

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

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

Year 2 Interim Report

EVALUATION (ID #61137)

July 2009

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**ENSURING THE CONSUMER VOICE
IN MASSACHUSETTS COVERAGE AND QUALITY**

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INTRODUCTION

Three years ago, with the passage of health reform legislation known as Chapter 58 of the Acts of 2006, Massachusetts undertook what has been called the “boldest state health care experiment in American history”¹ with the goal of assuring access to quality affordable health care for all state residents. Policy makers and health advocates nationwide have been watching closely as Chapter 58 moves through implementation, assessing the pros and cons of its particular policy approach to achieving universal health coverage. Reportedly, the Massachusetts program’s experience is powerfully influencing policy discussions at the federal level as the new Obama administration and the U.S. Congress consider options for national health reform.²

As it offers a testing ground for policy ideas, Massachusetts’ health reform effort is also serving as a laboratory for a different aspect of health system change: **consumer engagement**. Through the initiative described in this report (“**Ensuring the Consumer Voice in Massachusetts Coverage and Quality**,” funded by the Robert Wood Johnson Foundation), a great deal is being learned about what it takes to promote meaningful and effective consumer voice in the health reform process. The work of “Ensuring the Consumer Voice” during its initial year was documented in an earlier Year 1 Interim Evaluation Report.³ The present report, covering roughly the period from April 2008 to April 2009, describes what has been accomplished and learned as the three-year project completes its second year.

Clearly, the policy context now surrounding this initiative is very different from what it was a year ago. The recent financial market disruptions and deepening economic recession have swept through the decades-long national debate on health reform like a hurricane-force wind, raising health system change to a new level of urgency but also straining available resources to the breaking point. As increasing numbers of individuals and families find

¹ Sack K, “Massachusetts Faces Costs of Big Health Care Plan,” The New York Times; March 16, 2009.

² See “Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans,” U.S. Senate Finance Committee; May 11, 2009.

³ Needleman C, “Evaluation of Ensuring the Consumer Voice in Coverage and Quality in Massachusetts: Year 1 Interim Report” (August 2008), available on the Robert Wood Johnson Foundation website at rwjf.org.

themselves locked out of the present healthcare system or poorly served by it, enormous momentum is building for health reform both at the state level and nationally. But at the same time, states all over the country – including Massachusetts – face staggering budget shortfalls, and the political prospects for national health reform remain unclear. To put it mildly, these changed circumstances create new challenges for the project analyzed here. They also open new opportunities, and have been producing creative adaptations in terms of consumer engagement strategies.

Being arbitrarily set at one-year intervals, the project's Interim Evaluation Reports do not necessarily coincide with logical turning points in the project itself. Like the earlier Year 1 report, the present Year 2 report catches the initiative's work in the midst of rapid evolution as it responds to unfolding economic and political events – and this year especially, some of these events are potential game-changers for the project. Thus, the interpretations presented here should be viewed as preliminary snapshots of a moving target. The evaluation's Final Report, forthcoming in spring of 2010, will be better positioned to judge which aspects of this initiative ultimately yield the most useful general insights about consumer engagement and consumer voice in shaping health reform.

As context for the Year 2 evaluation, Part 1 of this report gives some background on the initiative itself; briefly explains key features of the state health reform policy framework that the project works within; and describes the approach being used for evaluation. Parts 2, 3, and 4 then describe the project's Year 2 consumer engagement activities and progress in each of its three focus areas: coverage, quality, and e-health. A final section, Part 5, summarizes preliminary conclusions from the initiative's second year and suggests some implications for advocates and donors.

PART 1: BACKGROUND

ENSURING THE CONSUMER VOICE AS A FOUNDATION INITIATIVE

Ensuring the Consumer Voice in Massachusetts Coverage and Quality (ECV)⁴ was launched in February 2007 through a \$1.5 million grant from the Robert Wood Johnson Foundation (RWJF) to a Boston-based consumer advocacy organization called Health Care For All (HCFA). The project aims to strengthen consumer participation in developing and implementing system improvements in three areas: **health insurance coverage, healthcare quality,** and **“e-health”** (also called health information technology, or HIT).

As the ECV initiative got underway in spring of 2007, Massachusetts presented an especially promising setting for learning more about how to support consumer engagement in health reform. The state’s new health reform law (known as Chapter 58) had just been passed after decades of advocacy and negotiation, and a new state administration strongly supportive of health reform was taking office. To Massachusetts’ consumer health advocates, the policy environment at that time seemed full of hopeful potential. However, they were well aware that the legislation was only a starting point, with many unknowns on the road ahead.

In particular, no one knew quite what to expect for **consumer participation** in shaping the multitude of implementation details that would determine the new law’s practical impact. Massachusetts policy makers were open in principle to the idea of hearing from consumers, but the actual **machinery for eliciting, focusing, supporting, and communicating consumer voice** in the state’s health reform still had a long way to go. State officials actively sought to tap consumer sentiment through mechanisms like focus groups and community meetings, but that input tended to be “raw” – unsystematic, lacking in background information, and not necessarily linked to specific policy decision points where consumer influence could realistically make a difference. By supporting a **partnership between concerned citizens and an experienced consumer advocacy organization,** the ECV project aimed to help consumer voice become a more effective force in shaping health reform.

The grantee organization charged with managing “Ensuring the Consumer Voice,” Health Care For All, was already well recognized as a leader in Massachusetts health reform. The group’s leaders and staff had been at the center of action to get Chapter 58 passed, working in concert with various organizational partners and coalitions. Now, with RWJF’s support, they hoped to build on that victory to **expand opportunities for consumer voice in implementing the Commonwealth’s expansion of coverage,** and also to **develop new strategies for engaging consumers in system changes related to healthcare quality and e-health.** HCFA used the grant funds primarily for expanding staff resources, growing from

⁴ For the sake of brevity, the initiative’s title is shortened to “Ensuring Consumer Voice” or ECV in this report.

about 12 full time staff to more than 30 (with additional part-time staff and interns bringing the organization's workforce to approximately 38 FTEs).

In a somewhat unusual arrangement, the initiative is being overseen jointly by two separate program teams within RWJF: **Coverage** and **Quality/Equality**. The hope is that – just as in this consumer engagement project itself – the explicit linking of different healthcare concerns within the Foundation's organizational structure will avoid “silo effects” and put a spotlight on complementarities and synergies that might otherwise be harder to see. In addition to its stand-alone goals, *Ensuring the Consumer Voice* lays groundwork for and complements other current RWJF initiatives on consumer engagement in health reform, notably a multi-state project titled *Consumer Voices in Coverage (CVC)* being directed by HCFA's national partner organization, Community Catalyst.⁵

THE PROJECT'S POLICY CONTEXT

While policy analysis per se is not the purpose of this report, some familiarity with the framework of health reform in Massachusetts is needed in order to understand the ECV initiative. Fortunately, analyses of Chapter 58's history and key provisions are readily available.⁶ To summarize very briefly, some of the more prominent policy features of the Massachusetts plan include:

- a requirement (the **individual mandate**) that all state residents must obtain public or private health insurance coverage judged to be affordable⁷ at their income level, or else pay the state a penalty. The plan offers an **exemption and appeal process** for hardship cases.
- an **employer responsibility mandate** that businesses with 11 or more full-time-equivalent employees must either make a “fair and reasonable” contribution toward employee coverage through a qualifying insurance plan, or else pay the state a “fair share” contribution of \$295 annually per employee.
- a set of **state-subsidized health plans** (Commonwealth Care), provided through authorized Managed Care Organizations (MCOs)⁸ overseen by a state agency (the

⁵ For information on the *Consumer Voices in Coverage* initiative, see RWJF's website (rwjf.org).

⁶ Many resources on Massachusetts health reform are listed, with links to relevant articles, on RWJF's website (rwjf.org) under “publications and research,” keyword “Massachusetts health reform.”

⁷ Specific definitions and income schedules for “affordability” have been a major focus for consumer advocacy. During Year 1, HCFA and its consumer partners won significant revisions in the Connector's original affordability rates by bringing consumer concerns to policy makers' attention and presenting carefully researched data on actual household budgets. They also raised important issues of how “affordability” would be figured for consumers with fluctuating or intermittent income, such as artists and seasonal workers. Since the affordability schedule is subject to change each year, the need for consumer monitoring and voice continues.

⁸ Originally, four plans were authorized. A fifth plan has recently been added.

Commonwealth Health Insurance Connector). Commonwealth Care is meant to make compliance with the individual mandate affordable for low-income state residents who lack employer-sponsored insurance and do not qualify for Medicaid or Medicare. This part of the program supplements and extends Medicaid (MassHealth), which is available to families under 150% of the federal poverty level (FPL) and also – in large part due to strong advocacy by HCFA – now free for children whose parents are covered by Commonwealth Care. Commonwealth Care covers adults with incomes between 150% and 300% of FPL,⁹ with a sliding scale of premiums based on income.

- a set of ***unsubsidized private plans*** (Commonwealth Choice), selected by competitive bid and authorized through the Connector,¹⁰ to offer a range of affordable coverage options grouped by type of benefits and cost-sharing at three levels (Bronze, Silver, and Gold) for small businesses and for individuals and families not eligible for the subsidized plans. This ***non-group market reform*** opens up previously closed group insurance markets to individuals, giving them cheaper rates and more choices. A special, lower priced Young Adults Plan (YAP) is available exclusively for individuals between the ages of 18 and 26 who are not eligible for employer-sponsored insurance.
- a specified package of core benefits (***minimum creditable coverage, or MCC***) that qualifying insurance plans must offer to those they insure, so as to prevent the value of coverage from falling to an unacceptable level.¹¹

Perspectives differ on how to interpret the program's results to date. Critics from the right point to the higher-than-predicted overall cost to Massachusetts taxpayers, and condemn on principle the idea of mandates imposed on individuals and businesses. Critics from the left argue that the state's health reform approach compromises too much with interest groups that stand to gain from high healthcare costs, and diverts effort from single-payer strategies felt to be better suited to the goal of sustainable universal coverage. HCFA staff and other supporters respond that while the Massachusetts approach most assuredly does pose challenges, it avoids the trap of "the perfect being the enemy of the good," and offers a realistic way to start immediately improving healthcare access and quality for large numbers of individuals in urgent need.

⁹ Maintaining the 300% FPL level requires federal approval through a Section 1115 Medicaid waiver from the Centers for Medicaid and Medicare Services (CMS). Massachusetts' waiver came up for renewal toward the end of this project's initial year, and its fate was much in doubt for awhile with some \$385 million in federal funding hanging in the balance. Fortunately for the Commonwealth's health reform plan, the waiver was approved in principle in September 2008 and a final agreement was reached in December 2008, reauthorizing the 300% FPL level for another three years.

¹⁰ At present, six private health plans participate in Commonwealth Choice.

¹¹ What exactly constitutes an "acceptable level" of benefits for the MCC has been a major concern for consumer advocates, focusing particularly on prescription drugs and oral health.

Evidence so far appears to favor the Massachusetts plan's supporters, since (despite provider shortages and rising medical costs that reflect national trends) the effort has in fact produced some remarkably positive outcomes in a very short period.¹² For example:

- Since the health reform program became law, coverage has been extended to 442,000 state residents who previously lacked insurance.¹³ **Massachusetts' coverage rate now stands at 97.4% of the eligible population – the highest coverage rate of any state in the nation, and one that cuts by half the Massachusetts pre-reform rate of uninsured adults.**¹⁴
- The public costs of Massachusetts' health reform initially skyrocketed, leading to concerns about the plan's affordability even among its supporters. However, **the state's cost for adding new entrants to the system through Chapter 58 was actually less than anticipated, when figured on a per capita basis** (a monthly cost \$352.43 per enrollee in FY 2008, 2% below the budget allocation of \$359 per enrollee and considerably less than the median cost of employer-sponsored coverage in the state).¹⁵ When spread over the program's first four years, public costs are now expected to fall **well within initial projections of how much the state would have to spend to implement health reform.** According to a recent analysis by the Massachusetts Taxpayers Foundation,¹⁶ the main explanation for the initial higher-than-anticipated public cost was the program's extraordinary success in bringing eligible individuals into the state's subsidized health plans faster than expected. Because of tapering-off enrollment in the public plans, a lightened burden of uncompensated care, support from federal matching funds, and active enrollment into employer-sponsored plans at no public expense, the MTF report concludes that "thus far the underlying financial model of shared participation is working well, with major strides in reducing the size of the uninsured population and only a marginal impact on state funding [estimated at \$88 million annually]."

¹² For two current assessments, see Long SK and Masi P, "Access and Affordability: An Update on Health Reform in Massachusetts, Fall 2008," *Health Affairs* 28(4): w578 (published online May 28, 2009); and Kingsdale J, "Implementing Health Care Reform in Massachusetts: Strategic Lessons Learned," *Health Affairs* 28(4): w588-w594 (published online May 28, 2009).

¹³ Massachusetts Department of Health Care Finance and Policy, "Health Care in Massachusetts: Key Indicators," November 2008. A Kaiser Family Foundation report, updated as of 5/19/09, puts the figure at 432,000. An exact figure is elusive, because individuals flow in and out of the insurance system, and not all assessments are describing the same population (for example, the Massachusetts Health Reform Surveys done by the Urban Institute include adults but not seniors and children, who generally have far higher rates of insurance than working-age adults).

¹⁴ Massachusetts Department of Health Care Finance and Policy, "Health Insurance Coverage in Massachusetts: Estimates from the 2008 Massachusetts Health Insurance Survey" (prepared by Long SK, Cook A, and Stockley K of The Urban Institute), December 2008, updated March 2009.

¹⁵ Steinbrook R, "Health Care Reform in Massachusetts — Expanding Coverage, Escalating Costs," *New England Journal of Medicine*, June 26 2008, vol. 358 (26), pp. 2757-2760.

¹⁶ "Massachusetts Health Reform: the Myth of Uncontrolled Costs," Massachusetts Taxpayers Foundation, May 2009; available online at www.masstaxpayers.org

- **Publicly subsidized insurance apparently did not replace (“crowd out”) private insurance**, as some had feared. As newly insured individuals entered the state’s subsidized health plans, participation in private insurance plans did not decline.¹⁷ On the contrary, the individual mandate has created an incentive for seeking private insurance among uninsured residents with incomes too high to qualify for the public plans. Since the start of Massachusetts’ health reform, employer-sponsored enrollment has increased by 148,000 as workers who had previously declined coverage decide to join, and the number of individuals buying private coverage directly has grown by 39,000.¹⁸
- **Public support for the program remains high**, running at 75% among surveyed households in Massachusetts (up from 64% two years earlier).¹⁹ Polls of likely voters also show strong and increasing support for the state’s health reform.²⁰
- **While out-of-pocket costs remain a major concern, fewer Massachusetts residents are reporting that they go without needed health care because they can’t afford it, and the use of preventive care services has increased**. The state’s most recent household survey found that in 2008, compared to 2006 (before health reform), state residents were more likely to have a regular health care provider and to have had health care visits over the prior year, with the gains in access to care greatest among low-income adults.²¹

Of course, the specific policy approaches that have yielded these strikingly positive results might not work as well, or in quite the same way, in other contexts. Massachusetts is in many ways atypical, and its health reform plan may or may not provide the best model for health reform elsewhere. However, one thing seems clear: **the ECV initiative’s experience with consumer engagement – i.e., developing practical, constructive strategies to ensure**

¹⁷ Gabel JR, Whitmore H, Pickreign J. “Report from Massachusetts: Employers largely support health care reform, and few signs of crowd-out appear.” *Health Affairs – Web Exclusive*, 27 (1): w13, November 14, 2007. See also Gabel JR, Whitmore H, Pickreign J, Sellheim W, Shova KC, Bassett V, “After the Mandates: Massachusetts Employers Continue to Support Health Reform as More Firms Offer Coverage,” *Health Affairs-Web Exclusive*, 27(6): w566–w575, October 28, 2008.

¹⁸ “Massachusetts Health Reform: the Myth of Uncontrolled Costs,” Massachusetts Taxpayers Foundation, May 2009; available online at www.masstaxpayers.org.

¹⁹ Massachusetts Department of Health Care Finance and Policy, “Health Insurance Coverage in Massachusetts: Estimates from the 2008 Massachusetts Health Insurance Survey” (prepared by Long SK, Cook A, and Stockley K of The Urban Institute), December 2008, updated March 2009.

²⁰ Harvard School of Public Health, “Poll shows strong support for MA Health Reform Law,” Internet Press Release; Boston: Harvard School of Public Health; 2008 July 15; available online at: <http://www.hsph.harvard.edu/news/press-releases/2008-releases/hsph-bcbs-poll-strong-support-for-ma-health-reform-law.html>).

²¹ Long SK and Masi P, “Access and Affordability: An Update on Health Reform in Massachusetts, Fall 2008,” *Health Affairs* 28, no. 4 (2009): w578 (published online 28 May 2009).

meaningful consumer voice in the process of designing and implementing health reform -- will remain relevant, whatever form health reform efforts may take in other states and nationally.

EVALUATION METHODS

As is usual for RWJF projects, assessment of this initiative is being carried out by an independent evaluator²² through a consulting contract with the Foundation.

Because the initiative itself was designed to be flexible with very broadly stated goals, the evaluation has been cast as **formative research** – exploratory, primarily qualitative, heavy on process description, and focused on extracting insights and strategies for consumer engagement that may be useful in other states or on a national level. The evaluation is structured as a collaborative effort, with HCFA’s leadership and staff and some of the project’s consumer partners regularly providing information and helping to guide the evaluation focus as the research goes along. RWJF project officers from both the Coverage Team and the Quality/Equality Team also contribute ideas, information, insights, and questions through monthly conference calls with the evaluator. The evaluator integrates all of this input, but remains responsible for overall data collection and development of independent conclusions.

A plan for data gathering and analysis, described in more detail in the Year 1 report, was worked out early in the project through discussions among the evaluator, RWJF officers, and the leadership and staff of HCFA as the grantee organization. Setting boundaries for evaluation posed something of a challenge, since HCFA supports consumer advocacy on a number of issues that are indirectly relevant to health reform but not funded through the RWJF grant (such as oral health, health disparities, and children’s health and mental health). It was finally decided that, since the study was meant to analyze the funded project rather than HCFA as an organization, the evaluation should focus on the three areas where consumer engagement was actually being supported through the Foundation’s ECV initiative: health reform implementation (at that point, mainly dealing with coverage); quality of care; and e-health.

The research approach in Year 2 remains essentially unchanged, except that the scope and volume of data-gathering has expanded. Data come primarily from three sources:

- **Ongoing review of electronic and print commentary** relevant to HCFA’s consumer advocacy activities, Massachusetts health reform, and health reform issues more generally. HCFA’s own website and blog provide a steady stream of information, supplemented by blogs of other stakeholders in Massachusetts health reform; state and national government reports; relevant articles published in journals and newspapers; and health reform policy updates and reports on foundation-sponsored websites.

²² The evaluator is Carolyn Needleman, PhD, Professor emeritus at Bryn Mawr College. She can be contacted at carolyn.needleman@cox.net.

- **Site visits** (approximately 4 each year) to observe HCFA-sponsored consumer advocacy activities in action and meet in person with HCFA leadership, staff, and participating consumers.
- **Open-ended telephone interviews** (approximately twelve each month, typically lasting about one hour each) with HCFA staff members who play key roles in the project, HCFA's executive director, and some of the consumers and consumer representatives who work with HCFA.

The evaluation is not intended to document every detail of HCFA's multifaceted, fast-paced consumer advocacy work on health reform implementation, quality of care, and e-health during the past year. Instead, **selected examples** are used to explore the following main themes:

- **In each of ECV's three focus areas, what kinds of consumer engagement activities and strategies are being used in the project's second year? What seem to be their strengths, challenges, and apparent results?**
- **If these activities and strategies depart from the approaches used in Year 1, how do they differ, and why?**
- **What new insights into consumer engagement have been gained, and what does the Year 2 experience imply for advocates and funders in terms of general lessons concerning consumer voice in health reform?**

* * * * *

With this introductory background information in place, we now turn to the substance of the Year 2 report.

PART 2

CONSUMER ENGAGEMENT IN HEALTH REFORM IMPLEMENTATION

GROUNDWORK LAID IN YEAR 1 ²³

As described in the earlier Interim Report, during its initial year the ECV project proved remarkably successful in building legitimacy and recognition for consumer voice in the expansion of quality affordable coverage. As Chapter 58 moved into implementation, HCFA and its participating consumers brought numerous concerns to policy makers' attention through public testimony, community surveys, media reports, letters and position papers sent to key decision makers, regular informal communication with key administrators, and citizen attendance at state-sponsored events and state agencies' open meetings.

In this work, HCFA relied on a *consumer advocacy coalition called Affordable Care Today (ACT!!) as the main mechanism for engaging consumers, developing and refining a consumer agenda, and helping to organize consumers' input for maximum policy impact.* ACT!! represents a collaborative made up of some 75 organizations with a stake in health reform, including large community-based consumer groups and a variety of other organizations representing the hospital industry, healthcare providers, unions, churches, atypical occupational categories such as artists, etc. HCFA has historically played a leadership role in the coalition, hosting its meetings and coordinating many of its activities. ACT!! pre-dates the ECV project, and in fact played a central role in getting Chapter 58 passed in the first place. However, thanks to the RWJF grant, HCFA was able to help ACT!! scale up its consumer advocacy efforts to a new level. Through increased organizational support, background research, issue-oriented workgroups, media expertise, and numerous formal meetings and informal discussions, HCFA staff worked with the coalition to craft a sophisticated, focused, policy-relevant consumer agenda on Chapter 58 implementation. During Year 1, this agenda was vigorously presented by HCFA and its coalition partners through written and oral testimony by and on behalf of consumers at public hearings and Statehouse events; press releases and TV interviews; letters to state officials and public position statements from ACT!! as a consumer coalition; consumer attendance at open sessions of state agencies; ongoing discussions with state administrators about unresolved consumer problems; and meetings with legislators to acquaint them with consumer concerns.

Two other mechanisms for consumer engagement complemented ACT!!'s work during Year 1 (and continue to do so). While not directly supported by the RWJF grant, they have played such a critical role in supporting consumer advocacy in health reform implementation that they need to be mentioned here:

²³ A more complete account can be found in last year's Interim Evaluation Report on the ECV project.

- ***An innovative HelpLine*** structured to serve as a bridge between consumers and policy makers. The Helpline provides an unusually responsive, multi-lingual support resource that each week helps hundreds (at some points, thousands) of callers get information and assistance with their new insurance options. It also generates “stories from real people” that add credibility to the consumer concerns that HCFA and ACT!! bring to policy makers, and provides moving examples for public media on why consumers need health reform and how it changes their lives for the better. Perhaps most important, the HelpLine serves as an early warning system to pick up unanticipated consumer problems emerging as health reform is implemented. HCFA can then communicate these problems to policy makers in time for corrective action, which greatly smoothes the implementation process and has helped policy makers appreciate the importance of timely consumer feedback.
- ***A very active electronic blog***,²⁴ open to the general public and also visited regularly by state decision makers and policy analysts. The blog supplies a steady stream of reports on health reform policy developments, alerts on upcoming public hearings and other relevant events, descriptions of HCFA’s consumer advocacy activities, links to important state reports and other publications, editorial commentary and analysis from various perspectives, etc. This user-friendly resource makes it easy for the public at large to keep abreast of important information affecting their interests that they might otherwise have missed, and informs them about opportunities for consumer input.²⁵ Since the blog is interactive, it also gives HCFA an open channel for receiving feedback – both positive and negative – from all sources.

Not every aspect of ECV’s consumer agenda on coverage got a favorable policy response that first year, but many did. By the end of Year 1, timely consumer input through the project had been able to correct a number of unanticipated administrative problems emerging as the new state policies on coverage expansion were rolled out, and consumer interests had been protected at some critical implementation decision points. Increasingly, state agencies, officials, and legislators were viewing feedback and advice from consumers as an expected and useful resource in Massachusetts’ expansion of health coverage. Thus, by spring of 2008, HCFA and its partners had carved out a vital role for consumer voice on Chapter 58 implementation issues such as premium affordability, maintaining an adequate benefit package, reducing administrative access barriers, detecting and reporting preventable churning, limiting consumers’ out-of-pocket costs, and outreach to those not yet insured. The coverage component of ECV project was running well, clearly having an impact on policy, and yielding useful lessons on consumer engagement.

²⁴ “A Healthy Blog,” accessible at blog.hcfama.org

²⁵ The blog focuses some sunshine on shadowy “public secrets” (information that is theoretically public, but so inaccessible that it might as well be secret), thus empowering consumers to use their democratic rights more effectively. For a discussion of how consumer advocates used disclosure of “public secrets” during the 1960s, see Needleman M and Needleman C, *Guerrillas in the Bureaucracy: The Community Planning Experiment in the United States*, New York: Wiley & Sons, 1974.

**YEAR 2: MASSACHUSETTS HEALTH REFORM
ENTERS “PHASE II”**

In the summer of 2008, the state’s health reform program itself also seemed to be going well, despite its higher-than-predicted costs as enrollment swelled beyond expectations. Some worrisome milestones had been passed without any serious problems; for example, there was no public outcry when the first tax penalties came due for noncompliance with mandated coverage. Negotiations moved ahead on the state’s application for federal renewal of its Section 1115 Medicaid waiver, essential to financing the health reform effort. Meanwhile, with the end of the state legislative session in July, lawmakers turned their attention to the upcoming fall elections and would not be working on legislation again until the new session’s start date (January 2009) drew closer. For HCFA and the ECV initiative’s coverage efforts, summer 2008 was a time for regrouping; updating the consumer advocacy agenda to build on the previous year’s work; and preparing for a transition to new organizational leadership²⁶ within HCFA, anticipated to take place in the fall. At that time, it seemed that HCFA’s successful strategies for engaging consumers in health reform implementation might continue relatively unchanged for the rest of ECV’s funding period (and beyond), perhaps with some fine-tuning but using more or less the same approaches for supporting consumer voice.

A year later, parts of the work on coverage issues do remain similar. However, the project has also needed to alter course in some important ways. The three mechanisms described above – ACT!!, the HelpLine, and HCFA’s blog – still represent the mainstay of the ECV initiative’s consumer engagement work on health reform implementation, but as we shall see, the way they function has begun to shift.

One major reason for change is that, after the previous year’s flurry of activity involved in setting up the basic machinery for coverage expansion, **the state’s health reform efforts have moved into a second phase (referred to by state officials as “Health Reform II”) that emphasizes containment of healthcare costs.** This policy evolution was planned, and would have occurred even if the state’s economy had remained strong. However, cost control has gained added urgency as it becomes clear just how critical this issue will be for the Massachusetts plan’s long-term sustainability.

In spring of 2008, to address the state’s growing sustainability concerns, the President of the Massachusetts Senate introduced a bill titled “An Act to Promote Cost Containment,

²⁶ As explained in the Year 1 Interim Evaluation Report, HCFA’s Executive Director (John McDonough, who had led the organization for the past five years and had played a leading role in crafting Massachusetts’ health reform effort) left in May 2008 to work in Washington DC, serving as senior advisor on national health reform for the U.S. Senate Committee on Health, Education, Labor and Pensions headed by Senator Edward Kennedy. A search to fill the Executive Director position at HCFA was carried out over the summer, and the new ED (Amy Whitcomb Slemmer, an experienced consumer advocate who previously served as the Executive Officer of Biomedical Services for the American Red Cross in Washington, DC) was appointed in October of 2008. During the search period and for the new ED’s first few months, executive leadership was provided by a senior HCFA staff member (Fawn Phelps) with strong support from the rest of the staff. While the transition process was not easy, the change of Executive Directors does not appear to have interrupted the ECV project or HCFA’s other work. As one staff member remarked, “We proved to ourselves that we could do it!”

Transparency and Efficiency in the Delivery of Quality Health Care,” which after its passage came to be known as “Chapter 305.” Signed into law in August 2008 shortly after the legislative session ended, **Chapter 305 has become the new centerpiece of Massachusetts health reform.** It contains provisions that take Chapter 58’s expansion of access a step further and confront more directly some of the factors felt to be driving up healthcare costs. Chapter 305 also includes important provisions related to quality and e-health, to be discussed in Part 3 and Part 4.

Consumer voice facilitated through HCFA and ACT!! was very active in discussions shaping Chapter 305 as it neared passage, using the techniques described for Year 1 – meetings with legislators to communicate consumer concerns, testimony at public hearings, citizen attendance at open sessions of state agencies, media reports, and well-informed public position statements at critical decision-making moments. However, **because of ACT!!’s internal diversity, reaching consensus on the coalition’s public position was more complicated for cost-related issues than it had been earlier, when the primary focus was on the shared goal of access.**

For example, Chapter 305 proposed some reforms related to conflicts of interest in prescription drug marketing. On this issue, some of ACT!!’s member organizations urgently wanted to see unnecessarily high drug costs reined in, while others – in particular, those representing the hospital industry and provider groups – found prescription drug reform hitting a bit too close to home for comfort. Discussion still generally unfolded in an atmosphere of mutual respect and underlying trust, with the coalition’s member organizations all understanding that they each have to be answerable to their respective constituencies, but it began to seem that ACT!! might not be able to rally behind prescription drug reform without putting some of its members in an untenable position. The solution worked out for this problem was simple and direct: take the drug issue out of ACT!! by forming a separate coalition to deal with it. Thus HCFA’s **new coalition on Prescription Drug Reform** was born, made up of some but not all of ACT!!’s membership, plus some additional groups not part of ACT!! With the ultimate goal of lowering high drug costs for consumers, the Prescription Drug Reform coalition took the lead in advocating for two measures that became law with the passage of Chapter 305: new disclosure requirements for provider conflicts of interest, and curbs on certain pharmaceutical marketing practices such as gift-giving to physicians and hospitals. Two other measures – state-supported “academic detailing” to make healthcare providers less dependent on pharmaceutical sales representatives for drug information, and disclosure of pharmaceutical companies’ research grants to academic institutions – remain on the Prescription Drug Reform coalition’s consumer agenda for the coming year. So far, **this strategy – spinning off a new coalition to deal with issues that might divide the primary consumer coalition – seems to be working well** to open up a new and very important topic of concern, while still preserving ACT!!’s cohesiveness and reputation as a major force in consumer advocacy on other health reform issues.

**BUDGET ADVOCACY –
NEW ISSUES, NEW ALLIANCES**

Cost containment would have been a health reform concern in Year 2 in any case, but the issue has become acute because of the current economic crisis. Like most other states, **Massachusetts faces a multibillion-dollar deficit and disastrous declines in revenue, yet must somehow find a way to balance the state budget for the coming fiscal year** (FY 2010, which starts July 1, 2009). Meanwhile, rising unemployment increases the need for many state services – unemployment insurance, housing assistance, emergency food programs, etc. State-subsidized health coverage ranks high among these escalating service needs, because many state residents are losing employer-sponsored health coverage along with their jobs.

As this report is being written (May of 2009), the state government has moved about halfway through the FY 2010 budget process, which ideally runs as follows:

- in January, as required by law, the Governor presents a spending and revenue plan that would bring the state's FY 2010 budget into balance;
- the House takes that plan into account, and by April 15 offers its own proposed budget, with a two-day window to add amendments, followed by floor debate;
- the Senate then develops its version, again briefly open to possible amendments followed by floor debate;
- compromises are hopefully reached during June;
- the Governor signs off on an agreed-upon budget that goes into effect on July 1.

Needless to say, political maneuvering is currently at a fever pitch. The cuts proposed so far are agonizing – across-the-board reductions for all state agencies, and curtailment or elimination of many badly needed state services. In the case of stalemate, the state government would probably be kept operating through temporary budget resolutions until agreement is reached, as has sometimes happened in Massachusetts during past recessionary periods. But everyone is hoping to avoid that. In this context, **HCFA is struggling mightily to carry out its consumer advocacy in ways that avoid direct competition for state funding among its own partner organizations, and do not pit health reform against other urgent consumer concerns such as education and housing.**

So far, the core of the state's health reform program has been preserved in both the Governor's budget and the House version.²⁷ This is encouraging to Massachusetts health reform advocates, since in times of budget crisis some other states have resorted to draconian measures such as capping enrollments. But some of the proposed cutbacks already threaten to roll back consumer gains that HCFA has painfully built up over years related to health disparities, oral health, and children's mental health. Of special interest for this evaluation, **some of the current budget proposals directly affect the consumer engagement strategies being used in the ECV project's health reform implementation work.** For example:

²⁷ At this writing, the Senate version of the budget was not yet set and health reform advocates were bracing for possible deeper cuts. The final state budget and its impact on the ECV initiative, along with other important events occurring after mid-May of 2009, will be discussed in next year's Final Evaluation Report.

- **Deep Cuts in Public Health Services**

The Governor's budget disproportionately reduced state funding for the Department of Public Health (DPH), and the House budget went even further. In the House's initial proposal, DPH loses nearly a quarter of its budget compared to FY09, and specific public health programs overseen by the Department are cut to the bone. For example, funding cuts of 30% to 50% are proposed for health promotion/disease prevention, oral health, domestic violence prevention and services, smoking prevention and cessation services, and infection prevention and control. Cuts of over 20% are sought in programs for early intervention, school health, teen pregnancy, and substance abuse. Even the Communicable Disease Control Program and the State Laboratory stand to lose 15% of their funding, in spite of the ever-present potential for pandemics or bioterrorism. Cutting these prevention-oriented programs seems counterproductive, likely only to undermine public health and increase health care costs in the future. But as a HCFA senior staff member commented ruefully, "Legislators are so used to hearing 'Don't cut my program because it saves money in the long run' that they just stop listening to that argument."

In response to the proposed public health cuts, **HCFA has formed a united front with the Massachusetts Public Health Association (MPHA), through a coalition called "United We Stand for Public Health" that now has eighty organizational members.** This new coalition promises to become an important force in Massachusetts health politics. The merger of the state's two consumer health advocacy giants – HCFA and MPHA -- coincides roughly with new leadership within both organizations, with the new chief executives in both cases very open to the idea of **explicitly linking health reform with public health.** While United We Stand²⁸ officially involves HCFA rather than ACT!!, strategy discussions within ACT!! are already beginning to reflect the partnership with public health. In recent rallies and public position statements, HCFA and ACT!! are deliberately encouraging public health to take the lead (and public credit) in order to strengthen the alliance.

- **Elimination of State Outreach and Enrollment Grants.**

For several years, the state has allocated \$3.5 million yearly for a statewide MassHealth Outreach and Enrollment Grant Program that enables about 45 community-based organizations to assist consumers with enrolling in Medicaid and other subsidized coverage programs, as well as with locating appropriate care. The grants also support eight "network" consumer organizations (one of which is HCFA) to provide statewide outreach and assistance. The outreach program has been crucial to getting information about the new Commonwealth Care coverage options and procedures out to uninsured state residents in their own communities, especially to those who require individualized support due to geography, ethnicity, race, culture, immigration, or disease status. Through its own outreach work, its HelpLine, and its Disparities Action Network, HCFA gets daily evidence

²⁸ HCFA staff take pains to refer to this coalition by its full title, so as to emphasize its public health focus. However, it is commonly called "United We Stand," and the shortened title is used in this report for the sake of brevity.

of just how confused and poorly served many consumers would be without outreach support.

Unfortunately, the Governor's budget proposal in January completely eliminated funds for this program, even though only about half its cost would be recovered because the federal match would be lost. To HCFA's dismay, the just-announced House proposal followed suit. HCFA's immediate reaction has been to pull out all stops in supporting consumers who wish to communicate with lawmakers about just how damaging to health reform the loss of this program would be. **The windows of opportunity for citizen input on budget issues are so brief and "buried in the weeds" that, without advocacy support, consumers' concerns would very likely be too slow and scattered to have much influence. HCFA is trying to get consumer voice focused in time to fit the budget process,** using the ACT!! network and the blog to provide background information, talking points, legislative contacts, and information on the best opportunities and timetable for explaining what outreach does and why it matters. These activities empower consumers and community-based organizations to make effective use of their democratic rights. The current effort is similar to the strategy used successfully in Year 1 to help consumers express their ideas and concerns on other coverage issues, but **the volume and pace of action have intensified** because of the issue's high importance and very short time frame.

- **Cutbacks for Safety Net Hospitals.**

In the Governor's budget proposal, funding was cut sharply for the state's two major public safety-net hospitals, Boston Medical Center (BMC) and Cambridge Health Alliance (CHA), both of which claimed that, as a result, they would be forced to eliminate critical community services and perhaps shut down entirely. The issue is a complicated one politically, since the two hospitals differ greatly and even the state's powerful hospital industry is divided on whether the cuts were fair or not. For purposes of this evaluation, the key point is that as a consumer advocacy organization, HCFA was put on the spot for how to respond to this funding decision. Some ACT!! members urged an all-out fight to rescind the cuts. At the very least, they wanted ACT!! to issue a strong public statement to defend the two hospitals' funding. At the same time, other ACT!! members felt this would be special pleading for particular institutions – a poor strategy for a consumer coalition that claimed to be inclusive and non-competitive. HCFA staff, not wanting to split the coalition or jeopardize their broader consumer advocacy agenda by damaging collaborative relationships that had worked well in the past, were cool to the idea of waging a militant public fight against state officials on behalf of two hospitals. What to do? After thorough discussion in meetings that had some tense moments, ACT!! reached a compromise that seems to have worked well: **A carefully worded official letter to the governor went out on ACT!! letterhead, calling not for restoration of funding to the two safety net hospitals by themselves, but rather for general support for hospitals and community-based health services across the board. This somewhat satisfied ACT!!'s more militant members while still preserving the coalition's cohesion,** and left member organizations free to take further action on their own if they wished to.²⁹

²⁹ At this writing, the two safety net hospitals are still in negotiation with the state. As a cost-saving measure, CHA has terminated its outpatient services for the chronically mentally ill.

- **Allocation of Federal FMAP Funds**

Massachusetts expects to receive some \$3.1 billion over the next three years from recent increases in the FMAP formula (the federal government's share of Medicaid costs).³⁰ This is considerably more than the state had anticipated. However, the unallocated portion of the funds (\$1.136 billion) carries no requirement that the money must be used to support health services. HCFA and its new partners in United We Stand have been strongly advocating that the FMAP "windfall" should stay in the health arena, specifically in the public health sector because public health took a disproportionate share of the state budget cuts. In the budget discussions now unfolding, HCFA, ACT!!, and United We Stand are pushing for more transparency in spending these funds – i.e., **setting up a separate state fund for the new FMAP money, instead of simply folding it into the general state fund**, so that consumer advocates can track how the funds are actually getting used. That method would follow the precedent set in the 2003 recession, when federal money from a similar FMAP increase was segregated in its own fund and used to restore health budget cuts.

At this writing, legislators have added numerous amendments to the House budget proposal as it moves into floor debate, some of which³¹ address the issues described above: securing administrative support for the Department of Public Health and restoration of important public health programs; restoration of funding for the state's outreach grants; support for the health safety net; and transparency in how the federal FMAP funds will be spent. **By providing a flood of background and resource information to consumers on the cuts and the amendments that might modify them, ACT!! is enabling consumer voice to be heard in a highly focused way.** In addition, in conjunction with United We Stand, HCFA and ACT!! have also supported several recent rallies at the Statehouse aimed at showing consumer concern about the House budget cuts. The process will be repeated for the Senate budget deliberations, and similar expressions of consumer voice are planned as the final budget takes shape – probably intensifying as the July deadline (the end of FY 2009) approaches.

³⁰ As part of the federal economic stimulus bill (American Recovery and Reinvestment Act, or ARRA), the FMAP for Massachusetts will increase from 50% to at least 56.2% -- possibly more, if unemployment in the state rises further. The Center for Budget and Policy Priorities estimates that the change will bring an additional \$920 million to the state in FY 2009; \$1,460 million in FY 2010; and \$720 million in FY 2011 -- a total of \$3.1 billion over the next three years. As noted in the HCFA blog, this is "big money."

³¹ In addition to the issues mentioned in this report, the amendments being supported by HCFA also include some related to prescription drug reform and support for an e-Health Institute, as well some that address issues not directly part of the ECV project (such as health disparities and child mental health).

REVENUE STRATEGIES

As the seriousness of the state’s economic situation sinks in, HCFA finds itself moving toward a crossroads in its strategies for promoting health reform. The impending budget cuts affect not only health and public health, but also education, housing, police and firefighters, infrastructure, social services, etc. Ultimately, consumers need all of these things for a healthful life. Should HCFA fight to preserve funding for health reform (now broadened to include public health) at the expense of other important consumer needs? So far, HCFA has stayed solidly within the health/public health arena, feeling that this is where the organization can contribute best. However, pressure is strong to find some area of common ground with advocates who are working on other consumer issues, so as to avoid a zero-sum budget struggle.

The common ground now emerging is advocacy for tax increases. **HCFA is concluding that, given the state’s present budget shortfall, the only responsible way to continue advocating for state-level health reform is to couple those efforts with support for new revenue streams to provide some budget relief for the state.** Besides being consistent with the collaborative problem-solving advocacy approach favored by HCFA, this revenue-focused strategy reduces the potential for competition among multiple worthy consumer needs.

Revenue enhancement strategies are not entirely new for the ECV project. For example, **HCFA and ACT!! have worked continuously to ensure that employers meet their part of the health reform bargain,** which was supposed to be a “three-legged stool” in which employers, consumers, and the state all carry a fair share of the costs. HCFA and ACT!! have tried to make the case (so far with partial success, for large employers only) that **the original definition of employers’ “fair and reasonable” contribution to employer-sponsored health coverage should be revisited.** A recent study³² finds that the relative contributions of employers, consumers, and the state have held fairly steady since Massachusetts health reform was enacted, but ACT!! argues that the employers’ share was set too low to start with. The “fair and reasonable” standard for employers’ health programs was originally defined as a company having at least 25% of employees enrolled or contributing at least 33% toward employees’ premiums – a requirement lower than the national average. ACT!! would like to see that raised to 25% and 33% (or even higher) for all employers with 11 or more full-time workers. This issue enjoys strong consensus within ACT!!, supported without second thoughts even by coalition members that are themselves large employers (for example, hospitals) because their health plans are already more generous than the Chapter 58 regulations require.

However, the idea of increasing costs for employers has a hard time gaining traction in the current economic slump, so HCFA and ACT!! have recently refined the argument. Consumer advocacy on the employer responsibility issue is being more sharply focused on **recovering state health care costs from employers who take unfair advantage of the state’s low employer “fair share assessment” penalties,** currently set at only \$295 per employee per year if a company fails to provide its workers with qualifying insurance coverage. As the issue

³² Seifert R and Swoboda P, “Shared Responsibility: Government, Business and Individuals – Who Pays What for Health Reform?” Blue Cross Blue Shield of Massachusetts Foundation, March 2009. Available online at: http://bluecrossfoundation.org/foundationroot/en_US/documents/090406SharedResponsibilityFINAL.pdf

is now being framed, the question becomes not “How much is the business sector contributing to health reform overall?” but rather “How much are certain employers with large numbers of low-income workers externalizing their healthcare costs to state-subsidized health insurance programs”? In the case of Wal-Mart, for example, this practice cost the state \$12,819,641 last year.³³

In addition, ACT!! supported last year’s tax increase on cigarettes, as a way of promoting public health and at the same time generating funds to support health reform when the higher-than-predicted costs became apparent. Some of the coalition’s current revenue-enhancing goals are similar – tax increases on tobacco products other than cigarettes (cigars, “little cigars,” and smokeless tobacco); taxes on sugared beverages; and a reclassification of alcoholic beverages so they would be covered by sales tax (alcohol is currently classified as a “food,” making it exempt). These are all tax measures with positive benefits for public health, as well as potential for raising revenue. Unfortunately, the amount of revenue they would generate falls far short of what is needed.

What is new – and a significant shift in direction for HCFA – is the organization’s growing interest in supporting broad tax reforms not directly related to health reform or public health, such as increases in the state income tax and/or the general sales tax. After thoroughly discussing the pros and cons, HCFA’s Governing Board recently approved the idea that such strategies should be actively explored. Accordingly, HCFA staff have been meeting with a broad-based advocacy coalition called “Stop the Cuts” (itself representing a merger between an advocacy organization backed by the Service Employees International Union (SEIU) and a group called “ONE Massachusetts” that seeks to change negative public perceptions about taxation). “Stop the Cuts” plans a large citizen rally in early May to voice concerns about the consumer impact of the proposed budget cuts across the board, related to health, housing, education, and a variety of local services. HCFA’s position so far has been to acknowledge that the state’s hand is being forced by circumstances, and to concentrate on reducing the need for spending cuts by increasing the flow of revenue. HCFA is interested in joining the “Stop the Cuts” effort on this basis, hoping that advocacy for growing the overall budget pie through revenue increases will unite the group around a practical, problem-solving strategy.

The HCFA Board’s recommendation on looking into broader tax policy gives permission and encouragement for a completely new advocacy direction in which the ECV project will likely play a part – not for direct lobbying, but for making sure that consumers are fully informed and can make their voices heard effectively on this issue. According to HCFA’s Chief Executive Officer, everyone remains acutely aware that the organization’s main mission is health and health reform, and there is no intention to dilute that mission. But in the present emergency, a hard reality must be faced: Without revenue enhancement, Massachusetts’ health reform will prove unsustainable – and thus, to be realistic, consumer advocacy for health reform needs to include fair and equitable taxes to support its publicly funded components.

³³ Massachusetts Division of Health Care Finance and Policy, “Employers Who Had Fifty or More Employees Using MassHealth, Commonwealth Care, or the Uncompensated Care Pool/Health Safety Net”; April 2009.

RISING MOMENTUM FOR FUNDAMENTAL SYSTEM CHANGE

Even with new taxes, consensus is growing among policy makers and analysts that health reform cannot succeed at either the state level or the national level if medical costs keep escalating. Minor cost containment measures and tax increases alone simply cannot keep pace. Accordingly, Chapter 305 included a provision (originated and strongly supported by HCFA) creating a 10-member **Special Commission on the Health Care Payment System** to explore approaches for more fundamental change – in particular, changes in the present structure of provider payment incentives that tend to inflate costs without improving health. The Special Commission is shaping up to be a powerful force in state policy, as well as a closely watched bellwether for national health reform. **Its work is leading toward a statewide demonstration project on payment reform that will put Massachusetts (again) on the cutting edge of health reform policy.**³⁴

Mounting a statewide experiment on payment reform will be a task of staggering proportions. As a first step, the Special Commission is undertaking some very rapid and very participatory planning, involving:

- sifting through the voluminous literature on different payment approaches that might be taken to support a cost-effective system of patient-centered care.
- holding a series of stakeholder meetings during the spring to hear from various affected interest groups, including consumers.
- by June of 2009, producing a report that recommends a specific approach for the state.

With strong support from the state's administration, lawmakers are expected to draft legislation within this year to establish a statewide mandate for the new payment system. The state will apply for the necessary Medicaid waiver from CMS as soon as that becomes feasible. Assuming passage during the spring of 2010, the payment reform law would presumably include a planning period prior to its effective date and phased-in implementation over the next three to five years, similar to what was done with Chapter 58.

This dramatic development, unforeseen at the beginning of the ECV project, represents an entirely new and critically important arena for consumer advocacy. While HCFA does not hold an official seat on the Commission, the organization is already serving as a major vehicle for consumer input at the stakeholder meetings now underway, by giving testimony on behalf of consumer interests, arranging (at the Commission's request) for participation by major consumer groups from the ACT!! coalition, and directly hosting (at the Commission's request) three of the consumer engagement sessions. HCFA staff have also been giving consumer-

³⁴ Other experiments with payment reform exist (for example, pilot projects through the PROMETHEUS program), but the planned reform in Massachusetts would be the first mandatory statewide effort.

oriented input to several studies³⁵ now underway on Massachusetts' cost containment options, and they expect to review the final reports and give feedback to policymakers when these studies are completed.

Effective consumer voice is urgently needed in this new state initiative on reforming the health care payment system. At this writing, the Commission is said to be leaning toward a recommendation for “global payments” to “Accountable Care Organizations” – that is, a form of capitated payment to provider networks – as the strategy to replace fee-for-service, procedure-linked provider billing. Logically, capitated payments to providers do hold promise to cut costs and potentially can encourage more appropriate treatment and disease prevention. But, as well-documented experience shows, this strategy is also fraught with serious hazards for consumers (such as provider “stinting” or denial of care) if it is not carefully planned, regulated, and monitored. Well aware of these potential problems, the Commission is currently exploring ways of incorporating various quality protections into the plan, along with the concept of “medical home.” HCFA too is researching the pros and cons of global payments to clarify how consumer interests can best be protected.

Whatever specific approach is chosen, major policy changes in the structure of health provider payments seem very likely in Massachusetts within the next year or so. Consumers have a stake in having a voice in the experiment at every step – planning, legislation, implementation, and program monitoring to bring unexpected problems to light and get them corrected. HCFA hopes to use the momentum now being established through the ECV project to help that happen.

ISSUES FOR YEAR 3

In its work so far, the coverage component of the ECV initiative has succeeded well in making consumer voice an integral part of Massachusetts health reform. The most visible and urgent challenges for Year 3 relate directly or indirectly to the project's economic context and its political implications:

- **Cost containment.** Can medical costs be brought under control through some combination of Chapter 305's provisions, further progress on prescription drug reform, and the structural changes now being considered for the healthcare payment system? More to the point for the ECV project, can this be done in a way that involves consumers in a meaningful way?
- **Holding past gains in the context of an economic recession.** Strains on the state budget will require a formidable amount of advocacy simply to maintain past gains in the quality and affordability of coverage, and to ensure that consumers continue to have

³⁵ For example, a cost containment study being conducted for the state by the RAND Corporation to evaluate cost savings achievable from various policy interventions, and an analysis commissioned by the MA Division of Health Care Finance and Policy and the Division of Insurance to look at the reserve levels of hospitals and insurers.

a strong voice in health reform implementation. Three particular battlegrounds will be restoring state funding for outreach and enrollment; protecting the coverage of certain vulnerable populations (for example, the 28,000 legal immigrants currently threatened with losing their eligibility for state-subsidized health programs); and maintaining adequate benefit requirements for minimum creditable coverage.

- **Managing coalitions and alliances in the context of resource scarcity.** ACT!! members have diverse and sometimes diverging interests, which may make consensus on advocacy strategies difficult to reach in a weak economy. In addition, HCFA's goals and preferred strategies may not always mesh completely with those of its two new partner coalitions, Stop the Cuts and United We Stand for Public Health. At some point, Year 3 seems likely to put HCFA's well-honed conflict management skills to the test.

PART 3

CONSUMER ENGAGEMENT IN HEALTHCARE QUALITY

GROUNDWORK LAID IN YEAR 1³⁶

The most innovative aspect of the EVC project deals with health care quality, an area where consistent, ongoing consumer engagement has historically been hard to achieve. Much evidence suggests that consumers are reluctant to think about quality-of-care problems until they or a loved one personally experience poor quality treatment, and they have few supports and little information for dealing with quality lapses when these do occur. As a result, consumer voice related to health quality tends to consist of individual complaints and lawsuits rather than organized advocacy focused on system-level reforms.

The ECV project seeks to change this situation through the following strategies:

- Creating a ***Massachusetts Consumer Health Quality Council*** – a recognized council of consumers who are committed to quality improvement and patient safety in MA, and are trained, ready, willing, and able to engage at all levels;
- Developing a MA consumer-driven patient safety and quality improvement agenda;
- Recruiting and training consumer groups and new consumers and leaders with interest in quality of care and patient safety;
- Designing a curriculum to educate new consumers about quality, the MA health care system and public policy;
- Producing educational materials to teach consumers about quality improvement;
- Orchestrating systematic consumer engagement concerning quality issues, with public policy makers and state-based quality improvement and patient safety organizations;
- Beginning educational conversations with state and national consumer advocacy groups about quality improvement and patient safety.

As described in the earlier Interim Evaluation Report, extraordinary progress was made on these goals during the project's first year. By the end of Year 1, a Consumer Health Quality Council with about 45 members had been recruited and was holding monthly meetings at HCFA headquarters, governed by bylaws developed by the consumers themselves. The Consumer Council also meets twice a year with HCFA's Quality Advisory Board, a group of prominent experts on healthcare quality issues, to discuss overall strategy (the Advisory Board meets independently twice a year as well). During Year 1, with HCFA's assistance and support, the Consumer Council sharpened its understanding of advocacy methods and resources, gained familiarity with state government process and the state's network of institutions relevant to quality improvement and patient safety, and became more knowledgeable about how to make consumer voice heard effectively. The more active

³⁶ A more complete account can be found in last year's Interim Evaluation Report on the ECV project.

Consumer Council members (including some who were initially uneasy about public speaking) grew increasingly comfortable and effective in giving public testimony and media interviews, meeting with policy makers, and educating others about quality issues at professional conferences and community meetings.

During Year 1, again with staff support from HCFA, the Consumer Council membership crafted a well-thought-out consumer agenda on patient safety and quality improvement that they hoped to see sponsored by lawmakers in the next legislative session. Their agenda advocated the following six reforms:

- Requiring 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.**
- Requiring medical facilities to **publicly report so-called “never events” [more recently referred to as “serious reportable events,” or SREs], identify problem areas, and develop quality improvement initiatives;** in addition, **prohibiting hospitals from billing for care needed because of the occurrence of a “never event.”**
- Requiring physicians ... to **notify patients of actual and potential adverse medical events** that occur during their care.
- Allowing 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.
- Requiring hospitals to establish and convene **“Patient and Family Advisory Councils”** through which consumers would have a voice in improving hospitals’ quality of care.
- Requiring hospitals to establish **Rapid Response Teams** that patients and families can activate when immediate medical attention is needed.

Council members presented this consumer agenda to legislators, state officials and the press, providing hard-hitting public testimony and interviews recounting their personal stories of harm. With assistance from HCFA and an intern from Boston University’s School of Public Health, they also produced and publicized a series of dramatic professional-quality videos for use in educating lawmakers and the public about patient safety concerns, describing some of the Council members’ personal and family experiences in dealing with devastating medical errors and hospital-acquired infections.³⁷ In addition, they began work on a consumer education resource based on their own experiences, to provide guidance for patients and families on preventing medical errors and dealing with them if they occur.

³⁷ These videos are posted on the web for public access at www.hcfama.org/quality/stories.

The Consumer Council's Year 1 efforts at strengthening consumer voice clearly affected policy. In a major victory, four of the consumer agenda's six items³⁸ were incorporated into last spring's Cost Containment Bill (Chapter 305) described in Part 2 of this report. With passage of Chapter 305, these quality provisions became law and the Department of Public Health was charged with issuing regulations by spring of 2009 to implement them – a process discussed further below. Thus, within a very short time period and somewhat to its own surprise, the new Consumer Health Quality Council became an established, visible, and effective voice in Massachusetts' health policies related to quality and patient safety issues.

YEAR 2: THE CONSUMER AGENDA ON QUALITY EVOLVES

The quality component of ECV has continued this progress in Year 2, with some significant modifications as the project moves with changing circumstances. Some developing trends include:

- ***Supplementing Year 1's emphasis on educating legislators with a new focus on administrative rulemaking.***

After winning substantial support among policy makers for the Year 1 consumer agenda, the Consumer Quality Health Council was faced with a strategy choice: Should Year 2 effort center on urging lawmakers to break new ground legislatively, or should the Council instead consolidate its gains by concentrating on the implementation of the Chapter 305 quality provisions? Following much discussion and consultation with HCFA staff and the Quality Advisory Board, the Council decided that the latter should be the main priority. Because long time frames in the legislative process sometimes require early “placeholders,” the consumers still continued their efforts to interest potential legislative sponsors in several additional important consumer issues (for example, reducing hospital-acquired infections by screening high-risk patients for MRSA on admission; using “checklists of care” to reduce medical errors in hospitals; reducing medication errors by convening an expert panel to study their occurrence in Massachusetts and recommend ways to decrease them). However, implementing Chapter 305 became the year's central emphasis. ***This decision – very wise in retrospect, because of the complexity of the task – has allowed the Council to focus its attention on making sure that the Chapter 305 quality regulations develop in ways consistent with the consumers' intent.***

To prepare themselves for work on rulemaking, Consumer Health Quality Council members have used their meetings to become informed and share ideas about the implementation details of the four relevant provisions, which require hospitals to:

- Publicly report infections and serious reportable events (SREs).

³⁸ The two items not adopted were those dealing with apologies and patient notification after a medical error has occurred.

- Not bill third-party payers or patients for care needed following a preventable serious reportable event.
- Establish Patient and Family Advisory Councils in hospitals.
- Create rapid response methods that allow for patient and family activation.

This preparation has armed the Council's consumers with models and best practices, information about various approaches to measuring quality, details on the ins and outs of infection and SRE reporting procedures, and background on legal issues. As a result, they have been able to present their concerns in a knowledgeable and sophisticated way at DPH's public hearings on the regulations, as well as informally with DPH administrators who serve on the HCFA Quality Advisory Board. In addition, just as they did in legislative hearings last year, they have gotten their points across in human terms by sharing their own dramatic personal stories in regulatory public hearings and by serving as visible examples of medical errors' consequences.

As this report is being written, the DPH quality regulations have just been issued in final form. They clearly reflect the consumers' participation, which balanced the input of other stakeholders such as provider organizations and the hospital industry. Without the Council's consumer advocacy, the final version of the regulations would probably have looked quite different.

One interesting observation from the Council's work on quality regulations is that *some issues important to consumers lie at a "sub-regulatory" level, left to guidance documents that will later be developed by DPH to flesh out the regulations themselves* (for example, exactly when and how patients should be informed when a serious error in their treatment has occurred). Unlike regulations, the DPH guidance documents have no requirement for public hearings; the process by which they are developed is vague. Thus the consumers have discovered that behind implementation's infamous "devil in the details," there is another devil – less obvious but potentially just as troublesome – lurking in the "sub-details." Since both levels affect what ultimately emerges as de facto policy, both levels call for consumer input. However, the opportunities for consumer voice at the regulatory guidance-document level at this point remain informal and undefined.

- *Exploring budget advocacy.*

The Consumer Health Quality Council did not concern itself much with state budget matters during Year 1. However, Year 2's prospect of large budget cuts for the Department of Public Health could hardly be ignored, since DPH was charged with implementing Chapter 305's quality provisions. Without adequate staff, how would DPH be able to do an effective job of developing and enforcing the new regulations? Thus, *to prevent their hard-won consumer gains from unraveling, the Council has felt it logical and necessary to get involved with budget advocacy as part of their overall consumer quality agenda.* Particularly during the spring of 2009, the Council has issued letters and public statements concerning budget issues and Council members have presented consumer perspectives on the funding cuts at various public events at the State House.

- **Broadening the boundaries of “quality care.”**

Initially, the Council’s consumers focused almost exclusively on medical errors and patient safety, and their primary goals were to raise awareness about these issues and support policy changes to make treatment safer for patients and their families. During Year 2, while reduction of medical errors remains central to their work, the scope of their concerns has begun to broaden. For example, through speakers and product demonstrations at Council meetings, they have become more aware of e-health’s strong potential for improving health care quality (as well as for posing possible threats to consumer privacy). As another example, they have provided state officials with feedback on the website developed by the state’s Quality and Cost Council,³⁹ which allows consumers to compare the area’s hospitals on various quality and cost measures. They have also given testimony at the stakeholder meetings currently being held as part of the planning for payment reform. Even their regulatory work during Year 2 propels them toward a broader definition of quality care, by involving them with hospital-based Patient and Family Advisory Councils (discussed further below). **As the Council matures, its consumers are continuing their work on medical errors and patient safety, but also moving into additional areas of health care system change that fit within a broader definition of quality of care.**

SOME GROWING PAINS

The Consumer Health Quality Council’s first year was full of excitement, as consumers whose lives had been damaged by medical errors discovered that, collectively and with the support of an advocacy organization, they actually could exercise a meaningful voice in policy-making around quality issues. Developing a consumer agenda and presenting it to legislators were clear and concrete goals, and the production of high-impact videos to present their personal stories of harm was absorbing and satisfying. During Year 1 the partnership between the Council’s consumers and HCFA operated fairly smoothly without much attention, with HCFA staff fully embracing the principle of consumer empowerment and emphasizing to the consumer members that “this is YOUR Council,” and the consumers feeling very appreciative of the staff support provided in large amounts by HCFA. The partnership also benefited from the fact that one of the Council’s most active consumers was an experienced nonprofit executive and also a member of HCFA’s own Board (and in addition, during Year 1 she was appointed by the Governor to the Massachusetts Public Health Council, a state decision-making body with regulatory powers through the Department of Public Health). As someone who had personally experienced a fatal medical error in her own family and who also had worked with HCFA and other nonprofit organizations for many years, she identified with both sides of the ECV initiative’s quality partnership. She brought that dual perspective with her

³⁹ A HCFA staff member who plays a key role in the ECV project’s quality component serves as a member of the Advisory Board for this state body. The connection facilitates communication between consumers and policy makers, and is another example of how partnering consumers with an advocacy organization like HCFA can help make consumer voice more effective.

when she was elected as the Consumer Council's President in December 2007 in the group's first formal elections.

In Year 2, as the Consumer Council moved out of what all concerned refer to as its "infancy," some internal strains developed. They reflect the kind of organizational processes typical of volunteer organizations in general, and might best be thought of as growing pains. For one thing, **as the newness of the effort wore off, getting the routine organizational maintenance work done became more of an issue and the boundaries of the partnership became less clear.** Who was ultimately responsible for the Council's agendas, minutes, recruitment, new chapter development, meeting facilitation, drafting public statements and letters, and general "invisible work" – HCFA staff, or the Council's volunteer members? How much control should the Council President have over the group's direction, as one individual with strong ideas of his/her own?

Ambiguity in the nature of the partnership was magnified by turnover in key personnel at some critical moments. On HCFA's side, the organization experienced a transition in top leadership during Year 2, with a hiatus of several months during the summer and a settling-in period for the new Executive Director during the fall. This did not affect the Consumer Council directly because HCFA's executive functions were handled well on an interim basis; fortunately, a long-time HCFA senior staff member with extensive policy experience and strong organizational and interpersonal skills was able to serve temporarily as Acting Director. However, during the same period, the HCFA community organizer assigned to work with the Consumer Council left in order to enter graduate school – a common reason for turnover among HCFA's younger staff members. This departure definitely did affect the Council, since virtually all of the consumer members had been recruited by this individual and they had "grown up" together in the ECV project. His successor (another young community organizer) brought many skills, but the sense of bonding and comfortable familiarity with the consumer members was not as strong.

On the Consumer Council's side, the group's second annual elections were held in December 2008 and an individual with a different personal style was elected as President. The new Council President came not from the nonprofit sector but from the world of consulting, and his perspective was more entrepreneurial than the group had grown accustomed to. His idea of how the partnership between HCFA and the Council should work departed somewhat from the patterns of collaboration that had been developed in Year 1, and he began to expand the role of Council President toward greater independence. Procedural questions began to emerge: Should the Council's e-mails and public statements all go through HCFA prior to release so as to keep them coordinated with HCFA's health reform advocacy more generally, or should the Council President be able to send things out independently without consultation? In the Council's public statements, should the contact listing for responses be the HCFA office, or the private number of the Council President? Were the HCFA staff working with the Consumer Council, or for it? HCFA staff were torn about how to respond, since they didn't want to over-control but at the same time they felt responsibilities to the ECV grant expectations and to HCFA as an organization. They hoped that other consumers on the Council would bring things back into balance by themselves.

Fortunately, that is exactly what happened. During the spring, without prompting from HCFA staff, other consumer members spoke up at a Council meeting and called for a restoration of the partnership model that had prevailed in Year 1. Subsequently, HCFA's new Executive Director met with the Council President to discuss the organizational model built into the ECV project, adding her weight to the idea of collaborative partnership. Meanwhile, the Council as a whole took another look at the bylaws they had crafted the year before and decided that too much had been left unstated, so a new and more detailed set of bylaws may eventually be developed. Under the leadership of the same Council President and supported by the same HCFA staff, the group is currently functioning smoothly – effectively presenting consumer voice on quality issues and deep into work on a new project focus (discussed further below).

A PERMANENT FORMAL ROLE FOR CONSUMERS IN HEALTHCARE QUALITY

During Year 2, largely in response to consumer advocacy on healthcare quality issues, **Massachusetts made a major move to institutionalize consumer voice within hospital services by mandating (through Chapter 305) that all acute care hospitals in Massachusetts must have Patient and Family Advisory Councils (PFACs).** Regulations just issued by the Department of Public Health set deadlines requiring the hospitals to have a plan in place by September 2009 and to have the actual Patient and Family Advisory Councils operational by October 2010. While some of the state's 65 acute care hospitals already have PFACs, most do not. Now they will need to establish them from scratch within a very short timeframe.

Existing PFACs take different forms. Basically, they all aim to bring together current and former patients and family members who are committed to helping the hospital provide high quality care to its patients, their family members, and the community it serves. A PFAC operates in partnership with its sponsoring hospital, with the participating consumers volunteering their time and the hospital providing staff support, operating resources, and open access to hospital administrators. One example familiar to many in Massachusetts is the very active PFAC at the Dana-Farber Cancer Institute.

Mandated statewide establishment of hospital-based PFACs is a powerful action that no other state has taken so far. It creates a legitimized channel for consumers to present their concerns and ideas to hospital administrators and boards on a regular basis, contributing an ongoing consumer perspective on issues such as infection control, follow-up care, checklists, rapid response teams, etc. If the new requirement is well implemented, consumers will have a seat at the policy table within the hospital itself, instead of only knocking on the policy door from the outside. They will have a permanent formal role in helping to shape hospitals' quality improvement initiatives and facility planning, affecting what happens for patients and families at the hospital bedside, in the operating room, and in the outpatient examining room.

Recognizing the value of a permanent institutionalized role for consumer voice in hospital policies, the Consumer Health Quality Council has made Patient and Family Advisory Councils a major focus of its present and planned activities. While the consumers

are working on implementation of all the quality provisions in Chapter 305, the PFAC issue is in a category of its own because of its potential for long-term consumer empowerment. To deepen their understanding and network with other quality advocates, several of the Council's consumer members recently joined HCFA staff in attending a national conference on patient and family-centered care, including PFACs. The Council's consumers have also examined local models and best practices, inviting as speakers some representatives from Dana-Farber Cancer Institute's exemplary PFAC (including some of the consumer volunteers as well as hospital staff). They are initiating conversations with a number of hospitals that currently lack this service, exploring how the Consumer Council might help them meet the new requirement's fast-approaching deadlines.

If resources allow, the Consumer Health Quality Council hopes eventually to play a coordinating role among the state's hospital-based Patient and Family Advisory Councils, helping them maximize their effectiveness as a vehicle for consumer voice. HCFA and the Consumer Council would like to help the state's PFACs – especially the new ones – share ideas and benefit from each other's experience. The exact mechanisms, yet to be developed, might include regional meetings, a HCFA-maintained website and list-serve, and/or an annual statewide conference. No other entity is emerging to play this kind of coordinating role, and the Consumer Council is concerned that without such support, consumers on the new Patient and Family Advisory Councils could become simply window dressing. In collaboration with HCFA, they hope to interest potential funders in supporting this unusual opportunity for strengthening consumer voice.

ISSUES FOR YEAR 3

The Consumer Health Quality Council enters its third year as a strong, active organization with much to be proud of, but also with three persistent concerns:

- ***Recruitment of new consumer members remains a challenge.***

Recruitment of volunteers is likely to be difficult in any advocacy effort, but the problem is magnified for the Consumer Health Quality Council because the group decided early on that they want a specific kind of membership. They are seeking people who have direct experience with serious medical errors either personally or through a family member; who can volunteer time to join with other victims of medical error as consumer advocates; and who have worked through their anger and grief enough to focus effectively on system change. Being this selective considerably limits the recruitment pool. When appropriate candidates are found, they may live in remote parts of the state and need to travel long distances to attend the Consumer Council's meetings. In addition, those who fit the criteria may have disabilities and ongoing health issues resulting from their medical misfortune, making volunteer work physically difficult, especially if they are also managing a work life. For all these reasons, recruitment has been an ongoing concern throughout the Council's history.

In Year 2, the pace of recruitment slackened somewhat, in part due to preoccupation with the advocacy work itself, and the size of the membership has shrunk. Around a dozen consumer members, compared to last year's twenty or so, now typically attend the monthly meetings. Both the Council's consumers and HCFA's quality team feel that more consumer members are needed in order to keep the group fresh and add to its diversity. However, it's unclear how the time-consuming process of going into communities to locate and talk with potential new members will get done. The ECV project's community organizer carries formal responsibility for recruitment, but the growing demands of the advocacy work and the group's internal dynamics have swamped his available time. New strategies for recruitment are currently being explored by the group, to be tried in Year 3.

- ***The initial plan of starting new Consumer Health Quality Council chapters around the state remains on hold.***

The Consumer Council would like to engage consumers not only in the Boston area, but also in other regions of Massachusetts that may have different issues and interests – for example, in western Massachusetts with its more rural population and in the Cape Cod area where provider shortages are especially acute. In Year 1, groundwork was laid for starting up two local chapters that would work with the Boston-based main Consumer Council -- one in “MetroWest” (a cluster of nine towns along the Interstate Highway 495 corridor west of Boston) and another in the Plymouth and Upper Cape area. During Year 2, these efforts have proved hard to sustain because the labor power to provide the necessary staff support is simply not there. The idea of starting new chapters that would target ethnic minorities with low English proficiency – a priority of the Consumer Council's President during Year 1 – has also been postponed for the same reason (although the Council has made other progress on overcoming language barriers by producing a Portuguese-language video on quality problems, for public education use with the state's large Portuguese population).

- ***The workload of the ECV project's quality component is exceeding its resources.***

Ironically, the dramatic success of the Consumer Council's advocacy efforts has created a new source of concern: the opportunities for consumer voice on quality issues are expanding, but the resources for it are not. No matter what the arrangement of responsibility, there is now simply too much work to go around in the quality component of the ECV project, and consumer volunteer effort alone seems unlikely to fill the gap. This is not a matter of poor initial grant design; at the start of the project, it was impossible to foresee that its quality component would move ahead so rapidly in ways that call for more staff support. HCFA and the Consumer Council are hoping that resources can be found to maintain the current momentum.

PART 4
CONSUMER ENGAGEMENT
IN e-HEALTH

GROUNDWORK LAID IN YEAR 1⁴⁰

For the e-health component of the ECV initiative (a sub-part of the initiative's quality component, but sufficiently distinct to merit separate discussion), HCFA added to its staff a part-time ***E-Health Consumer Advocate***. The position itself appears to be a fairly novel one in the world of health information technology (HIT), unfamiliar to many of the policy and technical experts involved.

During Year 1, the e-health Consumer Advocate succeeded in turning her vaguely defined role into an important vehicle for introducing consumer concerns into the state's planning for electronic medical records. Her work focused primarily on three community-based pilot projects on e-health funded by Blue Cross Blue Shield of Massachusetts and managed by the Massachusetts e-Health Collaborative (MAeHC) – among the first demonstration projects in the nation to focus on e-health connectivity from the ground up.⁴¹ As a member of the MAeHC board and Executive Committee, she was able to keep a spotlight on consumer issues as the pilot projects developed, advocating for consumer voice through local consumer councils; transparency in consumer-focused documents and consent forms; and the development of “patient portals” (secure web-based windows that consumers can use to access their own health information). As a board member for the Massachusetts Health Data Consortium, she also participated in that group's federal-state Health Information Security and Privacy Collaborative (HISPC) project assessing how the state's privacy and security laws would fit with a statewide electronic health information network. In addition, she kept in communication with national organizations interested in consumer engagement issues related to e-health. In general, she served as HCFA's main resource person for clarifying consumer interests and advocacy opportunities in the rapidly developing area of e-health, both nationally and in Massachusetts.

Because e-health is still so unfamiliar to consumers, most of her work took the form of advocacy on behalf of consumers, rather than by them. However, considerable progress was also made on public education and direct consumer involvement through creation of an electronic Consumer Network for Healthcare e-Quality; a series of lively “e-health lunches” with speakers on consumer e-health issues; and an informative and well-attended second annual “e-health Summit” conference. ***The most important result of her work in Year 1 was to strengthen some basic prerequisites for consumer voice*** – identifying what specific aspects

⁴⁰ A more complete account can be found in last year's Interim Evaluation Report on the ECV project.

⁴¹ The three communities involved are Brockton, Newburyport, and North Adams. For a description of the pilot projects, see Tripathi M, Delano D, Lund B, and Rudolph L, “Engaging Patients For Health Information Exchange,” *Health Affairs*, March/April 2009; 28(2): 435-443.

of e-health most need consumer input; promoting consumers' understanding of how e-health may affect them; heightening policy makers' awareness of e-health consumer issues; and making a convincing argument that consumers need to be taken at least as seriously as other e-health stakeholders as HIT programs develop.

YEAR 2: NEW MANDATES, NEW OPPORTUNITIES

Year 2 ushered in extraordinary changes in the e-health policy arena, as – with a breathtaking speed that surprised even the idea's supporters – Massachusetts moved toward a statewide mandate for electronic health records. A provision for establishing such a mandate was written into the bills that became Chapter 305, and with the passage of that legislation, Massachusetts found itself again on the cutting edge of policy. **Chapter 305 requires that by 2015 – an extremely short development period for such a complex task – all health care providers in the state must participate in a statewide electronic health information system.**

In February 2009, **the HCFA Consumer Advocate was appointed by the Governor to serve on the body created to oversee the e-health mandate's implementation, known as the Massachusetts Health Information Technology Council.** She is the only consumer representative on the 8-member panel. Her involvement is proving extremely time-consuming, but important because the state's e-health implementation plan needs the approval of this body. Her appointment opens a highly significant channel for consumer voice in the planning process, which would otherwise focus mainly on technical concerns and issues of provider acceptance.

In another equally breathtaking Year 2 development, **the recent Federal economic stimulus bill (the American Recovery and Reinvestment Act of 2009, or ARRA) allocates a very large amount of funding to health information technology** – a total of \$2 billion for e-health and \$27 billion for incentives for providers, to be parceled out in grants to states over a number of years. According to the HCFA Consumer Advocate, Massachusetts could receive something in the neighborhood of \$40 million for e-health development, and about \$500 million in incentives for providers to adopt the new technology. This year's grants will be available to states between April and September, an extremely short time frame for planning. Since different approaches carry different federal matching provisions, the exact amount of funding will depend on the direction that e-health development takes, and also on the number of providers who apply and qualify for the incentive reimbursements. But by any calculation, the state's e-health planning is shortly going to be flooded with federal resources – possibly on a “use it or lose it” basis, although that is not yet clear.

The large amount and short time frame of the federal funding are adding even greater urgency to the work of the Massachusetts Health Information Technology Council. The whole e-health issue is being described as a runaway freight train that can't be stopped, even though no one knows exactly where it's going. Unfortunately, in the rush to get the statewide program up and running, it would be easy to neglect the kind of things that concerned consumers in MAeHC's three community-based e-health pilot projects – privacy and security issues;

transparency and public education; patient portals so consumers can access their own medical records; consumer web resources that allow consumers to use health information technology to locate quality affordable care and better manage their chronic health conditions; etc. Once an e-health system is established, these components cannot easily be added in as afterthoughts. In this context, the importance of having some kind of consumer voice represented at an early point in the planning can hardly be overstated.

Meanwhile, other e-health consumer advocacy activities started in Year 1 have continued in Year 2 – presentations at relevant conferences; collaboration with state and national organizations working on consumer issues in e-health; planning a third annual E-Health Summit conference; continued e-health lunches; and providing input for analysis and articles on the MAeHC community pilot projects now that their funding period has ended. Some new activities have developed as well, involving greater interaction between the e-health Consumer Advocate and the consumer members of HCFA's Consumer Health Quality Council.

CHANGES IN THE ROLE OF THE e-HEALTH CONSUMER ADVOCATE

All of these ever-expanding activities are welcome and consistent with the e-health goals of the ECV initiative. However, many aspects of Year 1's work are now being carried out on top of the e-Health Consumer Advocate's unanticipated new responsibilities as the lone consumer representative on the Massachusetts Health Information Technology Council, as that group puts the statewide e-health plan in place within a very short time frame, driven by massive federal funding. The combination puts a large strain on the time and resources originally allotted to ECV's e-health component (one part-time staff member). It was not really possible at the start of the grant period to foresee the rapid acceleration of e-health policy development in Massachusetts, so again, this is not a matter of poor planning or a flaw in the initiative's original design. But by now, it seems that the rapidly growing opportunities for consumer voice in e-health may call for some rethinking.

The need is not only for more staff time devoted to e-health consumer advocacy, but also additional kinds of staff time and perhaps a different kind of linkage between this part of the project and the ECV project's other components. The Year 1 work of the e-health Consumer Advocate – focused on monitoring the MAeHC community pilot programs and identifying useful focal points for consumer voice – was fairly different from the kind of consumer advocacy that preoccupies most of HCFA's project staff. That has gradually changed as state action on e-health gathers momentum. For example, more legislative work is now involved in the ECV project's e-health component. During Year 2, the Consumer Advocate collaborated with state branches of AIDS Action and ACLU to advocate for strong consumer protections in Chapter 305's e-health provisions, and subsequently collaborated with ACLU to secure House and Senate sponsorship for a bill to fill some of the remaining gaps such as security audits, remedies for information breach, and whistleblower protections. More recently, she secured a House sponsor for a budget amendment to continue funding for the

state e-Health Institute that had originally been planned as a mechanism for implementing the statewide e-health mandate. (In a seemingly illogical move,⁴² the House budget proposed defunding this Institute, even though the expected influx of federal funds for e-health greatly increases the need for it.) These newer, more policy-related e-health activities would be made easier by closer connections between the e-health staff and HCFA's experienced policy staff working on other aspects of health reform.

ISSUES FOR YEAR 3

As the ECV initiative enters its third year, policy events related to consumer engagement in e-health are moving ahead very rapidly, if anything even faster than for the project's other focus areas. At the same time, the project's e-health component seems disturbingly fragile in several ways:

- ***Project resources devoted to e-health have not increased to match the growing need for timely consumer voice in the state's accelerating e-health planning.***

As mentioned earlier, the project started with just one part-time HCFA staff position devoted to e-health, and has remained at that level. The original resource level, staff deployment, and specific work assignments appear to need updating in order to keep moving effectively toward the project's e-health goals.

- ***The e-health work needs to be better integrated with HCFA's overall consumer advocacy efforts and resources.***

The appointment of the project's e-health Consumer Advocate as the consumer representative on the state's key planning body for e-health has potential for introducing critically important pro-consumer perspectives. No other equivalent channel for consumer advocacy exists. However, the fact that the new planning council has only one consumer representative to balance powerful stakeholder groups with different interests means that realizing the potential for consumer voice will be a challenge. To make maximum use of the opportunity, the full advocacy resources of HCFA would probably be needed – and that would require the e-health effort to become better integrated with the work of the overall organization than it has been to date.

- ***HCFA is feeling increasing budget pressures that may affect the e-health work.***

Like many nonprofits, HCFA has been hit hard by the economic recession. Despite active fund-raising efforts and internal austerity measures, the organization's developing

⁴² As a senior HCFA staff member explained, "the June budget deadline is around the corner, and 2015 [the deadline in the statewide e-health mandate] is a long way off."

budgetary problems may soon reach a point where staff reduction becomes unavoidable. In making difficult choices, there is a possibility that having a separate e-health Consumer Advocate position will be seen as something that has to go. If that happens, other HCFA staff will probably pick up aspects of the current consumer advocacy related to e-health, as part of the ECV project's overall quality efforts. However, losing this position would sacrifice existing professional networks and two years of immersion in e-health consumer issues, and the seat on the Massachusetts Health Information Technology Council would no longer be directly associated with HCFA or the ECV project. Next year's Final Evaluation Report will discuss how the situation unfolds.

PART 5

YEAR 2's IMPLICATIONS FOR ADVOCATES AND DONORS

This final section offers some food for thought from ECV's second year of consumer engagement effort – ideas and interpretations potentially useful for RWJF, for other interested donors, and for consumer advocates working on similar projects. Given the ECV initiative's rapidly changing circumstances, the conclusions discussed here are necessarily preliminary. The evaluation's Final Report a year from now will revisit the project's entire three-year funding period and will present consolidated findings from the initiative as a whole.

SOME EARLIER LESSONS REAFFIRMED

In general, the numerous “lessons” presented in the evaluation's Year 1 Interim Report still hold up. Some that were related to the initiative's start-up phase seem less central as the project matures, but will still be of interest at the beginning stages of any similar consumer engagement effort.

Three ideas raised in the Year 1 report have such strong continuing importance that they bear restating and updating here:

- **More so than many funded projects, advocacy-oriented initiatives like ECV require flexibility.** In response to unpredictable events, the exact organizational activities and staff roles being supported by the original grant are almost certain to change during the funding period. As we have seen in the present report, even the project's original goals and scope may need to adapt over time, and changes may need to be made in the way the project resources are deployed.

Recommendation: In this kind of situation, sponsors need to expect and encourage evolutionary change in the project, and grantee organizations need to work out good mechanisms for keeping the sponsors well informed about adaptations on a regular basis. Formative process evaluation seems better suited than outcome evaluation for this kind of initiative, to understand why the project develops in a particular direction and what is needed to move the project goals forward.

- **In a consumer engagement project like ECV, allocating sufficient resources to support “invisible work” is extremely important.** As discussed, HCFA provides extensive staff support for the project's two major mechanisms for consumer engagement (the ACT!! coalition and the Consumer Health Quality Council). Some of the support consists of visible activities – ongoing background policy research; a steady

stream of information and key documents posted on HCFA's frequently updated blog; facilitation of meetings and workgroups; development of strategy options for discussion; arranging for speakers and visits with state officials to give consumers entrée they might otherwise not have; working with the media to cover consumer stories and perspectives; preparing discussion drafts of official letters, public statements, and proposed testimony to present the consumer agenda; making arrangements for consumer participation in public hearings and Statehouse events; and so forth. What may be less obvious is the large amount of informal "invisible work" done by HCFA staff, such as phone calls to participating consumers and consumer organizations before and after meetings to discuss special concerns, informal "schmoozing" (interactions that strengthen working relationships on a human level), and diplomatic intervention to smooth ruffled feathers and minimize conflicts if either the ACT!! coalition or the Consumer Health Quality Council threatens to develop serious internal divisions. HCFA staff spend enormous amounts of time doing this kind of under-the-radar activity. It seems essential to the project's success, judging from the fact that problems have temporarily arisen in the (very few) instances where invisible work was neglected. Despite its importance, this kind of work is hard to describe in a grant proposal and hard to link directly with outcomes, so it could easily be overlooked in planning a project like ECV. Yet it is largely because of HCFA's less visible support work that ACT!! positions were able to impress policy makers as the kind of consumer input that should be taken especially seriously, because it was not only informed and policy relevant, but also coordinated and constructive.

Recommendation: In grant planning, both grantees and donors need to be realistic about budgeting for enough extra staff time to do the "invisible work," since this element could make or break a consumer engagement project.

- **HCFA's HelpLine plays a crucial role in the ECV project, not only as a service but also as a key tool for consumer advocacy.** On one level, HCFA's HelpLine functions as a badly needed support for consumers, handling as many as 4,000 calls in an average month. Callers often prefer a non-governmental source of information on their new coverage options and related issues, and many truly need the kind of culturally and linguistically sensitive service and individualized follow-up available through this HelpLine, but not through the state's call-in centers. With their permission, some of the callers' stories also get used very effectively for public education on the HCFA blog and in media interviews, to illustrate why health reform matters. But beyond the individual help and stories, on a less obvious level, the HelpLine also serves as an "expressway" for consumer voice in system change by immediately flagging new or neglected implementation problems as they arise. For example, a cluster of calls might come in about unrecognized affordability barriers, long processing delays at a particular stage of insurance enrollment, confusing language in a particular printed form, or concern about a particular quality-of-care issue. HCFA staff can then do some checking, determine whether a systemic problem seems to exist, and alert appropriate decision makers about the need for corrective action. This kind of continuous and

timely feedback on a system's operational problems – in other contexts, sometimes called “deficit monitoring” – is a tremendous boon for both consumers and policy makers.

Recommendation: A HelpLine with deficit-monitoring capacity would be of great value in any project with goals similar to the ECV initiative.⁴³

ADDITIONAL LESSONS FROM YEAR 2

New lessons have emerged in Year 2, related to the shift of emphasis in Massachusetts health reform policy, the state's worsening budget crisis, and the maturation of the ECV project itself:

- **Both advocates' and policymakers' conceptions of what constitutes “health reform” are growing more complex, comprehensive, and sophisticated. In response, the ECV project's scope of effort has needed to broaden.**

Initially the primary goal of Massachusetts' health reform plan was universal coverage, but by now, it's increasingly clear that the uninsurance problem was the tip of a very large iceberg. Even with insurance coverage, people may still lack access to care. The care they get may carry high risks of medical error and other quality deficiencies. Even with high overall coverage rates, important health disparities can still exist. Even if high coverage rates are achieved, the escalating costs of healthcare may render any kind of insurance plan unsustainable in the long run. Most unsettling of all, we may not even be working for the right kind of outcome, because making healthcare more available is ultimately no substitute for preventive measures that keep people healthier in the first place.

In designing the ECV initiative, both RWJF staff and consumer advocates at HCFA were well aware that coverage by itself was simply an opening wedge into a complex issue, and early on began using the term “quality affordable coverage” to underscore that health reform needs to include more than insurance coverage alone. The deliberate linkage of coverage, quality, and e-health within the ECV project represents a conscious effort to connect various dimensions of health reform in a way that encourages synergies. But within the past year, as Massachusetts health reform shifts its primary emphasis from access to cost containment, the state's policy makers are seriously considering system changes aimed at even more comprehensive reforms – new legislation and regulations to reduce the unnecessarily high prices being charged for prescription drugs; possible statewide experimentation with an entirely new structure of provider payments to encourage more appropriate and effective care; and a statewide mandate for all Massachusetts physicians to develop capacity for using electronic health records within the next six years.

⁴³ According to legislative staff working with the Senate Committee on Health, Education, Labor, and Pensions, federally supported HelpLines may be built into the proposals currently taking shape on national health reform.

The convergence of previously separated issues and the redefining of what health reform entails on a more fundamental level is leading the ECV project to broaden its own scope and activities, since consumers will unavoidably be affected (for better or worse) by the kind of sweeping systemic changes now being discussed. Unfortunately, broadening the project's scope also means stretching the original ECV resources ever thinner as new focal points of effort are added to HCFA's project-related activities.

Recommendation: When meeting the goals of a multi-year consumer advocacy grant starts to require significant and unavoidable expansion of the project's original scope and activity level, the original grant resources may no longer match the work required. Under such circumstances, it would be useful to have some mechanism for the grantee and sponsor to discuss updating the project's needs and, if necessary, consider the possibility of a supplemental grant in order to meet them. If the project has developed a new emphasis (in this case for example, payment system reform) that reflects entirely different and possibly better ways of meeting the grant's original goals, a separate complementary grant might be considered.

- **Budget advocacy has become an increasingly necessary part of health reform.**

Initially, the ECV project focused mainly on strengthening consumers' ability to communicate with and educate legislators and state officials, so that health reform's administrative machinery would take the consumers' agenda into account and new legislation could address unmet consumer needs. State budget concerns did hover in the background, in recognition that rising healthcare costs would eventually become a problem. But with strong support from state leaders and no imminent budget emergency, the state budget was a secondary emphasis.

The state's present \$2 billion budget shortfall, which by law must be balanced by July 1, has rearranged these priorities. Support for health reform's core coverage programs remains strong among Massachusetts policy makers, but it is now painfully clear that the whole program's long-term sustainability demands serious cost containment and probably additional revenue streams. More immediately, as discussed earlier in this report, the budget crisis is forcing proposed cutbacks in state agency budgets that could seriously undermine important aspects of health reform.

The hard reality is that, if the proposed budget cuts stand, some of last year's impressive gains for consumer voice in health reform will be weakened and perhaps even lost. Therefore, the success of the ECV initiative now seems to demand that some of the project activity be refocused, at least temporarily, on budget issues. At this writing, various budget amendments consistent with ECV's consumer agenda have been introduced by legislators, and HCFA's consumer partners – now more fully informed and engaged because of ECV – are able to exercise their democratic rights to express “voice” in support.

In addition, as discussed earlier, HCFA and its consumer partners are explaining to legislators and policy makers that they understand and accept the need for new revenue streams to support key elements of health reform, and support the passage of new taxes. Effort has so far focused on strategies that also carry public health benefits, such as increased taxes on alcohol, sugared beverages, and tobacco products other than cigarettes (which are already heavily taxed). However, because these sources cannot by themselves deliver the amount of revenue needed, HCFA and its partners are beginning to consider advocating for broader tax strategies such as raising the state sales tax and/or state income tax. As previously mentioned, the HCFA Governing Board recently authorized such exploration, after concluding that increased revenue might be the only way of keeping the state's health reform afloat while more fundamental cost containment measures are being debated.

Recommendation: State budget issues and tax policy may seem to fall outside the mission of consumer advocacy organizations working on health reform. However, experience in the field is suggesting that budget advocacy and support for new revenue streams, far from being a dilution of mission, may be essential to making health reform work. Both grantees and sponsors need to consider this issue and its implications realistically.

- ***As a more fundamental definition of health reform begins to emerge, the management of coalitions and alliances becomes more complicated.***

In the past, HCFA has deliberately built its health reform coalitions to include diverse stakeholder viewpoints, and has worked out effective mechanisms to keep divisiveness at a minimum. However, the cost control measures and fundamental system changes now being considered will inevitably make consensus more elusive within HCFA's primary health reform coalition, ACT!!. In addition, the broader organizational alliances now emerging may put new kinds of strain on the idea of collaboration. For example, HCFA staff have noticed that some policy makers and voters seem to feel that universal insurance coverage makes disease prevention and public health programs less necessary, because people can now get treatment if they get sick. At some point, might this attitude end up creating strategy and priority conflicts between advocates for health reform and advocates for public health, now working together in "United We Stand for Public Health"? In the same way, the members of the comprehensive coalition "Stop the Cuts" are currently uniting around the common goal of revenue enhancement, which is needed in order to make a broad conception of health reform work. But if "growing the pie" proves impossible, the constituent organizations (representing health reform but also education, housing, and many local services) may find themselves in competition for limited state funding.

One advocacy technique used by HCFA staff when a consensus stand on an issue has not yet coalesced is to frame initial public positions in terms of principles rather than

detailed proposals. For example, seven principles are currently being put forward for any changes in the healthcare payment system: transparency; simplicity; phased-in approach to bundled/global payments; protection of vulnerable consumers; patient activation and empowerment; value-based benefit designs that support prevention and primary care; and supporting the role of public health through the payment system. This approach allows for promoting consumers' general interests, even before the exact direction of a policy is clear and before a coalition's consumers themselves have decided on a common position.

The "principles" method has led to some colorful testimony that may in fact have more impact on decision makers than would an elaborate position paper. At one of the stakeholder sessions recently held by the Special Commission on the Health Care Payment System, a HCFA staff member presented consumer concerns through the principles underlying selected fairy tales, citing:

- Snow White for *transparency* (the Queen's mirror on the wall truthfully disclosed who was the fairest of them all. Information for patients should be equally transparent and easy to understand).
 - Dumbo for *consumer empowerment* (Dumbo could always fly, he just needed some encouragement. In the same way, consumers need to feel empowered to make fully informed choices about their health care.)
 - Goldilocks for *balance* (She liked her porridge not too hot, not too cold, but just right. Similarly, it's important to strike the right balance with payment reform, so that patients are not harmed and appropriate care is not withheld.)
 - Little Red Riding Hood for *remembering the key role of prevention and public health*. (The community should have taken care of the wolf long before it got to Grandmother's house. So don't neglect health threats to consumers until it's too late.)
- **One commonly mentioned principle – transparency -- has become such a catchword that it needs to be "unpacked" as a concept.**

In terms of consumer empowerment, a great deal of faith has been placed in the idea that once relevant information is made public, consumers can use it to make wise personal health choices. This concept, usually summarized as "transparency," needs to be sub-structured. One component of transparency is *disclosure*, but disclosure is only a starting point. The disclosed information needs to be *accessible* to consumers. It also needs to be *understandable* to them, which may require consumer education as well as refinement of the information itself. And ultimately, consumers should be able to *make realistic use of the information* once they have it. **At any of these points, barriers can arise that essentially negate the spirit of transparency.** The Year 2 experience of the ECV project, particularly in its quality component, has underscored the importance of all the steps that follow disclosure on the way to genuine transparency.

HOW ARE THE ECV INITIATIVE'S GUIDING CONCEPTS HOLDING UP?

The Critical Importance of Consumer Voice

The ECV project was premised on the idea that health reform will take different (better) directions if it unfolds with meaningful participation by healthcare consumers, rather than being planned from the top down by experts and policy makers alone. The project's experience so far strongly affirms this idea. Consumer voice, organized and supported by HCFA, has influenced the progress of Massachusetts' health reform in ways that make its coverage more accessible and affordable, its quality aspects better able to meet consumers' needs, and the program in general easier for the public to understand, use, and support.

In fact, **one of the most important lessons from the project so far is that the need for consumer voice in health reform has no clear end point.** It is generally recognized by now that the way legislation gets implemented determines its actual real-world effect, so consumer advocacy needs to be focused not only on getting legislation passed, but also on its implementation. However, implementation itself is a multi-level process, starting at with legislation's broad brush strokes, leading down through the minutia of developing definitions and detailed regulations, followed by "sub-regulatory" guidelines, and then further into an ongoing need for monitoring enforcement, all reinforced by continuous two-way communication with the public to keep the program focused on meeting consumer needs. In stressful economic times, as we have seen, state budgeting decisions also become a crucial part of implementation. In other words, **the need for consumer engagement never ends. Without it, consumer legislative "victories" are likely to fade away over time, undone by weakened regulations, non-enforcement, and lack of public awareness.**

The Partnership Concept

Another key element of the ECV project was its assumption that the effectiveness of consumer voice in health reform would be enhanced by partnering consumers with a consumer advocacy organization. This assumption also has been validated by the project's results so far. Without the support of HCFA's resources, contacts, staff assistance, and decades of experience with health system reform efforts, its consumer partners would not have been able to bring such an organized, focused consumer voice to bear on health system change. They might still have expressed their views to decision makers, but in a less strategic, coordinated and timely manner – almost certainly with less impact on policy.

The partnership concept has become even more important as Massachusetts' health reform dives further down into the arcane "weeds" of deep-level implementation. Advanced implementation requires tireless persistence, constant policy monitoring, and a strong grasp of

complicated procedural and technical administrative details. Consumers, even those who have successfully engaged in legislative advocacy, are usually not well equipped to work on the deeper levels of implementation without organizational help.

The partnership has benefited HCFA as well. The consumers' direct personal experience, often presented to the state's decision makers by consumers themselves in meetings and testimony at public hearings, add an indispensable element of authenticity and credibility to the advocacy efforts. The personal stories about quality problems featured in the Consumer Health Quality Council's videos have had enormous educational value for lawmakers, as have the HCFA blog's regular reporting of HelpLine callers' personal experiences with coverage expansion. In addition, the Consumer Health Quality Council's regular meetings and the freewheeling discussions within the ACT!! coalition's Steering Committee and workgroups have brought to light numerous consumer issues that HCFA's own policy experts might not have known about, in the absence of a strong partnership with consumers.

Reliance on Collaborative Advocacy Strategies

A third element built into the ECV project design is its implicit reliance on collaborative advocacy strategies based on inclusion, cooperation, and seeking common ground – very much along the lines of the well known text on negotiation, *Getting to Yes*.⁴⁴ This style of advocacy is one of many possible system-change strategies, some of them much more militant and “outside” the formal process of policy-making. Theorists of system change dating back to the 1960's have described different advocacy strategies as a continuum – for example, Rothman's three types of community organization practice (“locality development,” “social planning,” and “social action”) and Warren's continuum running from “collaborative” approaches such as planning and advisory committees, to “campaign” approaches such as lobbying and public information, to “contest” strategies such as picketing and protest marches.⁴⁵ In these two conceptual frameworks, choosing an appropriate advocacy strategy depends on the level of existing stakeholder consensus (or lack of it) concerning the problem's nature and urgency. A more recent related formulation is Kingdon's “window of opportunity” model, in which the choice of appropriate advocacy strategy depends on how closely three “streams” converge – problem definition, political will, and available policy proposals that fit

⁴⁴ Fisher R, Ury W and Patton B, *Getting To Yes: Negotiating Agreement Without Giving In* (2nd edition, revised), Boston: Houghton Mifflin Harcourt, 1991.

⁴⁵ Rothman J, “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; Warren RI, “A Community Model,” pp. 9-30 in Warren RI, *The Community in America*, Chicago: Rand McNally & Company, 1963. For a brief summarized discussion of these advocacy models, see Needleman C, “Nursing Advocacy at the Policy Level: Strategies and Resources,” pp. 253-262 in Pope AM, Snyder MA, and Mood LH (eds.), *Nursing, Health and the Environment: Strengthening the Relationship to Improve the Public's Health*, National Research Council, Institute of Medicine; Washington DC: National Academy Press, 1995.

the need for action.⁴⁶ If the three streams do not coincide, an advocacy style geared to promoting the missing element is the best choice.

While HCFA has experience with a range of advocacy strategies, the collaborative approach has been the organization's preferred method for many years, one that has certainly borne fruit in terms of policy influence in Massachusetts' health reform. Willingness to listen and sometimes compromise has allowed HCFA staff to build long-lasting, mutually trustful relationships with state decision makers (even though HCFA occasionally pushes them hard) and it also pervades the current ECV project work within the ACT!! coalition and the Consumer Health Quality Council.

The collaborative approach fits well with RWJF's preferred social change strategies, which have emphasized alignment of different stakeholders' interests, creation of reasonable change incentives, and educational strategies to further consensus on the direction of system change. RWJF's emphasis on collaboration stems in part from tax-related constraints on direct lobbying by foundations, but it also reflects carefully considered intellectual commitments to a model of health system change that appears to work.

Concerning this third project assumption, the picture is somewhat complex. On the one hand, the collaborative advocacy strategies central to the ECV project so far have proved enormously successful in introducing a consumer perspective into policy planning for health reform and quality improvement – as would be expected in a policy context like the early stage of Massachusetts' health reform, with a high degree of consensus among major stakeholders. At the end of Year 2, the ECV project's advocacy activities still rest solidly within a collaborative framework, with every intention of keeping this successful strategy going.

On the other hand, the previous high level of consensus in Massachusetts' health reform policy environment may be eroding, as competition for diminishing state funds increases and stakeholders find their interests diverging in the more fundamental cost containment measures now being considered. **In that case, the project's consumer advocacy efforts might well be pulled a notch or two toward the more conflictual end of the strategy continuum.** It's not unlikely that some of HCFA's consumer partners themselves will argue for more militant strategies (exercising their now-strengthened consumer voice!) The evaluation's Final Report will discuss how this issue develops during Year 3.

⁴⁶ Kingdon J, *Agendas, Alternatives and Public Policies*, 2nd ed. New York: Harper-Collins College, 1995. For a summary and illustration of Kingdon's "window of opportunity" model, see McDonough J, *Experiencing Politics: A Legislator's Stories of Government & Health Care*, Chapter 7, pp. 237-284; Berkeley, CA: University of California Press & the Milbank Memorial Fund, 2000.

UNDERLYING CONCERNS

As Year 2 ends, the “Ensuring the Consumer Voice” initiative has so far delivered on its goals with remarkable success, but three worrisome concerns cloud its future work:

- **Project Sustainability.**

From the initiative’s beginning, both HCFA as its grantee and RWJF as its sponsor recognized that what was being undertaken through ECV was a long-term effort, aimed at building consumer engagement infrastructure that would take time to gather momentum. The funding period for the project was set at three years⁴⁷ in the expectation that a good start could be made during that time frame, and that if further funds were needed to support the effort, they could be found at a later point either through RWJF or from other donors. Unfortunately, the end of the ECV initiative’s funding period is now clearly in sight, but additional resources are not.

In the current economic recession, the fund-raising environment for grant-dependent nonprofit organizations has taken a disastrous turn. Many of the annual donors that HCFA has relied on for years, themselves now struggling with diminished endowments, are unable to contribute at their past level of support. HCFA’s own fund-raising efforts are falling short of their goals, its state funding is in jeopardy, and by unfortunate coincidence, its large multi-year foundation grants are almost all approaching the end of their funding periods, with slim or no prospect of renewal. Under these circumstances, HCFA is actively seeking additional grants and also making deep cuts in its own operating expenses. Staff cutbacks seem fairly inevitable.

The worry is, how can the ECV project’s gains in strengthening consumer voice be sustained past the end of the RWJF funding period (February 2010)? As we have seen, consumer voice in Massachusetts’ coverage and quality reforms is moving closer to being institutionalized in various ways, and when that happens, external support will become less necessary. But that point has not arrived yet. The present gains could be easily reversed if not reinforced by persistent, continuous advocacy. It seems unlikely that the project’s consumers will be able to continue their current efforts effectively without the extensive support now being supplied by HCFA staff, and equally unlikely that HCFA can continue this kind of support without outside funding. Ironically, **the momentum achieved by the ECV project might be interrupted just as Massachusetts is on the verge of three dramatic new health reform experiments** (statewide mandated payment reform, statewide mandated Patient and Family Advisory Councils in hospitals, and statewide mandated adoption of electronic health information technology) – all of which urgently call for effective consumer voice, and all of which could yield insights important for national health reform.

⁴⁷ Preceding the ECV grant itself, HCFA received a six-month planning grant to lay groundwork.

- **National Action on Health Reform.**

This year's increased likelihood of national health reform is of course a positive and very welcome development, but it creates some uncertainty about how existing state-level reforms will connect with a national health plan. If some aspects of the national plan turn out to be weaker than what presently exists in Massachusetts, will the federal policies pre-empt Massachusetts' state-level policies in the name of interstate uniformity? Even if a solution to that issue is worked out, national health reform will inevitably bring changes and a period of confusion as the state's health reform program aligns itself with new federal policies. **During the period of alignment, effective consumer voice will be needed more than ever.**

- **A "Sleeper" Issue: Provider Shortage**

In effect, by foregoing routine and preventive care and using hospital emergency rooms only in case of serious illness, the uninsured have "helped" Massachusetts and the rest of the nation to avoid facing provider capacity problems that have existed for years. One result of expanding coverage is to reveal the fact that, at present, there are not enough providers to provide universal care as huge numbers of previously uninsured individuals seek care from a limited supply of physicians, nurses, clinics and hospitals. **Ironically, the more successful the health reform effort, the more acute becomes the provider shortage problem.**

The looming discrepancies between existing provider capacity and greatly expanded service demand are perfectly predictable; they are beginning to receive the policy attention they deserve. Permanent solutions to the problem are not yet clear and currently in some dispute, but any of the approaches now being discussed will take considerable time to develop. In the meantime, there will almost certainly be dislocations for consumers – long wait times for appointments, difficulty in finding providers, delayed treatment because of the access obstacles involved. These problems are already beginning to surface in Massachusetts,⁴⁸ and will inescapably arise in any successful national expansion of coverage.

Impending provider shortages put a project like the ECV initiative in a new perspective. **If the general public feel they have not had effective voice in shaping health reform, if they fail to understand the tradeoffs involved and feel no sense of ownership in the new policies, they may eventually turn against the whole concept of universal coverage when provider shortages become apparent.** The same applies to possible changes in the healthcare payment system and to increased use of health information technology – the two areas where Massachusetts is undertaking new cutting-edge experiments, with HCFA working to ensure the consumer voice.

⁴⁸ Long SK and Masi P, "Access and Affordability: An Update on Health Reform in Massachusetts, Fall 2008," *Health Affairs* 28(4): w578 (published online May 28, 2009).

As the ECV project demonstrates, organizing and supporting effective consumer voice is no simple matter. Thus *the project's lessons so far (and in its final year to come) can play a critical role in maintaining public support for health reform, despite the inevitable problems of transition, by arming health reform advocates with strategies for successful consumer engagement.*