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CONSUMERS' EXPERIENCE IN MASSACHUSETTS: LESSONS FOR NATIONAL HEALTH REFORM

SEPTEMBER 2009

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FOCUS *on* *Health Reform*

CONSUMERS' EXPERIENCE IN MASSACHUSETTS: LESSONS FOR NATIONAL HEALTH REFORM

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The Access Project

EXECUTIVE SUMMARY

In April 2006, Massachusetts enacted a comprehensive health care reform law. Its goal was to move the state towards universal health insurance coverage through a series of reform measures that included an individual mandate for insurance coverage, an expansion of public coverage programs, and the creation of a Connector that sets policies and facilitates access to insurance for state residents. As a possible model for national reform, the Massachusetts reform effort can provide useful lessons for how to make a restructured health care system work for consumers.

In partnership with the Kaiser Family Foundation, researchers from The Access Project conducted in-depth interviews with fifteen Massachusetts consumers, as well as with several key participants in the health reform effort, to better understand the impact of the Massachusetts health system reform on consumers. The study focused particularly on people's ability to afford and access needed care. The following key findings emerged from the research:

Public programs have increased access and provided affordable insurance coverage options for low-income individuals. The expansion of the Massachusetts Medicaid program and the creation of Commonwealth Care, a program that subsidizes coverage for adults under 300% FPL, have reduced the uninsured rate for low-income residents and allowed many people to gain access to affordable coverage and obtain care.

However, some people are still struggling to afford coverage and care. Low-income workers with access to employer-sponsored coverage, as well as moderate-income individuals without access to employer-sponsored coverage, are both ineligible for state subsidized insurance. Coverage options for these individuals often remain unaffordable.

People with chronic conditions still face greater cost barriers to care. While nominal co-payments may be affordable for people who need care only occasionally, lower-income people who need ongoing care may quickly find the out-of-pocket costs unaffordable.

System complexities can lead to gaps in coverage. With the multitude of programs offered by Massachusetts, all with varying eligibility and programmatic rules, residents with fluctuating incomes and employment statuses can fall through the cracks. These individuals, and others who are ineligible for existing programs, still rely on a health safety net program to obtain services and aid in paying for needed care.

Fear of incurring unaffordable medical bills and medical debt remains a barrier to accessing needed health care. Unaffordable medical bills and pre-existing medical debt still create anxiety and cause many to delay or forgo needed services.

These findings provide important lessons with respect to national health reform. Public programs can serve as an important foundation for health reform that can provide low-income individuals access to consistent, continuous and affordable care. The quality of employer-sponsored coverage, in terms of the comprehensiveness of the benefits and the affordability of coverage, matters for individuals with this coverage, especially for those chronic conditions or other significant health care needs. A health safety net is necessary for people who are not covered under public or private programs, for those who are underinsured, and for those who are between programs and coverage. Lastly, ongoing monitoring of access and affordability will be important to understand how the cost of insurance affects families' ability to access care.

INTRODUCTION

In April 2006, Massachusetts enacted a comprehensive health care reform law, "An Act Providing Access to Affordable, Quality, Accountable Health Care," or Chapter 58. The goal of the legislation was to move the state toward universal health insurance coverage through a series of reform measures. The measures included a requirement that almost all state residents have health insurance, as well as the creation of state-subsidized health insurance plans for low-income adults without access to other insurance.

Because the Massachusetts health system reform initiative has been viewed as a possible model for national reform, the progress of Chapter 58 has been followed carefully at both state and national levels. Assessments have been done on various aspects of the reform, including its impact on state finances, safety net providers, and employers. In addition, telephone surveys have provided data on the effects of health system reform on consumers.

The consumer surveys show that since the implementation of health system reform, Massachusetts adults experienced great improvements in health insurance coverage. Rates of uninsurance fell from 7 to 8 percent of non-elderly adults in 2007 to 3.7 percent of non-elderly adults in 2008. In 2008, among non-elderly adults, 8 percent of those with incomes under 150 percent of FPL were uninsured, as were 7.8 percent of those with incomes between 150 and 299 percent of FPL.[1] Rates of underinsurance also fell in Massachusetts between 2006 and 2007.[2]

Massachusetts residents also experienced a significant lessening in the burdens of health care costs. Out-of-pocket health care costs and levels of unmet need for care dropped for both lower-income and higher-income adults between 2006 and 2007, although these rates stabilized or increased slightly in 2008. In the fall of 2006, 17 percent of non-elderly adults did not get needed care because of cost; in 2008 this figure had dropped to 11 percent. In the fall of 2008, 20 percent of Massachusetts adults had debt resulting from medical bills. While lower than the 28 percent of all non-elderly adults nationally with medical debt,[3] the percentage of people with debt in Massachusetts in 2008 differed only slightly from the rate in the fall of 2006.[4]

These data suggest that many people have benefited greatly from Massachusetts health system reform, but also that a significant number are still finding it difficult to pay for care. One group that may be especially vulnerable is low-income workers with employer-sponsored health coverage. These workers are not eligible for subsidies to help pay for their insurance and they have fewer protections regarding the quality of their insurance than low-income adults with coverage under the state-subsidized plans. National figures suggest that rising health care costs have hit this group hard. Among workers earning less than 200% of FPL, the percentage of underinsured (those with high health care costs relative to income) increased from 13 percent to 18 percent between 2004 and 2007.[5]

Another vulnerable group in Massachusetts includes people who do not have access to employer-sponsored coverage and earn slightly more than the income limit to qualify for state-subsidized plans. This group constituted the majority of the approximately 76,000 Massachusetts adults in 2007 who were deemed to be without access to affordable insurance.[6] These people, although exempt from the tax penalties imposed under state health system reform on those who do not have health insurance, remain uninsured.

The goal of this study is to better understand the financial impact of Massachusetts' health system reform on consumers, focusing particularly on people's ability to afford and access needed care. The study highlights the experiences of those who have benefited from the law as well those who are still struggling to pay for care. It includes individuals covered by state-subsidized health plans, as well as workers covered by employer-sponsored insurance. This study also looks at the experiences of individuals and families who are not eligible for state-subsidized plans and do not have access to health insurance through their employment.

Methodology

The Access Project conducted in-depth interviews with 15 Massachusetts consumers who had debt resulting from unaffordable medical bills, and also gathered information from others who had contacted the organization about getting assistance in resolving medical debt. In some cases people had incurred medical debt prior to the implementation of health system reform that they were still trying to resolve. In other cases, people incurred medical debt after the implementation of health system reform. We considered medical debt an indicator that people were unable to access affordable care and felt that a better understanding of how and why the debt was incurred would provide insight into any remaining affordability problems in the system.

In addition, The Access Project interviewed some of the key participants in the health care reform effort, including managers of the Commonwealth Care program and of the Managed Care Organizations serving Commonwealth Care enrollees, directors and staff at Community Health Centers, officials at government agencies responsible for overseeing aspects of the reform effort, and consumer advocates.

Components of Massachusetts' Health System Reform

Chapter 58 required a variety of changes in Massachusetts' health care system and included the creation of new organizational entities. Some major components of Massachusetts health system reform included:

- Requiring people age 19 and older to purchase health insurance coverage if "affordable coverage" is available. This is known as the "individual mandate."
- Expanding MassHealth (the Massachusetts Medicaid program) to cover children with incomes up to 300 percent of the Federal Poverty Level (FPL).
- Creating a new subsidized health insurance program, Commonwealth Care, for adults with incomes up to 300 percent of FPL who do not have access to other insurance.
- Creating the Commonwealth Health Insurance Connector Authority (the Connector) to set policy and facilitate access to insurance for state residents. The Connector:
  - Sets affordability standards that specify the amount that people can afford to spend on health insurance premiums. People for whom insurance is deemed unaffordable are exempted from tax penalties for not having insurance.
  - Sets Minimum Creditable Coverage (MCC) standards for insurance plans to satisfy the individual mandate.
  - Sets rules for the Commonwealth Care plans and negotiates contracts with health plans that provide services to enrollees.
  - Approves non-subsidized health plans, called Commonwealth Choice plans, which are available to people who do not qualify for the subsidized plans and want to purchase insurance in the non-group market.
- Converting the Uncompensated Care Pool to the Health Safety Net (HSN), which reimburses hospitals and community health centers (CHCs) for a portion of the uncompensated care they provide. The HSN helps subsidize the costs for uninsured individuals not eligible for other programs and for people who are underinsured.

IMPACT OF REFORM

Public Programs Offer Affordable Coverage

Even prior to health system reform, Massachusetts had a robust safety net relative to other states. MassHealth – Massachusetts' Medicaid program – provided a wide range of programs, including coverage for children in families earning up to 200 percent of the Federal Poverty Level (FPL) and parents up to 133 percent of FPL, as well as programs for the long-term unemployed and for adults and children with disabilities whose incomes are too high for the standard MassHealth program. The state's Uncompensated Care Pool compensated community health centers (CHCs) and acute care hospitals for a portion of the care they provided to uninsured and underinsured low-income patients. In addition, the Medical Security Program (MSP) subsidized COBRA payments or provided transitional coverage for individuals collecting unemployment insurance, and the Insurance Partnership subsidized coverage for low-income employees and small employers.

Under Chapter 58, MassHealth coverage was expanded to include children in families earning up to 300 percent of FPL, and between June of 2006 and December of 2008, enrollment in MassHealth increased by 109,000 members.[7] The Uncompensated Care Pool, renamed the Health Safety Net (HSN), continued to subsidize coverage for low-income uninsured and underinsured people at hospitals and CHCs.

One of the most important features of health system reform for low to moderate income adults was the creation of the Commonwealth Care program. Commonwealth Care provides subsidized coverage for adults earning up to 300 percent of FPL who do not have any other source of insurance coverage. (In 2009, 300 percent of FPL for an individual is $32,508.) Adults enrolled in Commonwealth Care plans pay premiums on a sliding scale based on income; those earning below 150 percent of FPL do not pay premiums. The plans cover a full range of services and do not have deductibles. As of December 2008, 162,726 people were enrolled in Commonwealth Care plans, over half of whom did not pay premiums.[8]

Most advocates cited the expanded opportunities for lower income people to obtain health insurance through MassHealth and Commonwealth Care as the most successful aspect of health system reform for consumers. In a survey of outreach workers, when asked "What about Health Care Reform has most pleased you?" the most frequent response (61% of respondents) was expanded access to health insurance. When asked "What groups... are being helped the most by Health Care Reform?" most (53%) said working people previously unable to access or afford insurance.[9] One advocate said the most successful thing about Chapter 58 for consumers was "Creating new opportunities for coverage for people who previously have been unable [to get coverage]." A Helpline worker said:

> There were a lot more people falling through the cracks before health reform, before Chapter 58 was passed. It is just so amazing to have all of these options available now to folks that before would have absolutely no option.

Our interviews with consumers illustrated the value of both public coverage options that existed prior to reform and the expanded public coverage options that were implemented as part of reform.

Don, for example, had accrued medical debt when he was uninsured. He now is covered by a Commonwealth Care plan, for which he does not pay a premium. He said, "I've had two physicals since then, and an eye examination by an ophthalmologist, and it's a great peace of mind to know now that I do have insurance."

James accrued medical debt for back and leg pain and for injuries suffered from an assault because his employer-sponsored coverage had a $1,500 deductible that he could not pay on his $10 an hour salary. Since that time he lost his job and his employer-sponsored coverage and enrolled in a Commonwealth Care plan, for which he does not have to pay a premium. He said, "[My employer-sponsored insurance] had very strict rules for what they would cover and what they don't cover, and they didn't cover a lot. I feel that the Commonwealth Care that I have now covers a lot more than the [private insurance], which you would think would be the other way around."

Jeff accrued medical debt from injuries he incurred when he was uninsured. He and his family are now covered by MassHealth. In speaking about getting care now that he has MassHealth coverage, he said, "I am starting to believe that I can actually go to the doctor without worrying about getting a thousand-dollar bill in the mail. At first, if I wasn't feeling well,…I was kind of hesitant about going. Now that I have [MassHealth], I have no shame or no worries about it. A year later, I am very confident about it."

The Health Safety Net (HSN) has also been an important resource for people without insurance. Helen and her husband, for example, are small business owners. They had a high deductible health plan that left them with more than $2,500 in out-of-pocket costs when Helen needed shoulder surgery. The HSN reimbursed the hospital for almost its entire $1,800 bill, and Helen was able to negotiate discounts and payment plans with other medical providers for the remaining out-of-pocket costs. As a result, she and her husband were able to avoid accruing debt and to continue to meet their business expenses.

But Some Groups Still Struggle to Afford Coverage and Care

While the stories above show how the expansion of coverage options for lower-income adults has helped many people obtain needed care, some people are still struggling. In 2008, 17 percent of non-elderly Massachusetts adults with incomes under 300 percent of FPL did not get needed care because of costs, and 26 percent had medical debt.[10] While these rates are significantly better than national averages, they still suggest that substantial numbers of people are having trouble getting care that is affordable to them. The following sections explain the affordability and minimum creditable coverage standards that were implemented under Chapter 58 to protect consumers, and then examine why some people are still finding it difficult to afford coverage and care.

Affordability and Minimum Coverage Standards

Chapter 58 requires people to be insured or pay a penalty if they have access to "affordable" insurance. The Connector thus established affordability standards specifying what people at different income levels could afford to pay for health insurance premiums. (See Figure 1)

Figure 1: 2009 Affordability Schedules[11]

INDIVIDUAL		FAMILY	
Income Range	Affordable Monthly Premium	Income Range	Affordable Monthly Premium
$0 – $16,260	$0	$0 – $27,468	$0
$16,261 – $21,672	$39	$27,469 – $36,624	$78
$21,673 – $27,096	$77	$36,625 – $45,780	$154
$27,097 – $32,508	$116	$45,781 – $54,936	$232
$32,509 – $39,000	$171	$54,937 – $72,800	$364
$39,001 – $44,200	$228	$72,801 – $93,600	$569
$44,201 – $54,600	$342	$93,601 – $114,400	$820
$54,601 or greater	Affordable	$114,401 or greater	Affordable

The Connector also established Minimum Creditable Coverage (MCC) standards defining the criteria insurance plans must meet to satisfy the individual mandate. The standards specify the services and benefits an insurance plan must cover and set limits on deductibles and total out-of-pocket expenses enrollees must pay. (See Figure 2)

Figure 2: Benefits Required Under Minimum Creditable Coverage Standards[12]

For most plans, the 2009 "Minimum Creditable Coverage" standards include:

- Coverage for a comprehensive set of services (e.g. doctors visits, hospital admissions, day surgery, emergency services, mental health and substance abuse, and prescription drug coverage).
- Doctor visits for preventive care, without a deductible.
- A cap on annual deductibles of $2,000 for an individual and $4,000 for a family.
- For plans with up-front deductibles or co-insurance on core services, an annual maximum on out-of-pocket spending of no more than $5,000 for an individual and $10,000 for a family.
- No caps on total benefits for a particular illness or for a single year.
- No policy that covers only a fixed dollar amount per day or stay in the hospital, with the patient responsible for all other charges.
- For policies that have a separate prescription drug deductible, it cannot exceed $250 for an individual or $500 for a family.

Affordability Issues for Low-Income Workers with Inadequate Employer-Sponsored Coverage

In order to make reform affordable for the state, a key goal of Chapter 58 was to keep as many people as possible covered by employer-sponsored insurance. For this reason, people with access to employer-sponsored coverage are ineligible for Commonwealth Care, regardless of whether the premiums are affordable according to the state's affordability standards.[13] While workers with unaffordable employer-sponsored insurance are exempt from the tax penalties imposed on state residents who do not have health insurance, they face a difficult choice – enroll in a health plan that is unaffordable or go without insurance coverage.

Workers whose employer-sponsored plans do not meet minimum creditable coverage standards are also ineligible for Commonwealth Care. But even workers whose plans meet MCC standards may still face significant deductibles, co-insurance, and other forms of cost-sharing. Plans that meet MCC standards can have deductibles up to $2,000 for individuals and $4,000 for families, and out-of-pocket maximums as high as $5,000 for individuals and $10,000 for families. This level of protection is significantly weaker than the protections provided under Commonwealth Care plans, which do not have deductibles and have out-of-pocket limits that range from $200 to $2,300 (including prescription medications) depending on income.

Most of our interviewees accrued medical debt while they were covered through employer-sponsored insurance. Judy and her husband, for example, have health insurance through her employer. She has conditions that could be improved by back and knee surgery, each of which requires a $500 co-payment. Her husband also needs medications for a chronic illness, which cost $50 to $100 a month. These out-of-pocket costs are unaffordable on their current income of $30,000 a year.

Michael earns about $27,000 a year before taxes and has employer-sponsored insurance. He has a chronic condition that has required ongoing medical treatment and, since 2006, two surgeries. Despite having insurance, over several years he has accrued medical debts that exceed his annual income. His current insurance has a $5,000 deductible and 10 percent co-insurance. His most recent hospitalization cost more than $130,000 just for room and board and tests. Although some of these bills will be reimbursed by the Health Safety Net, he still expects to be left with between $5,000 and $15,000 in out-of-pocket costs for services not covered by the HSN, which will add to his existing medical debt.

Theresa was earning about $25,000 a year and had insurance through her employer when she needed treatment for a variety of conditions, including blood work, a mammogram, medications, and surgery. She accrued medical debt because of her inability to cover the co-payments for her treatments — $250 for the surgery, $150 for emergency room visits, and smaller co-payments for ongoing doctors' visits and medications. As she put it, "those co-pays just kept on adding up when I kept on going to the doctors for different illnesses. And then they had to hospitalize me ….When I had the surgery the co-pays kept on adding up, and I just couldn't keep up with them." While HSN assists lower-income underinsured people with the unpaid portions of their bills, it does not cover co-payments. Theresa estimates that she currently owes about $1,200 for medical care.

The situations of people who have moved between employer-sponsored coverage and Commonwealth Care highlight how people may be affected by the current regulations. Dee has an autoimmune disease. She currently has medical debt of about $1,700. Some of this debt was incurred while she was insured through her employer because of co-insurance and co-payments she had to pay for procedures, tests, and doctors' visits. When Dee became unemployed and broke her arm, most of the bill was paid by the Health Safety Net. Then she applied for and enrolled in a Commonwealth Care plan. She had some difficulty finding doctors in her area that accepted this insurance, but she said "other than not having doctors, for the most part it was pretty good….Because with me being totally unemployed, I didn't have co-pays at first."

Dee then took a part-time job — her illness makes it impossible for her to work full-time – and had to go back on employer-sponsored coverage. As she put it, "you're mandated here in Massachusetts to have health insurance….You're considered insured if you have an employer that offers you insurance. It doesn't matter how much it is. I mean, it could have been $3,000 and they would have still considered me insured and kicked me off [Commonwealth Care]." She now earns $12 an hour, which is just enough to cover her mortgage. She is pleased that her current insurance charges co-payments rather than co-insurance, but still has not been able to keep up with the costs; she currently owes $275 in co-payments to a hospital and is finding it difficult to cover the co-pays for her prescription medications.

Affordability Issues for People With Moderate Incomes Without Access to Employer-Sponsored Coverage

While Commonwealth Care provides an important source of insurance coverage for uninsured adults with incomes up to 300 percent of FPL, people with incomes above that level who do not have access to employer-sponsored coverage may have difficulty affording private insurance. The Connector set rules for and markets non-subsidized Commonwealth Choice plans, which are designed to provide affordable options for people with incomes over 300 percent of FPL without other sources of insurance coverage. These plans have premiums that cost less than similar plans available prior to the implementation of health reform.

According to the Connector, the cost of non-group insurance for a 37 year old prior to health system reform was approximately $335 for a plan with a $5,000 deductible and no prescription drug coverage.[14] After reform, the cost for the same individual was reduced to $184 for a plan with a $2,000 deductible and prescription drug coverage. Nonetheless, the Commonwealth Choice plans may still be expensive, especially for people with incomes just over 300 of FPL, both in terms of their premiums and their out-of-pocket cost sharing. Also premiums are age-rated, and while Massachusetts sets limits on the degree of variance in premiums due to age, costs can be especially high for older people.

For example, the lowest cost Commonwealth Choice plan, which has a deductible of $2,000 and 20 percent co-insurance after the deductible, costs $417 a month for someone aged 62, or about $5,000 a year. For an individual earning $33,000 a year, just over 300 percent of FPL, this premium constitutes about 15 percent of his or her income. A Helpline counselor who advises people about insurance options said, "We always tell [people] about [Commonwealth Choice]. They call back. It's too expensive. I can't afford it. Everybody says it's too expensive."

As of May 2009, 22,048 people were enrolled in Commonwealth Choice plans. (This figure is an underestimate, because it only includes people who bought their plans through the Connector. The same plans can also be purchased directly from insurers outside of the Connector.) Enrollments in the program have slightly outpaced cancellations. In March of 2009, 40 percent of cancellations were for reasons other than qualifying for other coverage, although it is not possible to say how many of these people cancelled because of unaffordability.[15]

Mark, for example, is not offered insurance through his employer, and he and his wife make too much to qualify for Commonwealth Care. They are exempt from the tax penalties for not having insurance because they do not have access to an affordable insurance policy. However, they would like to have coverage. Mark found the non-subsidized Commonwealth Choice plans unaffordable. He looked at other insurance products on the private market, but the only plans with affordable premiums had high deductibles and co-insurance, which he knew he could not pay if he or his wife became ill. Mark and his wife have qualified for partial coverage through the Health Safety Net, but the HSN requires that they pay a deductible of almost $10,000, which will be difficult for them to afford if one of them gets sick.

Affordability Issues for People with Public Coverage

As the stories above illustrate, the cost of purchasing private insurance or the out-of-pocket costs associated with employer-sponsored or private insurance created affordability problems for many of our interviewees. Public programs provide important financial protections for enrollees by limiting premiums and cost-sharing at levels below those in typical private insurance plans. However, while these costs may be manageable for many enrollees, some of our interviewees found them difficult to pay.

Commonwealth Care: Commonwealth Care charges premiums for people with incomes between 150 and 300 percent of FPL. In 2009, premiums for the lowest cost plans range from $39 to $116, depending on income, representing approximately 3 to 4 percent of income for an individual. Co-payments are not required for people earning less than 100 percent of FPL, but for those with higher incomes, co-payments for outpatient services are in the range of $10 to $20 per visit. Co-payments for emergency care are $50 or $100, depending on income and plan type, and co-payments for a hospital stay are $50 or $250. Limits on co-payments, including prescriptions, are $1,250 or $2,300.

A manager of patient financial services at a hospital in Massachusetts commented that she had recently seen a lot of people who had stopped paying their Commonwealth Care premiums because they couldn't afford them. Similarly, a Helpline counselor reported "I hear a lot about [people not being able to pay their premiums] in the field. Just from other health advocacy workers that folks are struggling right now and they can't afford the Commonwealth Care premiums even though they're subsidized to a big extent." She said,

> What happened is they stop paying [the Commonwealth Care] premiums. They're still using the benefits, but they stop paying for three months and then [the Connector] cancels. Then they go to the doctor one day and they find out they were canceled….They call us, and we call and find out that they are behind three months and…they cannot use [Commonwealth Care] until they pay for that….

According to the director of Commonwealth Care, disenrollment for failure to pay co-payments has consistently been very low. However, advocates say they are seeing an increasing number of people who are having difficulties covering co-payments. The Helpline counselor said of some of her clients who were newly enrolled in Commonwealth Care, "Oftentimes these are folks who it's their first time…they have never had health insurance [before], so they don't understand it's not just the premium that you have to pay, but every time you go to a doctor or a specialist, every time you need a prescription drug." She pointed out that affordability standards set by the Connector only take into account the cost of premiums, and not other out-of-pocket health care costs (even though that is required in the Chapter 58 legislation). Co-payments may be especially difficult for people with chronic conditions who need to get treatment or use medication frequently.

One of our interviewees, Mona, has a chronic illness and is covered by a Commonwealth Care plan. She said the plan was a "good thing" for her. Nonetheless, she found it hard to keep up with the co-payments. She said, "It was tough for me to pay all those co-pays when I have to go almost every week, it is tough. It is tough. Medication and everything…. I saw my primary care doctors, my cardiologist doctors, [they] all add up."

The Connector does allow people on Commonwealth Care to apply for premium and co-payment waivers. According to the Connector, between June 2007 and August 2008, among the over 200,000 people who had been enrolled in Commonwealth Care, fewer than 800 submitted waiver requests for premium or co-pay reductions.[16]

Health Safety Net (HSN): For uninsured individuals without access to affordable insurance, such as those exempted from the individual mandate, and for underinsured individuals, the state provides support through the HSN. In our interviews with clients, we found that HSN coverage was of great assistance to many individuals with unaffordable medical bills. However, HSN does not cover some services and out-of-pocket costs, and it also requires payment of a deductible for people over a certain income threshold. For example, the HSN does not provide coverage for co-payments for underinsured people. The failure to cover co-payments becomes more significant as cost sharing in many employer-sponsored plans has increased,[17] and we have already described some people who have struggled with co-payments not covered by HSN.

Depending on people's income, the HSN may also require that people pay a "deductible." For some people, this deductible is unaffordable. Mark, described previously, had an HSN deductible of almost $10,000. Linda, who had an inadequate insurance policy, incurred $1,800 in unaffordable medical bills. She applied to and was enrolled in the HSN, but the program required that she pay a $3,000 deductible. Thus she did not receive any assistance paying the medical bills that she found unaffordable.

Finally, HSN only covers services provided in acute care hospitals and CHCs. It does not cover other bills, such as those resulting from doctor visits, ambulances, or labs. A patient may receive care in a hospital and have a portion of his bill covered, but the ambulance trip to the hospital, bills from physicians who treated him in the hospital, and tests sent to external laboratories may not be covered. A Helpline counselor said that among her clients, the most common services not covered by HSN are ambulances and laboratory technicians. Even with HSN support, some patients are still left with substantial bills that they cannot afford to pay.

System Complexity Can Lead to Gaps in Coverage

The multiplicity of programs in Massachusetts provides health coverage options for a variety of populations. However, the programs have varying eligibility criteria and program rules, which create the potential for gaps in coverage as people move in and out of programs or move from one program to another. People may also fall out of programs because of confusion over program procedures. In addition, the complexity of the system makes it more likely that people will not learn about programs that may benefit them. In a survey of outreach workers who help people in program enrollment, respondents identified the biggest barriers their clients experienced to getting and keeping health insurance as general confusion about paperwork (78%) and general confusion about systems and programs (50%).[18]

The following sections describe some of these issues in more detail.

Churning in Commonwealth Care

A major problem in Commonwealth Care is the high number of enrollees who lose coverage and then reenroll within relatively short periods of time, a process called churning. Enrollment in Commonwealth Care plans increased steadily through October 2007, but leveled off starting in early 2008. One of the key factors was the initiation of a formal process of redetermining eligibility for existing enrollees, which began in November 2007.[19] Because of confusion over the re-determination process, many people who were still eligible for Commonwealth Care were dropped from coverage. Between February and December of 2008, 19 percent of people terminated from Commonwealth Care reenrolled within 5 months.[20]

A patient financial services manager at a Massachusetts hospital said that her department had seen a lot of people in the previous year who hadn't filled out the redetermination forms and were seeking help in completing them. A Helpline counselor echoed these concerns. She attributed the problem to people's confusion about why they were receiving a form from MassHealth, which handles the redetermination process for Commonwealth Care. She said,

> Folks only have 30[21] days to fill out a [redetermination] form that comes from MassHealth [Medicaid], when this person doesn't associate themselves with MassHealth....[Commonwealth Care has] found through studies they've done with their members that people don't even associate themselves with Commonwealth Care. They associate themselves with their health plans. So folks get these things in the mail. They look like a bill....[The person] doesn't do anything until they call us two months later when they went to the doctor and the doctor says your [insurance] is not active … there's this cycle of people churning on and off of that program.

The director of a Community Health Center also reported major issues with churning. He said that about ten percent of his patients were "falling through the cracks in Chapter 58," primarily because of losing Commonwealth Care coverage. Under new HSN rules, people who have lost Commonwealth Care coverage because of failure to pay premiums are not eligible for HSN coverage. During the period when patients lack coverage, they may thus accrue medical debt or the CHC may need to absorb the costs as uncompensated care.

Advocates also say that gaps in Commonwealth Care coverage have resulted from errors in the process for screening applicants to see if they have access to employer-sponsored coverage. The application form asks people if their employer offered insurance in the last six months. If applicants leave this question blank or answer yes (even if they are not eligible for their employer's insurance), they are denied Commonwealth Care and sent a follow-up form. According to the advocate, it can take anywhere from a couple of weeks to a month or more to process the follow-up form. She said, "So if they conclude yes, you were improperly denied, you're eligible after all, you still only get enrolled the first of the next month or the first of the month after you pick a plan and choose a premium. So meanwhile months have passed in which you could be without insurance."

The Connector has, in fact, acknowledged that the redetermination process is a significant problem and has made creating a more user-friendly process one of its key goals for Commonwealth Care. For example, it is sending inserts specific to Commonwealth Care to draw members' attention to the redetermination forms, developing online tools people can use to enroll in or renew Commonwealth Care coverage, improving questions asked to determine eligibility, and improving the process for determining whether people have access to employer-sponsored coverage.[22]

Problems Moving Between Public Programs

Because Commonwealth Care coverage is reserved for people who do not have access to other insurance, people eligible for other public coverage programs are not eligible for Commonwealth Care. As people's situations change, they may become newly eligible for a public program and thus cease to be eligible for Commonwealth Care. Moving between programs can be bureaucratically complex and leave people with significant gaps in coverage. This can occur, for example, when enrollees move between Commonwealth Care and MassHealth.

In Commonwealth Care, as in commercial health insurance plans, enrollment always starts on the first day of the month after an enrollee pays the first premium and ends on the last day of the month. The director of the Commonwealth Care program said the state wanted to develop a program that took "the best of commercial insurance and Medicaid," and she saw this enrollment policy as an example of applying commercial design principles to the program. In MassHealth, in contrast, both enrollment and termination can occur on any day of the month.

From the perspective of the Commonwealth Care director, Commonwealth Care's enrollment policy was an advantage for plan members. "You can lose eligibility on the second day of the month and have Commonwealth Care until the end [of the month]. I think that's a huge benefit because for those members who need to find other options, it gives them time to do that." Advocates reported, however, that because of the difference in enrollment procedures, people moving from MassHealth to Commonwealth Care may experience a period without insurance while they are waiting for Commonwealth Care coverage to begin.

A similar situation occurs when people on Commonwealth Care become unemployed and start receiving unemployment insurance. In Massachusetts, the Medical Security Program (MSP) helps people who are receiving unemployment assistance pay their COBRA premiums or provides them with transitional private insurance coverage. People eligible for MSP lose their eligibility for Commonwealth Care. However, the process can be extremely difficult for people who need to move between Commonwealth Care coverage when they are employed and MSP when they become unemployed.

An outreach worker on Cape Cod described the situation for seasonal workers who move frequently between Commonwealth Care and the Medical Security Program. Her description gives a sense of how extremely complicated the process can become.

With the seasonal employment swing on Cape Cod, we and our patients are lost in the maze of Commonwealth Care and Medical Security Program (MSP) enrollment. There are new applications, coverage gaps, frustration and confusion at every turn…

Typical seasonal employees here on the Cape work between April/May and September/October and collect unemployment compensation for up to 26 weeks during the winter. While seasonal employees are working, they may be eligible for Commonwealth Care. Once they begin to collect unemployment, however, they are technically ineligible for Commonwealth Care and are supposed to enroll in the Medical Security Plan instead. A seasonal worker may switch between Commonwealth Care and MSP up to four times a year. Unfortunately, this switch sounds simpler to make than it actually is.

Last week, I had a patient who mailed in the MSP application the day after opening her unemployment claim at the end of September because she knew she was about to lose her Commonwealth Care eligibility. In turn, she received a denial from MSP because she had Commonwealth Care. We learned through her experience that MSP is requiring a termination letter from Commonwealth Care before considering an application, even though the state denies Commonwealth Care to anyone collecting unemployment.

The MSP representative referred her back to her Commonwealth Care plan for a termination letter. Her plan referred her back to Commonwealth Care customer service, who referred her back to the MassHealth Enrollment Center (MEC).[23] Assuming that everything goes as smoothly as possible and there is no further confusion, the patient will wait up to 4 weeks for MSP to reprocess her application. The coverage is retroactive to the opening of her claim, but she will not have a card to receive services until the application is processed. In the meantime, her Commonwealth Care has been terminated and the patient is left with an enormous amount of frustration and a coverage gap during which she can get only Partial Health Safety Net (HSN).

In the spring, when she returns to work and reports her earnings—ideally within the first two weeks—the MEC will take another two weeks to process the change. Since Commonwealth Care coverage starts on the first day of the month after her first premium check is received, rather than the date of application, she may have to wait up to eight weeks after losing MSP coverage to be re-enrolled in Commonwealth Care.

Seasonal workers are required to switch coverage types more frequently if they have to re-open their old unemployment claims in the fall until their benefits are exhausted (during which time they're MSP-eligible). This is followed by the requisite waiting period before opening a new unemployment claim (now they're Commonwealth Care-eligible), the opening of a new unemployment claim (back to MSP-eligible again), and finally, going back to work in the spring (when they become Commonwealth Care-eligible once more). In cases like this, a seasonal employee becomes subject to a gap in coverage between the two programs four times a year.

Some patients are even willing to pay their Commonwealth Care premium while on unemployment just to avoid the on-and-off-again insurance coverage, but do not seem to be permitted to do so. They should be. Scheduled appointments, referrals, procedures, and continuity of prescription therapy are all undermined by the inconsistent coverage.[24]

System Complexity and Program Awareness

One unintended consequence of the complexity of the public coverage systems in Massachusetts is that consumers may often be unaware of resources available to help cover the costs of their medical care. Frequently, people only learn about available resources if they are lucky enough to come into contact with a community health worker who can assist them. Some people do not learn about available resources until it is too late to apply for them.

A Helpline counselor noted that she still hears from many people, especially those treated in emergency rooms, who are not screened for coverage for public programs. She said that people often call the Helpline for assistance *after* they have received a bill. While public programs may be available to provide coverage retroactively for some or all of the bill, people often call for assistance after the period for retroactive coverage has been exhausted and they no longer qualify for assistance. Michael, one of our interviewees, is currently covered by HSN. He said he found out about the program on the back of one of his bills "in small print at the bottom." However he only learned about the HSN after he had already incurred significant medical debt.

The Helpline counselor also noted that the Customer Services representatives employed by the Connector and MassHealth are sometimes only knowledgeable about the programs they service, and not about other programs callers may be eligible for. She said, "Unless they are really savvy, they aren't trained to give people information about the MSP. They're only trained to give information on the programs they administer. There's a huge disconnect. You're laid off and given the unemployment packet, which has [the Helpline's] number, but also includes the number of Commonwealth Care and MassHealth," and if consumers call those organizations they may not get the right information. (Some advocates have reported that this situation is improving because of money from the federal economic stimulus plan directed towards subsidizing COBRA payments for people laid off from their jobs.)

Martina, one of our interviewees, ended up with medical debt because of these types of complexities. She became ill when she was unemployed and receiving unemployment assistance. When she went for care, hospital staff helped her apply for public coverage. She was mistakenly approved for MassHealth. She then went to get a physical, thinking she was covered by MassHealth. Later she discovered that her MassHealth coverage had been revoked and the bill for the physical would not be covered. She said, "I had no idea that MassHealth…couldn't give me insurance…because I have to get my insurance through the Unemployment Office." She then submitted an application to MSP, but was told that her unemployment was going to run out soon, and she was unsure if she would be able to extend it. She now has a $900 bill for her physical that is not covered by any program. She said she didn't submit her MSP application earlier because she didn't know she was supposed to do so.

THE CONSEQUENCES OF UNAFFORDABLE MEDICAL BILLS

A great deal of research has documented the consequences of medical bill problems for people, both in terms of their financial stability and their access to health care. A Commonwealth Fund study showed that in 2007, among people who had medical bill problems in the previous year, nearly 3 in 10 (29%) were unable to pay for basic necessities, nearly 4 in 10 (39%) used up all of their savings to pay medical bills, 3 in 10 took on additional credit card debt to pay medical bills, and 1 in 10 took out a mortgage against their home or took out a loan.[25] With respect to access to care, a Kaiser Family Foundation study found that insured people with medical debt acted more like the uninsured than the insured without medical debt: 28 percent of the privately insured with medical bill problems postponed care and 30 percent skipped a test or treatment due to cost, figures similar to those for people without insurance.[26]

Our interviews of people with medical debt showed that they experienced many of the problems reported in these national studies. For some people, debt from unaffordable medical bills was their only debt. For others, medical debt compounded problems they faced paying off other bills, such as student loans. In a number of cases, people's illnesses affected their ability to work and their incomes, which affected their budgets overall. Nearly everyone reported reducing their standard of living and many people had used up their retirement or other savings to pay off medical and other bills.

Although almost everyone we interviewed wanted to pay off their debts, people's choices about how to deal with them varied depending on their circumstances. Some people paid their medical bills before other bills because they needed to maintain their relationship with their doctors. Others said they had to pay bills for basic necessities first, such as their mortgage or utilities bills. Some people put their medical bills on credit cards, while others said they did not want to pay the interest on the debt, even though they knew that their outstanding bills would have a detrimental effect on their credit record.

People's ability to pay their medical bills was also often affected by the willingness of their providers to negotiate over the amount of the bill or the terms of a payment plan. Some of our interviewees had very positive experiences negotiating with providers, while others did not. In cases where providers were unwilling to negotiate, many found that their bills were turned over to collection agencies.

Michael, for example, has a chronic disease. He accumulated very large medical debts because of his need for treatment, including surgeries. He tried to set up a payment plan with one of his providers to deal with his unpaid bills. He said, "I have set up payment plans with them before. And then if your payment's a day late, they call you and say, 'You broke the payment plan. We want it all.' They're not reasonable at all." He has been harassed by collection agencies because of his bills, which have had a negative effect on his credit record. He said, "It's nearly impossible for me to get credit anywhere." However, he has avoided charging his medical bills to his credit card. He said, "I've never borrowed to pay [the medical bills] because I didn't want to put myself further in debt. And then I would have to pay interest [on the debt]."

Moira's husband earns about $55,000 a year. She has one son who had a serious injury, another with a congenital problem, and she herself has a chronic illness. All contributed to her accrual of large unaffordable medical bills. Because of the bills, she said they have reduced their standard of living. "We certainly made changes in terms of food, lowering the thermostat…." Moira negotiated with a hospital about one of her bills. The hospital was willing to put her on a payment plan but not willing to negotiate a discount. She said, "[The hospital] will lower the bill sometimes to ten dollars a month. They have been very helpful; they have not been very helpful with writing anything off." However, she said that the ambulance company was very difficult to negotiate with. "I filled out applications for them and we have fit none of their criteria. So it must be rather strict criteria, I don't know what it is." To pay her medical bills, she and her husband have charged some to credit cards, borrowed $5,000 against his 401K plan, and withdrawn $45,000 from her retirement account.

Dee said that prior to her current illness, "I've had…almost the highest [credit] rating score you can have. And I've never had debt. Never….I've never been sick." Since she became ill, she has only been able to keep her heat turned on because she received fuel assistance, and she gets food from food pantries. She has put off paying some of her past medical bills because she needs to save the money to pay for current doctors' visits and prescription medications. She said that she doesn't think she will be able to get another credit card because the fees would be too high because of her debts.

Delaying care because of cost and fear of incurring more debt was also a common occurrence, especially when people were uninsured or had employer-sponsored coverage with cost sharing. Of the 15 people with medical debt we interviewed, 13 reported delaying care at some point because of cost.

- Theresa, who also has employer-sponsored coverage, said her doctor wants her to come in for a mammogram because of lumps in her breast, but she said "I've been putting that off because I keep telling them I can't continue with the co-pay because I don't have it."

- Ida, who is covered by the HSN but with a large deductible, said she has put off getting a mammogram and care for her eyes. She said, "I think I went [to the eye doctor] three years ago and I really feel like I need to go, but I haven't gone because I don't have the money."

- Michael, who has insurance through his employment, including dental coverage, said he is delaying going to the dentist because he cannot afford it. He knows his dental insurance covers annual cleanings, which he gets, but it won't cover the bridgework and other things he needs done.

- Judy who has employer-sponsored coverage, is putting off hip surgery because of her unpaid bills. She said "I didn't want to be having to owe another $500 [for the co-payment]. I hate owing money."

As we described earlier, some of our interviewees were finally able to access needed care once they became enrolled in a Commonwealth Care plan and were grateful for the ability to seek care without experiencing anxiety about the costs. However, for a few people with chronic illnesses, even the relatively moderate Commonwealth Care co-payments were a barrier.

One final consequence of unaffordable health care bills should also be noted. Almost all of our interviewees experienced great stress and anxiety because of their inability to pay off their bills and their fear of incurring further debt. It is striking that for many, it is the unpredictability of medical expenses and uncertainty about how medical expenses may affect their futures that cause the greatest anxiety. The sense that medical debt undermines their control over their own lives is reflected in many interviewees' comments.

Martina fears what might happen because of her debt. She said, "I've seen it on the news where medical doctors want their money and they'll come and repossess whatever you have. My kids are in METCO (a program that allows minority children in Boston to attend schools outside of the city) and they go to school in the suburbs. So I'm so concerned that in the middle of the night they're going to come and take my car."

For Jeff, the debt inspires a sense of inadequacy. "You get washed up and you end up on the beach like a whale, useless...I wish I could just hit a lottery. The first thing that I would do is pay taxes and my hospital bills....Because it would just relieve this amount of pressure."

Don, Judy's husband, perhaps put it most directly. He said, "I just find the lack of clarity is horrifying. You're just not sure what is going to happen....The uncertainty is as bad as high debt. If you knew for certain everything was going to cost too much you'd deal with things in a different way. And if it costs reasonably, then you'd deal with it too. But if you don't know...."

LESSONS FOR NATIONAL HEALTH REFORM

In developing its health reform initiative, designers of the Massachusetts system tried to ensure that programs were available to help almost everyone get either insurance coverage or assistance in paying for health care. MassHealth continues to serve traditional populations, such as low-income families with children. Commonwealth Care plans are designed for low-income adults without access to other sources of coverage. People with employer-sponsored coverage are expected to keep that coverage. For higher income people without access to employer-sponsored coverage, non-subsidized Commonwealth Choice plans were created to provide what was considered affordable non-group coverage. And for people who still "fell through the cracks," the Health Safety Net subsidizes certain costs for uninsured people or people with inadequate insurance. This structure incorporated and built upon the wide array of public programs and safety net coverage that existed in Massachusetts prior to health reform.

In many ways, this reform effort has been a success. The impressive drop in rates of uninsurance in the state has been widely noted, and many of our interviewees have benefited from the available programs – both ones that existed prior to reform and the new Commonwealth Care plans implemented as part of reform. However, when looked at from a consumer point of view, the reformed structure presents two major barriers to getting affordable care.

One issue for consumers is that the protections provided to Commonwealth Care and MassHealth enrollees regarding limits on premium and out-of-pocket health care costs were not extended to all lower and moderate income people. As a result, workers in employer-sponsored coverage, especially those with lower incomes, may end up with insurance premiums and out-of-pocket costs that are unmanageable given their incomes. For moderate income workers without access to employer-sponsored coverage, especially those just over the limits for Commonwealth Care eligibility, the options available to them may be an improvement on what was available prior to health reform but still unaffordable. Although the HSN provides some back up coverage, it does not cover everything and the support it provides may not be adequate for everyone.

These problems in part reflect affordability decisions that set coverage limits based on the state resources available. They may also reflect misconceptions about the costs that people at various income levels are able to absorb. People generally think of financial problems resulting from health care costs as the result of catastrophic bills people incur because of major illness. However, a recent study found that most people who reported problems paying medical bills had relatively modest levels of out-of-pocket spending; 59 percent had expenditures of $1,000 or less a year, and about half spent 2.5 percent or less of family income on out-of-pocket medical expenses.[27] Thus, even costs that seem nominal for those with higher incomes can have a strong negative impact on the finances and access to care of lower-income people, especially those with chronic conditions.

The second issue is that the reformed system is complicated for consumers to navigate, which may lead to gaps in coverage as people move among different types of insurance, both public and private. The situation in Massachusetts may be exacerbated by the fact that the various public programs are administered by different state agencies.[28] As one advocate put it,

> One of the challenges of incremental reforms, of trying to fill the gaps as opposed to just creating enough for everybody in a coherent way, is you still are making all of these little distinctions to figure out which bucket people fall into....That makes for complex administration.

The Massachusetts experience shows that to make affordable health care accessible to consumers, it is not sufficient to ensure that programs are available to cover everyone. The quality of the coverage provided and the interrelationships between the programs are also important. Based on our research, we believe that Massachusetts can provide some useful lessons for those developing a national reform program about how to make a restructured health care system work for consumers.

- **Public programs can be an important foundation for health reform efforts.** Health reform initiatives should take into account the realities faced by lower-income people, who tend to change jobs frequently, have spells of unemployment, and often have the least comprehensive employer-sponsored coverage. From the perspective of lower-income consumers, the expansion of MassHealth and the creation of the Commonwealth Care subsidized health insurance plans have proved to be the most beneficial aspects of Massachusetts' health system reform. Allowing lower-income people to maintain coverage under these types of public programs would eliminate the frequent cycling among different forms of coverage that has characterized their experiences under Massachusetts' reforms, and ensure them access to more consistent, continuous, and affordable care

- **The quality of employer-sponsored health coverage matters.** If a national health reform plan intends to keep as many workers as possible in employer-sponsored coverage, both the comprehensiveness of the benefits and the affordability of the coverage matter. Setting robust minimum benefit levels and limits on the percentage of income people can be required to pay for health care, taking into account both premiums and out-of-pocket expenses, could help assure that coverage is adequate.

- **Simplifying enrollment and redetermination procedures can ease barriers to obtaining coverage.** Creating "no wrong door" enrollment policies and procedures through which people can gain access to all programs available to them can help reduce system complexity and facilitate enrollment into the appropriate coverage program. This should include simplifying procedures for redetermining people's eligibility for programs and easing the transitions from one program to another. Strategies such as combining programs, continuously monitoring and improving the interfaces between programs, standardizing program rules and requirements, and using established techniques such as presumptive eligibility can reduce program churning. Also, outreach and enrollment support will be an important component of any mixed public/private health system, and ongoing funding for outreach will be important.

- **People with chronic conditions need special consideration because they face greater barriers to care because of cost**. Nominal co-payments may be affordable for lower-income people who need care only occasionally. However, for those who need ongoing treatment and medications, the costs can quickly become unaffordable. Policymakers in the United States have experimented with eliminating or lessening co-payments for care that is known to be effective for certain chronic conditions, which has resulted in improved compliance and cost savings.[29] Other countries have also eliminated co-payments for people with chronic illnesses. Such approaches should be considered as part of any health system reform effort.

- **Medical debt is a barrier to accessing needed health care.** Pre-existing medical debt can act as a barrier to getting care, as people are often faced with the choice of getting care needed currently or paying off overdue bills. Providers may refuse to treat people until existing debts are paid off. Forgiving such debts or reducing them to levels that people can manage may help ensure that people are able to get the care they need. In addition, standardizing provider charity, discount, and billing and collections policies can help people avoid accruing new medical debt during the transition period. Prohibiting the sale of debt to third parties and the reporting of debt to credit bureaus would limit the harm people experience because of any existing debt.

- **Even in a reformed health system, a health care safety net will be needed.** National health reform will not eliminate the need for a safety net, for people who are not covered under public or private programs, for those who have periods without coverage as they move between programs and coverage, and for those who are underinsured. Including an easily accessible safety net program to help cover costs if and when people have interludes of un- or underinsurance, or to provide care at affordable rates, can help to ensure continued access to care and protect people against financial hardship caused by unaffordable medical bills.

- **Ongoing monitoring of access and affordability will be important even if a reform plan is implemented.** Setting affordability standards for insurance is a difficult task, because affordability depends on actual costs, people's resources, and the amount of care they require. Even relatively nominal costs can quickly become unaffordable and destabilize the financial situations of low-income people. In a reformed system, it will be important to gather information from consumers in an ongoing way to understand how the cost of insurance and care is affecting their ability to access care and the financial stability of their families.

This report was prepared by Carol Pryor and Andrew Cohen of the Access Project. The views presented are those of the authors and do not necessarily reflect those of the Kaiser Family Foundation.

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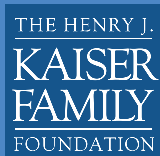

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