



FOCUS *on Health Reform*

IN PURSUIT OF AFFORDABLE HEALTH CARE
ON THE GROUND LESSONS FROM
FAMILIES IN MASSACHUSETTS

SEPTEMBER 2009



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INTRODUCTION

In 2006, Massachusetts passed comprehensive health reform that sought to achieve near-universal coverage for state residents. The state is a leader in developing strategies to reduce the number of uninsured and its approach—combining a foundation of public coverage with greater access to private coverage through employers and a reformed individual insurance market—has emerged as a model for national health reform. As such, the state’s experience in grappling with critical issues related to access to affordable coverage provides lessons for the national effort.

Examining the “on the ground” experiences with health reform from the perspective of low- to moderate-income consumers in Massachusetts offers insights into the impact of reform on the availability of health coverage and the affordability of that coverage. It can also shed light on the role public programs can play in improving health coverage. To explore these issues, the Kaiser Commission on Medicaid & the Uninsured and Lake Research Partners conducted three focus groups with adults in a variety of public and private health coverage situations in Boston, Massachusetts in July 2009. This report highlights their experiences in obtaining health coverage, accessing health care services, and managing out-of-pocket costs.

Background

The Massachusetts Health Care Reform Act of 2006 achieved unprecedented reductions in the number of people without health coverage by increasing options for residents to obtain coverage. These new coverage options were created in the context of a requirement that individuals obtain health insurance coverage. Those who fail to have coverage must pay a tax penalty unless affordable coverage is not available to them.

The Massachusetts reform builds on the foundation of existing public programs. A centerpiece of reform is a new public program, Commonwealth Care, which provides subsidized coverage for adults with incomes up to 300% of the federal poverty level (FPL) who do not have access to employer-based coverage. The state also expanded MassHealth, the state’s Medicaid program, to cover children in families with incomes up to 300% FPL. (In 2009, 300% of FPL is \$32,508 for an individual and \$66,168 for a family of four.) In addition to these more comprehensive programs, the Health Safety Net (HSN), formerly known as the Uncompensated Care Pool, provides assistance to pay health care costs for eligible un- and underinsured individuals. It does not, however, provide health insurance coverage.

To prevent an erosion of private coverage, the law requires employers with 11 or more employees to contribute toward health coverage for their employees or pay a small assessment. For individuals who do not have access to employer coverage, but who do not qualify for subsidized coverage, Massachusetts created the Commonwealth Health Insurance Connector (the Connector), which functions as an insurance exchange to provide individuals and small businesses access to more affordable insurance products. Currently, six private health insurers provide a range of coverage options referred to as Commonwealth Choice plans.

Massachusetts' health reform is credited with achieving near universal coverage with 97.4% of Massachusetts' residents now insured. The uninsured rate is 2.6% according to a Massachusetts Division of Health Care Finance and Policy study conducted by the Urban Institute, and the U.S. Census has determined that the state has the lowest rate of uninsured residents in the nation. Almost 430,000 individuals have enrolled in private or subsidized health insurance plans since reform implementation began in late 2006.¹ Employer-based coverage has also increased since reform, with 149,000 new enrollees between 2006 and 2008.² While challenges remain in Massachusetts in terms of health reform's impact on the state budget, the state has been a leader in demonstrating how a mixed public and private approach can achieve near-universal coverage.

Study Design

This report is based on discussions from three focus groups held during July 2009 in Boston, Massachusetts. The 14 participants in this study were recruited by the Access Project, a nonprofit organization in Massachusetts that works with consumers on health coverage issues. Study participants were enrolled in both public and private insurance coverage, including employer-sponsored health coverage, Commonwealth Care, the Health Safety Net, and Commonwealth Choice.

Participants ranged in age from 26 to 58 years old, included men and women, and all but one was working full or part-time. Eight of the participants have ongoing health conditions that require regular medical care and medications. Three have young dependent children while two others provide financial assistance to siblings and help them navigate health issues. Finally, the majority have low- to moderate-incomes, with about two-thirds having incomes under \$40,000 and another third with incomes between \$40,000 and \$60,000.

¹ Massachusetts Division of Health Care Finance and Policy, *Health Care in Massachusetts: Key Indicators*, May 2009.

² *Ibid.*

FINDINGS

Massachusetts' reform has made health coverage more available and affordable to state residents, particularly through public programs

All study participants are aware of their state's 2006 health reform law and feel it made health coverage more available and affordable to residents. They believe improving access to coverage is one of the most important aspects of the health reform law and applaud the state's effort to reach universal coverage. At the same time, some study participants were not aware of coverage available through public programs, particularly Commonwealth Care, or were confused about rules to qualify for assistance.

Reform has increased access to health coverage.

A number of study participants would have been uninsured without health reform. These low- to moderate-income individuals—self-employed workers, employees at firms that did not provide health coverage, and workers recently unemployed due to the recession—could not afford health insurance coverage through the private market. They praised the availability of affordable public coverage options, including Commonwealth Care and also the availability of private insurance options through Commonwealth Choice plans for people who do not have access to coverage through their employers. But even those with health coverage through their employers voiced support for reform both because it helps residents of the state find affordable coverage and because it provides them peace of mind knowing they could obtain health coverage if they lost access to their employer-sponsored coverage.

“It's a system that wants to include everybody so that everybody has some form of health care. I think it's good for that reason.”

*Emoro, 51, Self-employed,
Commonwealth Care*

As in the rest of the country, the economic downturn has hurt these families. In the midst of considerable financial uncertainty, study participants appreciate the security that the Massachusetts' health reform provides in assuring that affordable health coverage is available to them should they need it. Study participants working for large companies, including Starbucks and Bose, have seen their employers lay off workers and cut back on hours. Others who are self-employed or who work in the service sector have seen demand for their services shrink resulting in considerable financial distress and uncertainty for their future. This includes Elizabeth, a 45-year old chauffeur for a car service company who, when asked about her job, observed frankly that with the declines in the economy, “I might not have this job tomorrow.” But she knows coverage will be available to her through Commonwealth Care should she become unemployed. Moira, a 44-year old parent who has her primary coverage along with her three children through her husband's job and who has dealt with a number of health issues for herself and her children, said of these new health programs, “I have a safety net [if he loses his job].”

An additional element of reform that participants highly value is the ability to obtain health coverage despite having pre-existing conditions. This is important to many in these focus groups who have been diagnosed with cancer, heart disease, or other conditions. Prior to reform, many say they were unable to qualify for coverage. Moira, who purchased an individual policy through Commonwealth Choice to cover medical costs that were not covered by her husband's employer policy said, "Through reform, I was able to purchase that [BlueCross BlueShield] as an individual. I didn't have to deal with any kind of pre-existing clauses or anything like that. It was a very easy thing to get."

Reform has facilitated better access to care.

Prior to reform, a number of study participants or their children with ongoing health needs, including cancer, congestive heart failure, hypertension, depression, diabetes, and asthma, had been unable to obtain access to regular medical care or were saddled with medical bills they could not afford. A number of study participants had depleted retirement savings to pay for medical bills. But, many had accumulated substantial medical debt while uninsured. Mark owes \$3,000 for emergency room care he received after he was mugged. Elizabeth owes \$1,200 for a mammogram she thought was being provided without charge. Others accumulated debt because they or a family member was underinsured. Moira has accumulated \$15,000 in medical debt for diagnostic tests and specialist visits for her condition. These debts resulted in study participants placing current health needs on hold for fear of incurring more medical expenses.

Health reform enabled many of these individuals to take care of their medical needs, to start seeing a doctor, and in some cases to regain their health and control over their lives. Mark said, "I'm grateful for it. I was definitely putting stuff off [while uninsured]. I have a bunch of chronic things that I just put off." Mark was able to obtain coverage through Commonwealth Choice. Like Mark, Lynn (a freelance gardener) was uninsured before Massachusetts' health reform but was able to enroll in Commonwealth Care once the law passed. With her multiple chronic conditions, life was "horrible" when she was uninsured and she found it hard to work. Her new coverage enables her to get the treatment and medications that enable her to manage her conditions and work again.

"It's probably easier for me to sign up for health insurance as a result of [reform] because I didn't have to go into existing conditions. I just went online and put in some information and they give you the choices. That was nice."

***Mark, 30, Self-employed
Commonwealth Choice***

"I've gone through so much testing, what would the alternative be? For me to pay out-of-pocket for all of that, I would not have accessed care and I would not have found some of the answers and some of the things to get better."

***Moira, 44, Parent,
Commonwealth Choice to supplement
coverage through spouse's employer***

Participants in public programs report good access to affordable, high quality care

The Massachusetts health reform expanded public programs to create a foundation of coverage for low- to moderate-income residents. The creation of Commonwealth Care, which provides subsidized coverage to adults up to 300% FPL who do not have access to other coverage builds on MassHealth, the state’s Medicaid program. Study participants enrolled in these public programs are pleased with the level of access to care they have. Many did not know what to expect but are happy with their ability to see specialists, have necessary medical procedures done, and to obtain their medications with little to no problems.

Luis, who lost his coverage when he lost his job as a bus driver, now has Commonwealth Care that allows him to get treatment for his congestive heart failure. Under his former employer-sponsored care, Luis struggled with the premium payments and put off needed care because he didn’t have the money to pay for medical expenses. Now with Commonwealth Care, he sees a doctor regularly who monitors his heart disease and is able to access specialists, diagnostic tests, and medications as needed.

“I need it now more than ever because of my condition... I called all these specialists and I asked them which plan was best for them and [Commonwealth Care] kept coming up.” I’m very happy with *Commonwealth Care*...the best plan I've ever had.”

Luis, 50, Parent, Unemployed, Commonwealth Care

By covering a broad range of benefits, state programs promote better management of chronic physical and mental health conditions.

Study participants enrolled in Commonwealth Care say they are taking better care of their health now that they have affordable coverage. Most were uninsured before enrolling and they admit they put off medical care and medications because of cost. Lynn, who is 58 and has a number of chronic conditions, explained that her entire approach to health care had changed when she was uninsured. “I used to be good about preventive care and going [to the doctor] if I had a real problem...[without insurance] I avoid it... I’m an old person who never goes to the doctor anymore because I learned not to unless it was an emergency.” This learned behavior came as a result of being uninsured and not being able to afford the care she needed to treat her health condition. Since enrolling in Commonwealth Care she can finally afford the regular care and medication needed to manage her condition.

Study participants talk about now being able to obtain prescription drugs, dental services, mental health, specialty care, hospital care, screening, and lab tests. None would be able to access these services without coverage through programs created through reform.

Premiums and copayments have become affordable under state health programs.

Almost all study participants talked about ongoing stress related to financial security. They say money is tight and that they are watching expenses closely. Lynn revealed that she is “pinching pennies” trying to afford food. Others were in similar financial straits, struggling to afford food and housing.

Those enrolled in state programs newly available after reform say that these programs have removed much of the financial anxiety over health care. Under Commonwealth Care, coverage is subsidized on a sliding scale based on income. Study participants in Commonwealth Care say they do not have large premiums or cost-sharing. “I can't complain about Commonwealth Care – they're fairly cheap, about \$50 a month,” said Remy, who is employed in corporate security. Others with lower incomes were paying less and Luis, who is unemployed, and Lynn, a freelance gardener, have no premiums and low copayments for their coverage. This low cost enables them to access all or most of the care they need. In contrast, Mark, the self-employed consultant, has had difficulty paying the premium for his Commonwealth Choice plan, which is not subsidized, resulting in delays to begin his coverage.

Those with employer-sponsored coverage still struggle to afford health care, particularly if health care needs are high

Under the Massachusetts health reform, individuals with access to employer-sponsored coverage are not eligible to receive subsidies from the state to help afford coverage. While employer-sponsored coverage seems adequate for participants without medical needs, a number of study participants with insurance through their employers were struggling to afford their health care coverage. For some, it is not their monthly premiums or deductibles causing the financial problems but the copayments for seeing multiple specialists and taking numerous medications. For others, it is a high monthly premium on top of the copayments that causes them trouble. This is the case with Elvita, who is employed full-time and has employer-sponsored health coverage, who said, “The premium is about \$350 a month, and then in addition to that, you have the co-pay and if you see a specialist... unfortunately, I've had some health issues for about two years now. The other day I got a bill for about \$200 and I was just overwhelmed – and that was in addition to the co-pay.”

“On his 11th birthday, my youngest son was diagnosed with Type 1 diabetes and the initial bills were around \$6-8,000 and we had to fight to get some of that back from the insurance. We got lucky. My wife found a diabetic support group to help us navigate the bills. They helped to bring it down to \$3,000 but we're still working to make payments – \$50 at a time.”

*Dennis, 47, Employed Full-time,
Employer-Sponsored Coverage*

For those with significant health needs, out-of-pocket costs can mount under employer-sponsored coverage.

Individuals with employer-sponsored coverage who have needed the most medical care seem to be struggling the most with costs. Linda, for example, who is 56 years old and employed full-time, has received a significant amount of medical care in recent years due to cancer. While her premiums are manageable – her employer pays two-thirds of the cost – it is her copayments that have caused her financial trouble. She feels that she has “good insurance” but explained that her copayments have added up with her cancer treatments. “The amount of money that I make, I should be much more on top of things but so much of it goes to medical stuff more than other people that I’m not able to get on top.” Linda struggles to pay \$80 a month on her prescription medications and is more than \$3,000 in debt from medical care not covered by a previous health plan. Like Linda, Elvita is struggling to pay off bills related to cancer treatment, in this case for her partner, “Once my partner passed away...I still had all the bills for her radiation and chemo, around \$33,000. I charged them on my credit card.”

In the face of high out-of-pocket medical costs, management of health conditions suffers.

Despite having employer-sponsored coverage, a number of study participants are postponing and doing without medical care to avoid incurring more costs. Linda reported that she has gone without cancer treatments and other care because of copayments. Elvita is not taking medications she needs because she cannot afford them. Jacques, who is employed by a health plan and struggles to afford his employer’s coverage, is putting off medical care as his health care costs mount. In this study, a number of those with employer-sponsored coverage are taking risks with their health by regularly going without care because care is not affordable. This is a striking contrast to the study participants in state programs who appear to be able to better manage their chronic conditions and obtain preventive care because care is more affordable.

There is an emotional toll of so much financial stress and worry. A number say they have experienced negative health effects from all the stress. Jacques said, “Yeah, especially when you see the bills coming. They stress me out. I’ve tried to stay away from medication for stress but you know, my doctor wants me on it, but I don’t want to.” Many say that it is harder navigating the health system, taking care of their health, and making health decisions when under so much stress.

Getting to the right program can presents challenges for consumers

Study participants believe more education about key aspects of health reform would help Massachusetts residents. New programs are still not well known and even those enrolled in coverage created by health reform have questions about their plans. Jacques, who is enrolled in his employer's plan, said his children used to have MassHealth coverage, but they lost that coverage after health reform and he does not know why. Seana, who works with the school system in order to obtain her health coverage, has never heard of Commonwealth Care but thinks she might qualify given her low-income. Having access to affordable coverage outside of her job would give her the flexibility to advance her career as an artist without worrying that she could not obtain health coverage. Elizabeth, thought she applied for Commonwealth Care but was enrolled in the Health Safety Net program instead. This confusion over the programs is a reminder that health reform in Massachusetts is still new and requires ongoing education and outreach. It also stems from program complexity that doesn't translate easily to consumers, especially those who are most unfamiliar with public programs, including the newly unemployed and those in danger of losing their jobs.

Study participants want to know more about the various public health programs, income limits to qualify, and how to apply for coverage. Some of those with experience enrolling in the state programs found the process frustrating and confusing, while others found the process straightforward and easy. A number of study participants used the web-based Connector to learn about and sign up for private health coverage. Most of them found the site to be helpful but challenging. Mark, who uses the Internet as part of his job, appreciated the availability of plan information on a single website, but had difficulty doing some of the plan comparisons. He explained that the terminology on the site often confused him and said that he became overwhelmed by the details of the plans. "I looked at what the range was that I could pay for. It took a while. It was easy to compare them all but it was difficult to figure out which would be the best for me. A lot of choices, and it's inconvenient because you can't just finish online, you have to print something out and send a check." Lynn, Mark, and others with ongoing health problems feel that absorbing all of this information and actually enrolling can be especially difficult for those with chronic conditions or dealing with mental health issues. Elizabeth wondered, "How can sick people manage to do this?" Study participants support using community-based organizations more widely to inform people about the programs and help them sign up.

Study participants show less support for the financial tax penalty imposed on individuals who do not enroll in health coverage. None of these individuals has had to pay the penalty so far nor do they know anyone who has. Most believe that families who cannot afford health coverage probably cannot afford the penalty either. None of these participants knew of the financial hardship exemption the state put in place for those who cannot afford a health coverage plan.

CONCLUSION

Massachusetts' landmark health reform law has been hailed for its success in reducing the percentage of state residents without health insurance. These gains were made largely through the expansion of public programs and the availability of subsidized coverage for low- to moderate-income state residents. In this study, focus group participants who were uninsured prior to 2006 or who had lost private coverage since have clearly benefitted. These individuals have affordable care through programs like Commonwealth Care that would not have been available to them before. In many cases, these individuals are self-employed, work part-time, or work for companies that do not offer coverage. Having health insurance that covers a wide range of benefits and protects them from high out-of-pocket costs has translated to better management of their health conditions and greater use of preventive services.

Conversely, many with employer-sponsored coverage seem to be struggling more than ever with health care costs. These tend to be people with serious or chronic health conditions like cancer or diabetes who see numerous doctors, require diagnostic tests and medical procedures, and who take medications regularly. They have difficulty shouldering heavy out-of-pocket costs (e.g., copayments that can add up into the thousands over the course of the year) even when their employers pay most of their monthly premiums. They report going without recommended medical procedures and medications due to costs even though they have "good coverage." The state's decision to make individuals who have access to employer sponsored coverage ineligible for subsidies appears to have locked some individuals into inadequate coverage making it difficult for them to manage their health care costs on top of all of their other expenses.

Other insights from the study reveal that awareness about both new and existing programs could be improved and the processes for enrolling in these programs could be simplified. Enrolling in these programs seems difficult for some, particularly for those dealing with chronic illnesses, and confusion about program rules leads to gaps in coverage (for example, when people fail to follow procedures for reenrolling in the program). Those who have used the Health Connector have found it useful but want it streamlined. Study participants support more investment in outreach so that people can learn about these programs and perhaps enroll in them.

As the health reform debate continues at the national level, the important role public programs play in facilitating access to affordable coverage for low- and moderate-income people in the Massachusetts reform effort warrants consideration. The public programs in Massachusetts work for people because premiums and cost-sharing levels are affordable and benefits provide the range of services necessary for people to obtain preventive services and to manage their health conditions effectively.



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