in improving health care for citizens in Massachusetts. In July 2006, the Foundation made a six-month grant to Health Care for All, a leading health care advocacy group in Massachusetts, to capitalize on this opportunity and support effective engagement of consumers in coverage and quality issues in Massachusetts' health care reform implementation efforts. The second phase of this collaborative project will support a continuation of the activities begun under the first phase. This project fits with RWJF's Quality/Equality and Coverage strategic interests. Engaging consumers in demanding better quality from their health care system is relevant to the strategic objective of the recently revised Quality/Equality effort. It is also consistent with the Coverage effort to support state-based advocacy that will promote stable and affordable coverage for all. This project presents the Foundation with a unique opportunity to address two of its priority areas which are typically tackled independently and to learn how to coordinate its quality and coverage related work better. Project deliverables will include: enrollment of newly eligible individuals and families into appropriate coverage; educational materials about Chapter 58 implementation for the public and policy makers in Massachusetts and nationally; a Massachusetts' consumer-driven patient safety and improvement agenda; educational materials to teach consumers about quality improvement in Massachusetts; the addition of a consumer voice in key Massachusetts quality councils and other fora; and recommendations to ensure e-Health initiatives account for consumer interests.

# Telephone Interview Guide Used in Year 1's Evaluation of The Massachusetts Quality Coverage and Quality Care Initiative

## *Agenda for Monthly Phone Discussions*

1. Update on your part of HCFA's work for the RWJF project, since we last talked.
2. Your current thoughts on any special successes, challenges, surprises or concerns related to HCFA's work on this project.
3. Your current thoughts on consumer engagement issues related to the project.
4. Plans for the next steps in your part of the project.
5. Alerts – upcoming meetings, events, relevant documents, references, and contacts related to the project.
6. Anything else you think is relevant to understanding HCFA's consumer engagement work and general circumstances.

## Organizations Participating in the Act!! Coalition (as of March 2008)

### About ACT!!!

The ACT!! Campaign is backed by an ever-growing, broad coalition of consumers, patients, community organizations, religious organizations, businesses, labor unions, doctors, hospitals, health plans, and community health centers.

The ACT!! Coalition includes community and religious organizations, labor unions, doctors, hospitals, community health centers, public health advocates and consumers. The ACT!! Coalition is committed to implementing comprehensive health reform that honors the following five principles:

- MassHealth restoration and expansion
- Cost relief to moderate-income, working families including sliding-scale subsidies for private insurance
- Fair payment rates for doctors, hospitals, and other providers of MassHealth services
- Meaningful employer responsibility
- Fair and sustainable funding

To learn more about the Affordable Care Today!! Coalition, please contact Lindsey Tucker, Coalition Coordinator, at 617.275.2904 or [ltucker@hcfama.org](mailto:ltucker@hcfama.org).

### Coalition Leaders

AARP Massachusetts  
 American Cancer Society  
 American Heart/American Stroke Association  
 Artists Foundation, Inc.  
 Boston Center for Independent Living  
 Boston Medical Center  
 Boston Public Health Commission  
 Cambridge Health Alliance  
 Children's Hospital Boston  
 Children's Health Access Coalition  
 Coalition for Social Justice  
 Community Catalyst  
 Community Partners  
 Episcopal City Mission  
 Families USA  
 Greater Boston Interfaith Organization  
 Health Care For All  
 Health Law Advocates  
 Home Care Alliance of Massachusetts  
 Massachusetts Academy of Family Physicians  
 Massachusetts Building Trades Council  
 Massachusetts Business Leaders for Quality, Affordable Health Care  
 Massachusetts Chapter of the American Academy of Pediatrics

Massachusetts College of Emergency Physicians  
 Massachusetts Communities Action Network  
 Massachusetts Association of Community Health Workers  
 Massachusetts Council of Community Hospitals  
 MIRA Coalition  
 Massachusetts Health Council  
 Massachusetts Hospital Association  
 Massachusetts Law Reform Institute  
 Massachusetts League of Community Health Centers  
 Massachusetts Medical Society  
 Massachusetts NOW  
 Massachusetts Organization for Addiction Recovery  
 Massachusetts Public Health Association  
 Mental Health and Substance Abuse Corporations of Massachusetts  
 National Association of Social Workers, MA Chapter  
 Neighbor to Neighbor  
 Partners for a Healthier Community  
 Partners HealthCare  
 Public Policy Institute  
 SEIU 615  
 1199 SEIU  
 Tobacco Free Mass  
 UMass Memorial Health Care

# Alliance for Justice Materials on Advocacy Funding

## About AFJ

Alliance for Justice is a national association of environmental, civil rights, mental health, women's, childrens, and consumer advocacy organizations. Since its inception in 1979, AFJ has worked to advance the cause of justice for all Americans, strengthen the public interest community's ability to influence public policy, and foster the next generation of advocates.

## Member Organizations

ADA Watch	Lawyers' Committee for Civil Rights Under Law	National Lawyers Guild
AIDS Action	League of Conservation Voters Education Fund	National Legal Aid & Defender Association
Asian American Legal Defense and Education Fund	Legal Aid Society of New York	National Low Income Housing Coalition
Bazon Center for Mental Health Law	Legal Aid Society-Employment Law Center	National Mental Health Association
Business and Professional People for the Public Interest	Legal Momentum	National Partnership for Women and Families
Center for Children's Law and Policy	Mexican American Legal Defense and Educational Fund	National Senior Citizens Law Center
Center for Constitutional Rights	National Abortion and Reproductive Rights Action League (NARAL) Pro-Choice America	National Veterans Legal Services Program
Center for Digital Democracy	National Abortion Federation	National Women's Law Center
Center for Law and Social Policy	National Association of Criminal Defense Lawyers	National Youth Advocacy Coalition
Center for Law in the Public Interest	National Campaign for Sustainable Agriculture	Native American Rights Fund
Center for Reproductive Rights	National Center for Law and Economic Justice	Natural Resources Defense Council
Center for Science in the Public Interest	National Center for Lesbian Rights	New York Lawyers for the Public Interest
Childrens Defense Fund	National Center for Youth Law	One Connecticut
Comprehensive Health Education Foundation	National Center on Poverty Law	Physicians for Human Rights
Conservation Campaign	National Citizens' Coalition for Nursing Home Reform	Planned Parenthood Federation of America
Consumers Union	National Council of Nonprofit Associations	Public Advocates
Disability Rights Education and Defense Fund	National Council for Research on Women	Service Employees International Union
Drug Policy Alliance	National Education Association	Seton Hall Law School Center for Social Justice
Earthjustice Legal Defense Fund	National Employment Lawyers Association	Sierra Club Foundation
Education Law Center	National Family Planning and Reproductive Health Association	States United to Prevent Gun Violence
Equal Rights Advocates	National Immigration Forum	Tides Center
Food Research & Action Center (FRAC)	National Immigration Law Center	University of Pennsylvania Law School Public Service Program
Harmon, Curran, Spielberg & Eisenberg	National Law Center on Homelessness and Poverty	USAction
Human Rights Campaign Foundation		Violence Policy Center
Institute for Public Representation		The Wilderness Society
Justice Policy Institute		Women's Law Project
Juvenile Law Center		
Lambda Legal Defense and Education Fund, Inc.		

### Foundation Advocacy Brochure

*Practice Area: Nonprofit and Foundation Advocacy*  
*ADDED 05/30/07*

### Support Grantees that Lobby, And You Know What Will Happen? Better Public Policy



Publication Year: 2002  
 Length: Brochure  
 Cost: Free of Charge

Give your grantees the green light when it comes to advocacy. Download or order free copies of the Foundation Advocacy Initiative brochure to learn how foundations can support nonprofits that lobby. Not only is funding advocacy legal, it's fundamental to social and economic justice, the environment, the arts, community renewal, public health and safety, and civil rights. We can answer questions foundation boards and staff may have about legally supporting nonprofit public policy work. Click here to check out our brochure which includes testimonials from foundation leaders on supporting advocacy.

### Alliance for Justice Document

(available online at [www.allianceforjustice.org](http://www.allianceforjustice.org))

*Practice Area: Nonprofit and Foundation Advocacy*  
*ADDED 07/09/07*

### Myth v. Fact



Publication Year: 1995  
 Length: 26 pages  
 Cost: \$20

This handbook dispels the myth associated with funding advocacy organizations and offers a full range of advocacy activities that foundations can support.

To Order This Publication Please Fill Out Our Online Order Form.

### Alliance for Justice Document

(available online at [www.allianceforjustice.org](http://www.allianceforjustice.org))

*Practice Area: Nonprofit and Foundation Advocacy*  
*ADDED 06/05/07*

### Investing in Change



Publication Year: 2004  
 Length: 58 Pages  
 Cost: \$40

*Investing in Change: A Funder's Guide to Supporting Advocacy* is an indispensable guide for foundations in explaining the various roles they can play in the advocacy process.

*Investing in Change* can serve as an in-depth guide to navigating the tax code surrounding support of public charities, or a quick reference guide to answer a specific question.

To Purchase This Publication Please Fill Out Our Online Order Form.

This item is available for purchase alone or along with *Build Your Advocacy Grantmaking: Advocacy Evaluation Tool & Advocacy Capacity Assessment Tool*. Click here to purchase them together.

## Typical Action Alerts On The HCFA Blog

*From "A Healthy Blog," 18 March 2008*

### **CALLING HEALTH REFORM SUPPORTERS!**

The next Connector Board meeting is scheduled for Thursday, March 20th at 9am. An agenda has not yet been posted (update: it's here), but we think there are four key votes to be held: the Commonwealth Choice contracts and "Seals of Approval"; the Commonwealth Care contracts; the 2008 Affordability Schedule (a preliminary vote before a public comment period); and the Commonwealth Care co-pays.

We hope the votes on the Affordability Schedule and the Commonwealth Care cost-sharing will be postponed until we go through a broader discussion exploring all options. We should not ask more of Commonwealth Care consumers without also asking more from other stakeholders in the shared responsibility community. We're also waiting for data to understand better how the Affordability Schedule and co-pays are impacting those eligible for and enrolling in Commonwealth Care. Members of the ACT!! Coalition will be attending for the meeting—please join us!

Health Connector Board Meeting

1 Ashburton Place, 21st floor

As we hear more information, we'll post it here.

[Click here](#) to learn more about the Coalition's position.

*From "A Healthy Blog," 22 April 2007*

### **CLICK FOR A BETTER BUDGET**

On Monday the House of Representatives begins its debate on the budget for FY 08.

We have been working with a number of House members on critical amendments to the budget. The amendments restore funds for health reform outreach, improve children's mental health, revive the emergency prescription drug program, and fund several oral health priorities.

Use the links below today to send an email to your representative in support of these vital budget amendments.

1. Outreach and enrollment grants: This year \$3.5 million was distributed to dozens of community-based groups doing hands-on direct outreach and enrollment, and to statewide organizations (including HCFA) to coordinate activities and prepare materials. Our joint outreach website, [www.gethealthcoverage.net](http://www.gethealthcoverage.net) is a fruit of these grants. The funds compliment the top-down advertising from the Connector, by allowing trusted members of the community to provide understandable information that eases the complicated steps involved in signing up for coverage.

The House budget (like the Governor's budget) drastically reduces the grants for next year. An amendment was filed by Representatives Scibak and Kulik, with over 25 cosponsors, to restore this year's funding level. [Click here](#) to let your representative know you support continued funding for outreach and enrollment.



2. Children's Mental Health: The Children's Mental Health campaign is sponsoring comprehensive legislation to improve services for kids. In this budget, they are supporting an amendment filed by Rep. Grant to ensure that "stuck" children in acute, inpatient settings who are ready for discharge have access to the best placement.

The number of children stuck waiting for placement in more appropriate residential, step-down or community-based settings is at an all-time high. This provision will create a fund to move children with behavioral health needs who are in an inpatient facility waiting for discharge to more appropriate residential or community-based settings.

[Click here to send a support message to your representative.](#)

3. Oral Health: The Oral Health Advocacy Task Force and the Oral Health caucus are supporting five amendments to strengthen our commitment to effective oral health. An amendment filed by Representative Coakley-Rivera provides \$500,000 for the second year of the BEST Oral Health Pilot Program which brings education, prevention and treatment services to children under age five. Two amendments concern the Department of Public Health's Office of Oral Health. One, filed by Representative Fagan increases the Office of Oral Health line-item by \$725,000 to strengthen and enhance the work being done by the Office. The second amendment, filed by Representative Scibak, increases the Office's line-item by \$395,000 with these funds earmarked for the Tufts Dental Facilities program which serves children and adults with special needs.

Another amendment also filed by Representative Scibak increases funding for the Loan Repayment Program by \$250,000 to provide loan repayment assistance to newly graduated dentists and hygienists who commit to two years of service in a community health center or public clinic. And finally, an amendment filed by Representative Flanagan creates a \$2 million reserve account to fund a pilot project in Worcester County to study the impact that raising reimbursement rates for dental services provided to adult MassHealth members has on increasing the number of participating MassHealth providers as well as increasing the number of members accessing services.

[Click here to send an email to your representative in support of these amendments.](#)

4. Medicare Part D Safety Net: On December 31, 2006, a law expired that had provided crucial access to prescription drugs for seniors and people with disabilities. The safety net provided a 30-day emergency supply of prescription drugs to MassHealth and Prescription Advantage members who could not get the drugs they needed through Medicare Part D. Until it expired at the end of 2006, over 150 prescriptions were filled every day under the Medicare Part D Safety Net. Today seniors and people with disabilities are at risk of going without these life-saving drugs.

Representative Correia has filed budget amendment that would restore the Medicare Part D Safety Net. [Click here to send a supportive message to your representative.](#)

# “An Act Strengthening Health Reform”

(Proposed by the Act!! Coalition for Legislative Action in 2007-2008)

SENATE, No. 661

By Mr. Montigny, a petition (accompanied by bill, Senate, No. 661) of Mark C. Montigny, John W. Scibak and Richard T. Moore for legislation to strengthen health reform. Health Care Financing.



The Commonwealth of Massachusetts  
In the Year Two Thousand and Seven.

## AN ACT STRENGTHENING HEALTH REFORM

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

SECTION 1. Subsection (8) of section 9A of chapter 118E of the General Laws is hereby amended by adding the following sentence:- Premiums shall not be charged for medical benefits for children in households in which an adult is enrolled in the Commonwealth Care Health Insurance Program established in chapter 118H.

SECTION 2. The second sentence of subsection (4) of section 16C of said chapter 118E, is hereby amended by inserting after the word “level” the following words:- ; provided, that no premiums shall be required of households in which an adult is enrolled in Commonwealth Care Health Insurance Program established in chapter 118H.

SECTION 3. Subsection (d) of section 10F of said chapter 118E is hereby amended by adding the following sentence:- Premium contributions shall not be charged for children in households in which an adult is enrolled in the Commonwealth Care Health Insurance Program established in chapter 118H.

SECTION 4. Section 3 of chapter 118H of the General Laws, as appearing in section 45 of chapter 58 of the Acts of 2006, is hereby amended by adding after subsection (b) the following subsection:-

(c) Insurance plans made available by the program shall include, but not be limited to: (1) inpatient services; (2) outpatient services and preventive care by participating providers; (3) prescription drugs; (4) medically necessary inpatient and outpatient mental health services and substance abuse services; (5) medically necessary dental services, including preventive and restorative procedures; (6) smoking and tobacco use cessation treatment and information benefits, including nicotine replacement therapy, other evidence-based pharmacologic aids to quitting smoking and accompanying counseling by a physician, certified tobacco use cessation counselor or other qualified clinician; and (7) all emergency ambulance calls which result in a transport and all medically-necessary, non-emergency ambulance and wheelchair van trips.

SECTION 5. Subsection (a) of section 6 of chapter 118H of the General Laws, as so appearing, is hereby amended by striking the words: “and (5) medically necessary dental services, including preventive and restorative procedures.” and inserting in place thereof the following:- ; (5) medically necessary dental services,

including preventive and restorative procedures; (6) smoking and tobacco use cessation treatment and information benefits, including nicotine replacement therapy, other evidence-based pharmacologic aids to quitting smoking and accompanying counseling by a physician, certified tobacco use cessation counselor or other qualified clinician; and (7) all emergency ambulance calls which result in a transport and all medically-necessary, non-emergency ambulance and wheelchair van trips.

SECTION 6. Section 108 of chapter 58 of the Acts of 2006 is hereby repealed.

SECTION 7. Chapter 118E of the General Laws is hereby amended by inserting after section 10F the following section:-

Section 10G. The division shall provide coverage for smoking and tobacco use cessation treatment, information, and education, including relevant promotional activities, within its MassHealth-covered services. Smoking and tobacco use cessation treatment and information benefits shall include nicotine replacement therapy, and other evidence-based pharmacologic aids to quitting smoking and accompanying counseling by a physician, dentist, certified tobacco use cessation counselor or other qualified clinician. The executive office shall report annually on the number of enrollees who participate in smoking cessation services, number of enrollees who quit smoking, and Medicaid expenditures tied to tobacco use by Medicaid enrollees. The comptroller shall transfer not less than \$7 million from the Health Care Security Trust, established by Section 1 of Chapter 29D, to the General Fund in each fiscal year to fund this program.

SECTION 8. Chapter 118H of the General Laws, as appearing in section 45 of chapter 58 of the Acts of 2006, as amended by chapter 324 of the Acts of 2006, is hereby amended by striking out section 5 and inserting in place thereof the following section:-

Section 5. Premium assistance payments shall be made under a schedule set annually by the board, in consultation with the office of Medicaid and the health safety net office; provided that this schedule shall be published on or before September 30, starting in 2006. Premium assistance payments shall not be subject to appropriation from the fund, established by section 2000 of chapter 29, and shall be made directly by the connector to eligible health insurance plans, under chapter 176Q. If the board, after a public hearing, determines that amounts in the fund are insufficient to meet the projected costs of enrolling new eligible individuals, the director may impose a cap on enrollment in the program.

SECTION 9. Notwithstanding any general or special law to the contrary, all agencies and instrumentalities of the commonwealth, including, but not limited to the commonwealth health insurance connector authority, the executive office of health and human services and its constituent agencies, the division of insurance and the executive office of administration and finance shall fully cooperate with any independent evaluations of the health reform policies enacted by chapter 58 of the acts of 2006, as amended and implemented, including by providing all available data reports and information relating to the implementation of said chapter 58, including enrollment statistics, cost and spending statistics and raw survey results.

SECTION 10. Section 21 of chapter 118E of the General Laws is hereby amended by adding the following paragraph:-

The division shall assist applicants and recipients to obtain at no cost to said applicant or recipient any verification of citizenship required for purposes of obtaining federal reimbursement for Medicaid expenditures. A U.S. citizen who has not provided verification of citizenship required for a MassHealth determination but who satisfies all other conditions of eligibility for medical benefits, including benefits provided through the Commonwealth Care Health Insurance Program, Uncompensated Care Trust Fund or the Health Safety Net Trust Fund shall not have a determination of eligibility for such benefits denied or delayed so long as the applicant or recipient is making a good faith effort to obtain such verification; an individual who is unable to comply due to a physical or mental incapacity shall be deemed to be making such a good faith effort and the Division shall provide such further assistance as may be necessary to obtain required verifications for such an individual.

SECTION 11. Chapter 46 of the General Laws is hereby amended by inserting after section 19C the following new section:-

Section 19D. The state registrar shall exempt from payment of a fee any person requesting a copy of a birth certificate for the purpose of establishing eligibility for benefits under chapter 118E or chapter 118H, and payments so exempted shall be considered expenses of the executive office in administering said benefits.

SECTION 12. The third sentence of section 2 of chapter 118H of the General Laws, as appearing in section 45 of chapter 58 of the Acts of 2006, is hereby amended by striking out the words, “as determined by the board of the connector” and inserting in place thereof the following words:- as determined by the board of the connector, subject to section 7.

SECTION 13. Chapter 118H of the General Laws, as so appearing, is hereby further amended by adding the following section:-

Section 7. (a) Enrollee premium contributions for the commonwealth care health insurance program shall be subject to the following schedule:

(1) an eligible individual with financial eligibility that exceeds 100 percent of the federal poverty level and does not exceed 150 percent of the federal poverty level shall not pay enrollee premium contributions.

(2) an eligible individual with financial eligibility that exceeds 150 percent of the federal poverty level and does not exceed 200 percent of the federal poverty level shall pay an enrollee premium contribution that does not exceed 1 percent of the household’s income.

(3) an eligible individual with financial eligibility that exceeds 200 percent of the federal poverty level and does not exceed 250 percent of the federal poverty level shall pay an enrollee premium contribution that does not exceed 1.5 percent of the household’s income.

(4) an eligible individual with financial eligibility that exceeds 250 percent of the federal poverty level and does not exceed 300 percent of the federal poverty level shall pay an enrollee premium contribution that does not exceed 2 percent of the households’ income.

(b) Notwithstanding subsection (a),

(1) the connector board may set a single enrollee premium contributions for a range of incomes of not more than 50 percentage points, provided that the enrollee premium contribution does not exceed the level specified in subsection (a) for an individual at the middle point of the range of incomes; and

(2) if a member of a household is enrolled in the commonwealth care health insurance program, the enrollee premium contribution for additional persons in the household shall not exceed 75% of the enrollee premium contribution otherwise applicable to the additional person.

(c) total commonwealth care health insurance program enrollee costs for covered medical services, including, but not limited to, enrollee premium contributions and maximum copayments, shall not exceed a schedule set by the board of the connector, provided that the schedule for individuals who have a gross income that is greater than 100 percent of the federal poverty level to individuals with gross income that does not exceed 300 percent of the federal poverty level shall range from 0 percent to 4 percent of the individual’s income along a graduated scale that increases in increments of the federal poverty level; and provided further, that the total of premium contributions and maximum copayments shall not exceed the level determined affordable pursuant to subsection (q) of section (3) of chapter 176Q.

SECTION 14. Subsection (a) of section 2 of chapter 111M of the General Laws, as appearing in section 12 of chapter 58 of the Acts of 2006, is hereby amended by inserting after the words “established by chapter 176Q” the following:- , in accordance with the requirements of subsection (f).

SECTION 15. Subsection (b) of said section 2 of said chapter 111M of the General Laws, as so appearing, is further amended by striking out clauses subsections (ii) and (iii) of section (b) and inserting in place thereof the following clauses:- (ii) claims an exemption under section 3, (iii) had a certificate issued under section 3 of

chapter 176Q, or (iv) had gross income as shown on the individual's state tax return such that the percentage of said income required to purchase the lowest cost insurance on the market for which an individual would be eligible for creditable coverage, taking into consideration the deductibles, as shown in the schedule created pursuant to subsection (p) of section 3 of chapter 176Q, exceeds the percentage of income which an individual could be expected to contribute towards the purchase of insurance in the report published pursuant to subsection (q) of section 3 of chapter 176Q.

SECTION 16. Said section 2 of chapter 111M of the General Laws, as so appearing, is hereby further amended by inserting after subsection (c) the following subsections:-

(d) For the purposes of subsection (b) only, creditable coverage that begins on January 1, 2008 shall constitute coverage as of the last day of the taxable year of 2007.

(e) All health plans providing creditable coverage shall require all employers with whom they contract for group coverage to have open enrollment periods for coverage effective on July 1, 2007 and on January 1, 2008.

(f) The affordability schedule set by the board of the connector pursuant to subsection (a) shall be subject to the following requirements:

(1) for individuals with gross income up to 100 percent of poverty the affordability schedule for premium contributions shall be 0, and for individuals who have a gross income that is greater than 100 percent of the federal poverty level but does not exceed 400 percent of the federal poverty level, the affordability schedule for all expected enrollee expenditures shall range from 0% to 5% of the individual's income along a graduated scale that increases in 50 percentage point increments of the federal poverty level;

(2) in determining whether creditable coverage is affordable, the board of the connector shall consider expected enrollee expenditures as the 90th percentile of out of pocket costs and premiums for those enrolled in creditable coverage;

(3) For the purposes of this section, "out-of-pocket costs" shall mean the total amount paid by an enrollee to satisfy the applicable annual deductible, co-payments and co-insurance, not including monthly premiums.

SECTION 17. The definition of "Contributing employer" in subsection (a) of section 188 of chapter 149 of the General Laws, as appearing in section 47 of chapter 58 of the Acts of 2006, as amended by chapter 324 of the Acts of 2006, is hereby amended by inserting after the words "the division of health care finance and policy" the following words:- subject to the requirements of this section.

SECTION 18. Said subsection (a) of said section 188 of said chapter 149, as so appearing, is hereby further amended by inserting after the definition of "Employee" the following definition:-

"Fair and Reasonable", an employer will be deemed to make a fair and reasonable employee contribution if more than: (1) 50 percent of the employer's employees enroll in the employer's group health plan; or (2) the employer offers to contribute 50 percent or more of the premium cost of a group health plan offered to employees. Group health plans for purposes of this section shall satisfy the standard for minimum creditable coverage pursuant to chapter 111M. Calculations of the percentage of enrolled employees shall include the pro-rata allocation of part time and seasonal employees.

## Conceptual Frameworks Relevant to Consumer Advocacy

BRIAN FREDERKING, AS ELABORATED BY JOHN McDONOUGH:  
“THE CONVERSATION AND THE GAME”

**PRIMARY SOURCE:** Frederking, Brian. “Teaching Metaphors of Politics to Overcome Students’ Dislike of Politics.” *PS: Political Science & Politics*, June 1997: 157.

**BRIEF SUMMARY ADAPTED FROM:** McDonough, John. *Experiencing Politics: A Legislator’s Stories of Government & Health Care*. Berkeley, CA: University of California Press, 2000, pp. 288-294.

This [i.e., McDonough’s] book’s central premise is that there are compelling concepts, models, and structures that can explain politics in ways accessible and helpful to broad audiences. Once I realized useful models were out there, I became a scavenger for them.... In 1997, I found a pearl in the journal *PS*, published by the American Political Science Association. Professor Brian Frederking of Syracuse University wrote a brief item about how he makes political science more compelling for his students by presenting politics as two contrasting metaphors, the *conversation* and the *game*.... Frederking observes that Americans like and respect political conversations and despise political games.... He suggests that emphasizing the conversational aspects of the process can help to diminish disdain for politics and encourage enhanced participation.

...[I]n the game metaphor, politics is about “them,” others who are detached from real people’s lives. A major challenge for political leaders is to provide multiple opportunities to bring new people into the process, to encourage the uninvolved to participate, and to make politics about “us.” The conversation metaphor helps to do that in a useful and compelling way, by demonstrating that political controversies progress and that there are multiple, meaningful ways to become involved.

But a realistic and seasoned sense of politics leads to the recognition that both dynamics, the conversation and the game, are present at all times. To ignore the conversational aspect of politics is to miss a vital component that usually weighs heavily on the final outcome. At the same time, to ignore the game aspect of politics is to miss another vital aspect that frequently means the difference between success and failure. It is not one or the other. It is both.

JOHN KINGDON: “AN AGENDA SETTING MODEL”

**PRIMARY SOURCE:** Kingdon, John. *Agendas, Alternatives and Public Policies*, 2nd ed. New York: HarperCollins College, 1995.

**BRIEF SUMMARY ADAPTED FROM:** McDonough, John. *Experiencing Politics: A Legislator’s Stories of Government & Health Care*. Berkeley, CA: University of California Press, 2000, pp. 239-240.

According to Kingdon’s model, change can only happen when a “window of opportunity” for that change opens up – no open window, no change. For the window to open, three streams or dynamic processes must be moving at roughly the same time. The first stream is the *problem* stream, the sense

among *those with the power to act* that a legitimate problem exists that deserves to be addressed.... The second stream is the *political* stream, the sense among those with the power to act that the timing for action is right in relation to public sentiment and consistency with other policy objectives.... The third stream is the *policy* stream, the existence of an implementable policy that fits the scope of the problem, is understandable to those who need to understand it, and can attain sufficient support.... When all three streams are flowing at a sufficient pace, the window of opportunity opens, creating the possibility for substantive policy change.

#### DEBORAH STONE: “DISCOURSE THEORY”

**PRIMARY SOURCE:** Stone, Deborah. *Policy Paradox: The Art of Political Decision Making*. New York: Norton, 1997.

**BRIEF SUMMARY ADAPTED FROM:** McDonough, John. *Experiencing Politics: A Legislator’s Stories of Government & Health Care*. Berkeley, CA: University of California Press, 2000, pp. 51-55 and 261.

Deborah Stone... presents a compelling analysis of how we use and misuse words, metaphors, numbers, and other rhetorical devices to create shared meanings to achieve political goals. Sometimes, creative use of these devices enhances understanding and smoothes the path to progress; at other times, they confuse and impede, deliberately or inadvertently (p. 8).

To be effective in politics, it is helpful to be ever conscious of the narrative, of the techniques we all use, consciously or not, in constructing our stories, in making them interesting and convincing, in picking various rhetorical techniques and tools to win over our listeners or readers.... Three techniques are especially useful in political discourse: *metaphor* [figures of speech that suggest a comparison between two objects or concepts that are not literally related], *numbers* [both tools and weapons in politics, never complete unto themselves, always used in a specific context with a political purpose in mind], and *synecdoche* [a rhetorical device whereby a small part of a larger phenomenon or population is used – fairly or not – to represent the whole].

#### JACK ROTHMAN: “THREE MODELS OF COMMUNITY ORGANIZATION PRACTICE”

**PRIMARY SOURCE:** Rothman, Jack. “Three Models of Community Organization Practice,” from the proceedings of the 1968 National Conference on Social Welfare, *Social Work Practice 1968*. New York: Columbia University Press, 1968.

**BRIEF SUMMARY ADAPTED FROM:** Needleman, Carolyn. “Advocacy at the Policy Level: Strategies and Resources,” Appendix F (pp. 253-262) in *Nursing, Health and the Environment: Strengthening the Relationship to Improve the Public’s Health*, edited by Andrew M. Pope, Meta A. Synder, and Lillian H. Mood. Washington, D.C.: Institute of Medicine, National Academy Press, 1995.

One particularly useful framework for conceptualizing advocacy strategies is a model formulated by Jack Rothman during the 1960s, at a time when many health and human service professionals were working with communities in controversial, quasi-political roles. Rothman outlined three very different types of policy advocacy (or “community organization practice”), which he termed *locality development*, *social planning*, and *social action*.

The first of these types, *locality development*, is appropriate where a high degree of consensus exists about a social problem. Here advocacy is a matter of mobilizing slack resources and energizing the interested parties around a common concern.... A professional practicing this kind of advocacy needs skills in organizing, program development, communications and public speaking, coalition building, and mediation. The individuals and communities being helped are seen as clients, and the interactions between service providers and service recipients are warm and process-oriented. The effort is inclusive and cooperative. Any conflicts that arise are settled by empathetic understanding and compromise.

The second type, *social planning*, also presumes considerable consensus on the nature of the problem. This kind of advocacy effort tends to be highly technical.... The effort might well involve high-level interdisciplinary collaboration.... The skills needed emphasize scientific expertise, program planning, and evaluation research. In this kind of effort, those being helped are viewed as end consumers, who need to be consulted and kept informed but not necessarily involved in the technical details. The interactions among planners in this approach are usually task-oriented and somewhat impersonal. If conflicts should arise, they are (in theory) resolved rationally in the public interest, based on the best available expert opinion.

The third type, *social action*, applies to situations with strong disagreement over the nature of the problem, serious interest conflicts among the parties affected, and large power imbalances among different factions with a stake in the issue. Here value-based allegiances come into play, and advocacy activity is likely to be highly partisan, taking on the flavor of a crusade.... In this kind of advocacy, experts come under pressure to take sides and to get actively involved in the tactics of power politics. Those being helped are seen as citizens asserting legitimate rights, and allies in a social justice cause. The effort is passionate, emotional, and often conspiratorial. Conflict is seen as inevitable and warfare metaphors are common.

Rothman's formulation underscores the important idea that policy advocacy can be done in various ways, all legitimate in their own terms.... In almost any... problem, all three advocacy styles are likely to be relevant [and can reinforce each other, although they will likely be used by different advocates].

#### ROLAND WARREN: "TYPOLOGY OF SOCIAL CHANGE STRATEGIES"

**PRIMARY SOURCE:** Warren, Roland. "A Community Model," pp. 9-20; *The Community in America*. Chicago: Rand McNally & Company, 1963.

**BRIEF SUMMARY ADAPTED FROM:** Needleman, Carolyn. "Advocacy at the Policy Level: Strategies and Resources," Appendix F (pp. 253-262) in *Nursing, Health and the Environment: Strengthening the Relationship to Improve the Public's Health*, edited by Andrew M. Pope, Meta A. Synder, and Lillian H. Mood. Washington, D.C.: Institute of Medicine, National Academy Press, 1995.

Another relevant construct is a typology of social change strategies formulated by Roland Warren (1963). He distinguishes among *collaborative* approaches (as in planning and advisory committees) in which citizens and authorities work cooperatively to reach an agreed-upon goal; *campaign* approaches (as in lobbying and public information) in which citizens act singly or collectively to persuade authorities that new problem definitions and solutions are needed; and *contest* strategies



(as in picketing and protest marches) in which citizens organize to force attention to community problems that they feel are being ignored or mishandled by authorities.

ROGER FISHER AND WILLIAM URY:  
“PRINCIPLED NEGOTIATION”

**PRIMARY SOURCE:** Fisher, Roger and Ury, William. *Getting to Yes: Negotiating Agreement Without Giving In*. New York: Penguin Books, 1981.

**Adapted excerpt (pp. xi-xii):**

Everyone negotiates something every day.... People find themselves in a dilemma. They see two ways to negotiate: soft or hard. The soft negotiator wants to avoid personal conflict and so makes concessions readily in order to reach agreement. He wants an amicable resolution; yet he often ends up exploited and feeling bitter. The hard negotiator sees any situation as a contest of wills in which the side that takes the more extreme position and holds out longer fares better. He wants to win; yet he often ends up producing an equally hard response which exhausts him and his resources and harms his relationship with the other side. Other standard negotiating strategies fall between hard and soft, but each involves an attempted trade-off between getting what you want and getting along with people.

There is a third way to negotiate, a way neither hard nor soft, but rather both hard *and* soft. The method of *principled negotiation* developed at the Harvard Negotiation Project is to decide issues on their merits rather than through a haggling process focused on what each side says it will and won't do. It suggests that you look for mutual gains wherever possible, and that where your interests conflict, you should insist that the result be based on some fair standards independent of the will of either side. The method of principled negotiation is hard on the merits, soft on the people. It employs no tricks and no posturing. Principled negotiation shows you how to obtain what you are entitled to and still be decent. It enables you to be fair while protecting you against those who would take advantage of your fairness.

This book is about the method of principled negotiation.... The next four chapters lay out the four principles of the method... [*Separate the people from the problem; focus on interests, not positions; invent options for mutual gain; and insist on using objective criteria*].

MARTIN AND CAROLYN NEEDLEMAN:  
“ADMINISTRATIVE GUERRILLAS” AND “PUBLIC SECRETS”

**PRIMARY SOURCE:** Needleman, Martin L. and Needleman, Carolyn Emerson. *Guerrillas in the Bureaucracy: The Community Planning Experiment in the United States*. New York: John Wiley & Sons, 1974.

**Adapted excerpt (pp. vii, 16, 120, 131-133):**

This [interview-based] study's aim is a simple one: to provide a close look at *community planning programs* in a number of major American cities.... Many of the planners attracted to the community planning programs [established in the early 1970s, largely in response to urban riots] are “antiestablishment” in personal style, liberal-to-radical in their politics, and extremely sensitive to the needs of underdog groups such as the poor, minorities, and community residents fighting industry and highways.... Cynical about the “public interest” concerns espoused by most professional

city planners, they embrace the idea of advocate planning with enthusiasm.... However, since the city government that employs them defines the goals of the community planning program more conservatively, their advocate role is usually covert. They become what might be called *administrative guerrillas*, working undercover for a specific client [their assigned community] rather than the nebulous public interest they profess to serve as public city planners.... [As one planner put it: *“Planners who don’t fight the system get trapped into impossible moral dilemmas. As long as they accept the low level of federal commitment to the cities and try to plan rationally within that framework, they’re forced to act inhumanely. It’s like having one life raft for a hundred drowning people.... That’s why some of us feel we have to go outside the system”*....

One resource they do control [is] information.... It matters little that much information important to the community is nominally public. For most community residents, it might as well be stamped top secret. For instance, notices of public hearings appearing in back pages of the newspapers are not public information if no one sees them or understands how they affect the community. Citizen complaints are out of the question if no one can figure out which of the hundreds of city bureaucrats to complain to. The citizens can hardly apply for services and programs they never heard of, or mount opposition to planned policies they are unaware of. Deadlines will always be missed if no one knows they exist. Such recondite bits of information, which might be called *public secrets*, are just as inaccessible to a community without guidance as the city government’s carefully guarded private secrets. But suppose the community has an insider – like the community planner – who not only understands all this red tape but also has access to information about the city’s activities in the community. Through him, the residents [of disadvantaged communities whose interests are being disregarded] can lay their hands on the weapon of information and attack unwanted city policies at their weakest points.... [The planner] provides a vital service as a supplier of information, equipping the community residents to fight their own battles with the city. As their advocate, he can aid their struggle by delivering not victories, but arms.

## Members of the Expert Advisory Committee for the HCFA Quality Initiative (as of March, 2008)

Jim Conway, Institute for Healthcare Improvement (IHI)

Paul Dreyer, Department of Public Health (DPH)

Susan Edgman-Levitan, Mass General Hospital, John D. Stoeckle Center for  
Primary Care Innovation

Allison Fissel, National Patient Safety Foundation (NPSF)

Larry Gottlieb, Health Dialog Services Corporation

Paula Griswold, MA Coalition for the Prevention of Medical Errors

Linda Kenney, Medically Induced Trauma Support Services (MITSS)

Robert Mandel, Blue Cross Blue Shield of MA

Wendy Parmet, Northeastern University Law School

Barbra Rabson, Massachusetts Health Quality Partners (MHQP)

Nancy Ridley, Department of Public Health (DPH)

Stancel Riley, Board of Registration in Medicine (BORIM)

Julie Rosen, Kenneth B. Schwartz Center

# “An Act Promoting Healthcare Transparency and Consumer-Provider Partnerships”

(PROPOSED BY THE CONSUMER HEALTH QUALITY COUNCIL  
FOR LEGISLATIVE ACTION IN 2007-2008)

**SECTION 1.** Chapter 111 of the General Laws is hereby amended by inserting after Section 53D the following two sections:-

**Section 53E.**

- (a) All hospitals shall establish and convene patient and family advisory councils, referred to in this section as the councils.
- (b) The councils shall be composed of current and former patients and members of their immediate families. The minimum size of a council shall be 7 members. The rules and regulations for the councils shall be established by council members.
- (c) Each hospital shall appoint an employee to serve as a resource to the councils and to coordinate their activities.
- (d) Each hospital shall develop a committee to establish and maintain a council and to empower the council to provide meaningful input into hospital policy and management. The councils shall meet at least 4 times annually. The hospital shall provide a meeting place for the council.

**Section 53F.**

- (a) All hospitals shall establish rapid response teams. Each team shall consist of at least one physician, at least one registered nurse, at least one respiratory therapist, and other specialists as determined necessary by the hospital.
- (b) Rapid response teams shall be specially trained to assess a patient’s condition, stabilize a patient’s condition, assist with communication among the attending medical staff and the patient and family, educate and support medical staff and assist with transfers.
- (c) All Hospitals shall allow any patient, practitioner, family member, or other person present during the care to activate the rapid response team whenever they detect deterioration in the patient’s condition. Such deterioration shall include but not be limited to changes in heart rate, blood pressure, respiratory status, oxygen saturation, arterial blood gases, and mental functioning.

**SECTION 2.** Section 70E of Chapter 111 of the General Laws is hereby amended by inserting after the first paragraph the following paragraphs:-

As used in this section, “adverse event” shall mean injury to a patient resulting from a medical intervention and not from the underlying condition of the patient.

As used in this section, “health care provider” shall mean a person licensed or otherwise authorized under state law to provide health care services, including: a doctor, nurse, physician assistant, nurse practitioner, clinical nurse specialist, certified nurse anesthetist, certified nurse midwife, respiratory therapist, psychologist, certified social worker, registered dietitian or nutrition professional, physical or occupational therapist,

pharmacist, or other individual health care practitioner; and any other health care professional specified in regulations promulgated by the secretary of the executive office of health and human services.

**SECTION 3.** Said section 70E of said chapter 111 is hereby further amended by inserting after the ninth paragraph the following paragraphs:-

A health care provider who reasonably believes that an adverse event has occurred shall report the adverse event to the management of the facility where the event occurred unless the health care provider knows that a report has already been made. The report shall be made immediately or as soon as practicable, but in no event later than 24 hours after the provider's discovery of the adverse event.

Facilities, through a health care provider responsible for the patient's care or through an appropriately trained designee, shall provide notification in person and in writing to a patient affected by an adverse event or their health care proxy within 7 days. If no such proxy exists, notice shall be provided to an available family member. For patients who are under 18 years of age, the parent or guardian shall be notified, except in cases where medical treatment was given with only the consent of the minor patient, in which case only the minor patient shall receive notification unless the minor patient is unresponsive. If the patient or designee can not be notified in person, written notification shall suffice.

This notification shall include a description of the adverse event, the causes or potential causes of the adverse event as understood at that point in time, the consequences or potential consequences of the adverse event, the courses of action to be taken to alleviate the impact or potential impact on the patient's health, and any other information deemed by the facility or health care provider to be pertinent to the patient's health and understanding.

**SECTION 4.** Chapter 111 of the General Laws is hereby amended by inserting after Section 70G the following two sections:-

**Section 70H.**

(a) As used in this section, the following words, unless the context clearly requires otherwise, shall have the following meanings:-

“Department”, the department of public health.

“Hospital”, any institution, however named, whether conducted for charity or for profit, which is advertised, announced, established, or maintained for the purpose of caring for persons admitted thereto for diagnosis, medical, surgical or restorative treatment which is rendered within said institution.

“Hospital-acquired infection”, a localized or systemic condition (1) that results from adverse reaction to the presence of an infectious agent(s) or its toxin(s) and (2) that was not present or incubating at the time of admission to the hospital.

“Secretary”, the secretary of the executive office of health and human services.

(b) Individual hospitals shall collect data on hospital-acquired infection rates for the specific clinical procedures determined by the department by regulation, including, but not limited to the following categories:-

- (1) Surgical site infections;
- (2) Ventilator-associated pneumonia;
- (3) Central line-related bloodstream infections;
- (4) Urinary tract infections; and
- (5) Other categories as provided under subsection (e) of this section.

(c)(1) Hospitals shall submit quarterly reports on their hospital-acquired infection rates to the department. Quarterly reports shall be submitted according to a schedule set forth in regulations adopted by the department. Data in quarterly reports must cover a period ending not earlier than 1 month prior to submission of the report. Quarterly reports shall be made available to the public at each hospital and through the department on its website in a style and format that can be easily understood by the public.

(2) If the hospital is a division or subsidiary of another entity that owns or operates other hospitals or related organizations, the quarterly report shall be for the specific division or subsidiary and not for the other entity.

(d) (1) The statewide infection prevention and control program established in item 4570-1502 of section 2A of chapter 58 of the acts of 2006, and the Betsy Lehman Center for Patient Safety and Medical Error Reduction Expert Panel on Healthcare Associated Infection, referred to in this section as the Expert Panel, shall assist the department in the development of all aspects of the department's methodology for collecting, analyzing, and disclosing the information collected under this section, including collection methods, formatting, and methods and means for release and dissemination.

(2) The department shall disclose the data collection and analysis methodology as well as any public disclosure of hospital-acquired infection rates to the public through its website.

(3) The department and the Expert Panel shall evaluate at least annually the quality and accuracy of hospital information reported under this section and the data collection, analysis, and dissemination methodologies.

(e) The department may, after consultation with the Expert Panel, require hospitals to collect data on hospital-acquired infection rates in categories additional to those set forth in subsection (b).

(f) (1) The department shall annually submit to the joint committees on public health and health care finance and the clerks of the house and senate a report summarizing the hospital quarterly reports and shall publish the annual report on its website. The department may issue quarterly informational bulletins at its discretion, summarizing all or part of the information submitted in the hospital quarterly reports.

(2) All reports issued by the department pursuant to this section shall be risk adjusted, consistent with the recommendations of the Expert Panel.

(3) The annual report shall annually compare the risk-adjusted hospital-acquired infection rates, collected under subsection (c) of this section, for each individual hospital in the state. The department, in consultation with the Expert Panel, shall make this comparison as easy to comprehend as possible for the benefit of health care consumers. The report shall also include an executive summary, written in plain language, that shall include, but not be limited to, a discussion of findings, conclusions, and trends concerning the overall state of hospital-acquired infections in the state, including a comparison to prior years. The report may include policy recommendations.

(4) The department shall publicize the report and its availability as widely as practical to interested parties, including, but not limited to, hospitals, providers, media organizations, health insurers, health maintenance organizations, purchasers of health insurance, organized labor, consumer or patient advocacy groups, and individual consumers. The annual report shall be made available through the department's web site and also to any person upon request.

(5) No hospital report or department disclosure may contain information identifying a patient, hospital employee, or licensed health care professional in connection with a specific infection incident.

(g) A patient's right of confidentiality shall not be violated in any manner. Notwithstanding any general or special law to the contrary, patient social security numbers and any other information that could be used to identify an individual patient shall not be released.

(h) Hospitals shall reduce the rates of hospital-acquired infections reportable under this section to zero or as close to zero as feasible, in accordance with the recommendation of the statewide infection prevention and control program established in item 4570-1502 of section 2A of chapter 58 of the acts of 2006, and the Betsy Lehman Center for Patient Safety and Medical Error Reduction Expert Panel on Healthcare Associated Infection.

(i) A determination by the department that a hospital has violated the provisions of subsections (a) to (g) inclusive of this section may result in any or all of the following:

(1) Termination of licensure or other sanctions, as imposed by the department, relating to licensure under this chapter.

(2) A civil penalty of up to \$1,000 per day per violation for each day the hospital is in violation of the act.

(j) The department shall promulgate regulations consistent with this section.

**Section 70I.**

(a) As used in this section, the following words, unless the context clearly requires otherwise, shall have the following meanings:-

“Health care facility” shall have the same meaning as found in section 70E.

“Health care professional”, a person licensed or otherwise authorized under Massachusetts law to provide health care services, including:-

(1) a doctor, nurse, physician assistant, nurse practitioner, clinical nurse specialist, certified nurse anesthetist, certified nurse midwife, respiratory therapist, psychologist, certified social worker, registered dietitian or nutrition professional, physical or occupational therapist, pharmacist, or other individual health care practitioner; and

(2) any other health care professional specified in regulations promulgated by the secretary of the executive office of health and human services.

(b) Each health care facility shall report to the department the occurrence of any of the adverse medical events, known as “never events”, described in items (1) to (6) of this subsection as soon as is reasonably and practically possible, but no later than 15 working days after discovery of the event. The report shall be filed in a format specified by the department and shall identify the facility, but shall not include any information identifying any of the health care professionals, facility employees, or patients involved. The department may consult with experts and organizations familiar with patient safety when developing the format for reporting and in further defining events in order to be consistent with industry standards. These reports shall be available to the public through the department’s website.

(1) Surgical events reportable under this subsection shall include:-

(i) surgery performed on a wrong body part that is not consistent with the documented informed consent for that patient. Reportable events under this clause do not include situations requiring prompt action that occur in the course of surgery or situations whose urgency precludes obtaining informed consent;

(ii) surgery performed on the wrong patient;

(iii) the wrong surgical procedure performed on a patient that is not consistent with the documented informed consent for that patient. Reportable events under this clause do not include situations requiring prompt action that occur in the course of surgery or situations whose urgency precludes obtaining informed consent;

(iv) retention of a foreign object in a patient after surgery or other procedure, excluding objects intentionally implanted as part of a planned intervention and objects present prior to surgery that are intentionally retained; and

(v) death during or immediately after surgery of a normal, healthy patient who has no organic, physiologic, biochemical, or psychiatric disturbance and for whom the pathologic processes for which the operation is to be performed are localized and do not entail a systemic disturbance.

(2) Product or device events reportable under this subsection shall include:-

(i) patient death or serious disability associated with the use of contaminated drugs, devices, or biologics provided by the facility when the contamination is the result of generally detectable contaminants in drugs, devices, or biologics regardless of the source of the contamination or the product;

(ii) patient death or serious disability associated with the use or function of a device in patient care in which the device is used or functions other than as intended. Device includes, but is not limited to, catheters, drains, and other specialized tubes, infusion pumps, and ventilators; and

(iii) patient death or serious disability associated with intravascular air embolism that



occurs while being cared for in a facility, excluding deaths associated with neurosurgical procedures known to present a high risk of intravascular air embolism.

(3) Patient protection events reportable under this subsection include:-

- (i) an infant discharged to the wrong person;
- (ii) patient death or serious disability associated with patient disappearance for more than 4 hours, excluding events involving adults who have decision-making capacity; and
- (iii) patient suicide or attempted suicide resulting in serious disability while being cared for in a facility due to patient actions after admission to the facility, excluding deaths resulting from self-inflicted injuries that were the reason for admission to the facility.

(4) Care management events reportable under this subsection include:-

- (i) patient death or serious disability associated with a medication error, including, but not limited to, errors involving the wrong drug, the wrong dose, the wrong patient, the wrong time, the wrong rate, the wrong preparation, or the wrong route of administration, excluding reasonable differences in clinical judgment on drug selection and dose;
- (ii) patient death or serious disability associated with a hemolytic reaction due to the administration of ABO-incompatible blood or blood products;
- (iii) maternal death or serious disability associated with labor or delivery in a low-risk pregnancy while being cared for in a facility, including events that occur within 42 days postdelivery and excluding deaths from pulmonary or amniotic fluid embolism, acute fatty liver of pregnancy, or cardiomyopathy;
- (iv) patient death or serious disability directly related to hypoglycemia, the onset of which occurs while the patient is being cared for in a facility;
- (v) death or serious disability, including kernicterus, associated with failure to identify and treat hyperbilirubinemia in neonates during the first 28 days of life. “Hyperbilirubinemia” means bilirubin levels greater than 30 milligrams per deciliter;
- (vi) stage 3 or 4 ulcers acquired after admission to a facility, excluding progression from stage 2 to stage 3 if stage 2 was recognized upon admission; and
- (vii) patient death or serious disability due to spinal manipulative therapy.

(5) Environmental events reportable under this subsection include:-

- (i) patient death or serious disability associated with an electric shock while being cared for in a facility, excluding events involving planned treatments such as electric countershock;
- (ii) any incident in which a line designated for oxygen or other gas to be delivered to a patient contains the wrong gas or is contaminated by toxic substances;
- (iii) patient death or serious disability associated with a burn incurred from any source while being cared for in a facility;
- (iv) patient death associated with a fall while being cared for in a facility; and
- (v) patient death or serious disability associated with the use of restraints or bedrails while being cared for in a facility.

(6) Criminal events reportable under this subsection include:-

- (i) an instance of care ordered by or provided by someone impersonating a physician, nurse, pharmacist, or other licensed health care provider;
- (ii) abduction of a patient of any age;

(iii) sexual assault on a patient within or on the grounds of a facility; and  
 (iv) death or significant injury of a patient or staff member resulting from a physical assault that occurs within or on the grounds of a facility.

(c) The department shall annually submit to the joint committees on health care finance and public health and the clerks of the house and senate a report summarizing the hospital quarterly reports and shall publish the annual report on the internet. The department may issue quarterly informational bulletins at its discretion, summarizing all or part of the information submitted in the hospital quarterly reports.

(d) Notwithstanding any general or special law to the contrary, no third party payer, including the commonwealth, an insurer licensed or otherwise authorized to transact accident or health insurance organized under chapter 175, a nonprofit hospital service corporation organized under chapter 176A, a nonprofit medical service corporation organized under chapter 176B, a health maintenance organization organized under chapter 176G and an organization entering into a preferred provider arrangement under chapter 176I, may knowingly reimburse a health care professional or a health care facility for services that resulted in any of the adverse health care events listed above, and no health care professional or health care facility may bill the patient for such services.

(e) A determination by the department that a hospital has violated the provisions of this section may result in any of the following:

(1) Termination of licensure or other sanctions relating to licensure under this chapter, as determined by the department.

(2) A civil penalty of up to \$1,000 per day per violation for each day the hospital is in violation of the act.

**SECTION 5.** Section 23D of chapter 233 of the General Laws is hereby amended by inserting after the definition of “Family”, the following definition:-

“Provider of health care”, shall have the same meaning as found in section 60B of chapter 231.

**SECTION 6.** Section 23D of said chapter 233 is hereby further amended by inserting at the end thereof the following paragraph:-

In an action for malpractice, negligence, error, omission, mistake, or the unauthorized rendering of professional services against a provider of health care, statements or writings by such provider of health care expressing apology or sympathy relating to the pain, suffering or death of a person which is not the result of intentional misconduct by such provider of health care and made to such person or to the family of such person shall be inadmissible as evidence of an admission of liability.

**SECTION 7.** Section 1 shall take effect on January 1, 2010.

**SECTION 8.** The reports required by subsections (c) and (f) of section 70H of Chapter 111 of the General Laws, created by section 4 of this act, shall be submitted on January 1, 2009.

**SECTION 9.** Subsection (h) of section 70H of chapter 111 of the General Laws, as created by section 4 of this act, shall take effect on January 1, 2010.

