INTRODUCTION

As health care costs rise throughout the country, Americans are paying more for care, even when they are insured. A recent issue brief found that persistent underinsurance affects a significant portion of the U.S. population, who as a result do not enjoy the financial protection that insurance is supposed to provide. According to the report, “more than one of five 19-to-64-year-old adults who were insured all year spent 5 percent or more of their income on out-of-pocket costs, not including premiums, and 13 percent spent 10 percent or more.” The situation in Massachusetts is similar to the one in the U.S. as a whole. The cost of health care is a problem for many people across the economic spectrum. Though the Commonwealth leads the nation in health insurance coverage, with 95 percent of Massachusetts adults insured, a significant number of people struggle with the affordability of health care.

As employer-sponsored insurance (ESI) plans—the source of health insurance for most people—increase cost sharing in the form of high deductibles, co-payments, and co-insurance, many middle-class workers and their families are struggling to pay medical bills, even when they are insured. In 2013, one of five Massachusetts adults insured for all of the previous year reported out-of-pocket health care spending that was more than five percent of their income, and nearly one of five reported problems paying medical bills or reported paying them off over time (Figure 1). People who have low incomes, those who are in poor health or have chronic conditions needing regular care or medication, and those who are only intermittently insured experience even greater difficulties with the high cost of health care.

Unless otherwise indicated, all data in this report are from the 2013 Massachusetts Health Reform Survey (MHRS), funded by the Blue Cross Blue Shield of Massachusetts Foundation and the Robert Wood Johnson Foundation.

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Photography by Tim Dailey, University of Massachusetts Medical School


Figure 1: Many full-year insured adults report health care affordability problems.

The 2006 Massachusetts health care reform law has been successful in insuring most residents and protecting people financially against potentially catastrophic costs, such as for expensive hospitalizations or other specialized treatments. However, affordability continues to be a challenge for a sizable portion of the state’s population. Most people with health insurance are required to share in the cost of care, and the costs can accumulate to a prohibitive level over time, resulting in financial hardship and diminished access to care.

FACTORS INFLUENCING HEALTH CARE AFFORDABILITY

Why is affordability a problem for many people in a state with near-universal health insurance coverage? Three important factors are the rising costs of health care without corresponding adjustments in income, the insurance market’s and employers’ responses to cost trends, and individual health care needs.

1. Health care costs and family incomes

The primary reason why health care affordability remains persistently challenging is that health care costs continue to rise. Per capita spending on health care in Massachusetts increased an estimated 27 percent from 2006 to 2012.\(^3\) Incomes have risen as well, but at barely half the pace. Though recent health care cost growth has been more moderate,\(^4\) that follows years of significant increases. Consumers’ own spending on health care (including their share of insurance premiums) grew 38 percent between 2006 and 2012, but median income increased only 15 percent, widening the affordability gap (Figure 2).

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2. Changes in the insurance market and employer plan offerings

The rising cost of health care puts upward pressure on insurance premiums. In response, employers and health plans try to limit premium increases using strategies such as offering more high-deductible plans and increasing co-payments, co-insurance, and out-of-pocket maximums. These approaches represent a cost shift from insurers and employers to consumers. A longitudinal look at the MHRS results reflects this change in the marketplace (Figure 3). The use of high-deductible plans is particularly prevalent in the individual and small-group markets, with 45 percent of the individual and 38 percent of the small-group membership in such plans.\(^5\) One rationale for this strategy is that by making consumers sensitive to the price of health care services, they will seek less-expensive care and reduce unnecessary utilization. However, this approach can result in less financial protection when people need to use health care. In addition, some analysts have argued that this can result in consumers forgoing needed care, especially medications.\(^6\)

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Health plans with deductibles, many over $1,000, have become more common in Massachusetts in the last several years, an indication of increasing expenses for consumers.

Health savings accounts, referenced in Figure 3, are financial tools intended to help consumers make out-of-pocket medical costs more manageable. These accounts must be used in conjunction with a high-deductible health plan. Flexible spending arrangements (FSA) are a different but related tool also designed to help consumers with out-of-pocket medical costs. FSAs may be used without a high-deductible health plan. According to the MHRS, only 19 percent of currently insured lower-income respondents with ESI have an FSA, and only 32 percent of people with higher incomes have such an account. Those who are self-employed do not have access to FSAs to help manage out-of-pocket costs.

The impact of these changes in health insurance products can be seen in spending trends, which show that by 2013, nearly one in ten adults spent over 10 percent of income on out-of-pocket health care costs (Figure 4). For an insured family of four with an income three times the federal poverty level (about $71,000 in 2013), that represents a burden of more than $7,000 per year over and above the cost of insurance premiums.

Source: 2012 MHRS.
Note: The MHRS did not include questions about deductibles over $1,000 prior to 2008. In addition, many respondents have public insurance, which does not include deductibles, and some respondents are not included in the chart because they did not know the details of their health plans.

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7 An FSA is an employer-established benefit plan, generally funded by a voluntary salary reduction. FSA funds are not taxed and are held in an account that can be used to pay health care expenses. See “IRS Publication 969: Flexible Spending Arrangements (FSAs)—Distributions From an FSA,” Irs.gov.

8 “Lower-income” is defined here as having family income at or below 300 percent of the federal poverty level (FPL).
3. Health care needs

While Massachusetts is one of the healthier states by some measures, more than half of adults in the survey report having a chronic health condition—a proportion similar to that reported by adults nationwide. In the MHRS, asthma and hypertension are the conditions most frequently reported. One in five respondents report that health issues interfere with their daily activities, and nearly 15 percent consider themselves in either fair or poor health. The health status of Massachusetts adults has remained relatively stable since 2006, but out-of-pocket spending has increased markedly. This suggests that while those with greater health care needs might have even greater affordability challenges than others, health status is not the only driver of this spending trend.

9 Massachusetts ranks fifth in life expectancy and obesity rates, according to Kaiser Health Status reports, http://kff.org/state-category/health-status/.
Nonetheless, the burden of high health care costs falls particularly hard on those in poor health. Three in ten of those who say they are in fair or poor health reported having problems paying medical bills in the last 12 months, compared with 10 percent of those in very good or excellent health. Because chronic health issues disproportionately affect the poor, those who can least afford the out-of-pocket costs are the most likely to incur them.

WHAT ARE THE CONSEQUENCES?

Financial consequences

Medical bills result in a variety of financial issues, including difficulty paying other bills, the need to pay medical bills over time, and bankruptcy. The issues are widespread, with 25 percent of full-year insured adults reporting that health care spending caused financial problems for their family in the past 12 months. The issues are more pressing for those without ESI, who are more likely to purchase lower-value plans and, if they do not receive a state subsidy, may have to cover the full cost of their premiums. Forty percent of those with non-ESI coverage and incomes over 300 percent of FPL (a level of income that generally makes them ineligible for state subsidies) report experiencing financial problems associated with medical care.

While financial issues caused by medical costs disproportionately affect low-income people, middle-income people are increasingly experiencing medical debt. Since 2007, the percentage of people with medical debt increased from 8 to 19.5 percent for people in the income group between 300 and 399 percent of FPL. People in this group generally do not qualify for public insurance; and premiums, co-insurance, and deductibles make health care unaffordable for many of them. While the percentage of respondents paying off high medical bills (greater than $1,000) decreased in all income groups immediately following the 2006 health care reform, the levels have been rising since then and now exceed the levels recorded at the time of the 2006 reform (Figure 5). This is consistent with national trends, which show an increase in non-elderly adults with medical debt, regardless of insurance status, from 21 percent in 2005 to 26 percent in 2012. Among adults who were insured all year in 2012, 24 percent reported having medical debt.

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12 As of 2014, as a result of the Affordable Care Act, members of this income group may be eligible for subsidies if they do not have access to affordable ESI.
**Impact on access to health care**

A third of the full-year insured Massachusetts population say they have unmet medical care needs, and nearly half of that group (13.8% of all respondents) report cost as the reason. Certain survey populations report even higher rates of avoiding care due to costs—particularly younger adults, parents, people who identify themselves as Hispanic or Latino, and those without ESI.

People with chronic conditions need the most medical care and are the most likely to experience financial difficulties as a result. One in seven full-year insured adults did not get needed care because of costs in the last 12 months. The types of care most frequently avoided due to costs are dental care and prescription drugs.

Avoiding care due to costs is most common among people in fair or poor health, those who live just above the federal poverty level, and those who have less than a high school education. Nearly a quarter of the people in these groups have unmet needs due to cost (Figure 6), and nearly 30 percent have experienced problems paying medical bills.
Figure 6: Poor health, low income, and lack of ESI are most strongly associated with people not receiving care due to cost.

These survey data give an overall but abstract picture of the challenges that remain in ensuring that all Massachusetts residents can receive and afford the care they need. Behind the data are people confronting these challenges, making real-world choices, and experiencing the consequences. The remainder of this report is devoted to telling a few of their stories, in their own words.
Katharine Jackson wondered if the bills would ever stop. The 41-year-old knew she’d have to bear some of the costs to diagnose and treat her rare inflammatory disease, but she never expected the process to take nearly a year and cost $10,000.

“Bills would continue to come in dribs and drabs. $1,000, $1,500, $500—it all starts to add up. You can’t really budget for it,” said Jackson, who used an online financial management system to keep track of the bills. “We are very conservative with our money. We were lucky to have the money to pay the bills. But it’s still a struggle to see another $500 bill and know that another check is going out. It doesn’t take that much to knock you right down.”

The treatment for Jackson’s transverse myelitis, an inflammatory disease that causes spinal cord injury, was already complete when the first bill arrived in her Plym-outh mailbox in November 2009. The bills would continue through the end of 2010, often with no warning and sometimes no clear explanation.

“Probably half the things, we don’t even know what we were paying for. We just paid for them because the bill came,” said Jackson, who was covered through employer-sponsored insurance at the time of her medical emergency. “For the first few months that they were coming I said, I get this, I know I have to pay something toward these. But then probably after three months of getting bills I was thinking, okay, now what am I really paying for?”

The now self-employed portrait photographer learned how easy it is to become saddled with medical debt even when you are never admitted to a hospital or warned you’ll have to pay for expensive treatment. For Jackson, the charges piled up from the multiple tests and doctor’s visits it took to finally diagnose her condition. “It all added up over time. It wasn’t one specific thing,” she said.

Jackson’s journey began on Memorial Day weekend five years ago, when she woke up with a buzzing sensation that started at the base of her skull and traveled down to her right arm. When the sensation was still there a week later and was accompanied by muscle weakness, she went to the doctor. “They didn’t know what was wrong,” Jackson said.

It would be two months before a neurosurgeon would diagnose her with transverse myelitis. Getting to that point required multiple co-pays for doctor’s visits, trips to the emergency room, CAT scans, a spinal tap, physical therapy sessions, optical tests to rule out multiple sclerosis, and a series of MRIs that cost $500 each.

When Jackson received the correct diagnosis, she began a new treatment regimen that would drive her medical bills even higher. She underwent two hours of steroid infusions for three consecutive days to stop the inflammation. Physical and occupational therapy three times a week for six months was prescribed to help her gain the motor skills she had lost. The therapy sessions cost $240 a week in co-pays.

When she could, Jackson tried to research the costs of her treatment and services and often called the billing department at the hospital where most of her tests were performed.

The experience fundamentally changed the way Jackson thinks about insurance and makes medical decisions. “Unless you have something like this happen, you don’t even pay attention to your insurance,” said Jackson, who is now on her husband’s employer-sponsored health insurance.

“No I try to look at overall, if something really happens, what is this going to cost me. We read through everything for insurance options now; it can make a huge difference.”

When possible, more needs to be done to help consumers clearly understand the costs of medical services before treatment, Jackson said. And when emergencies with unexpected costs arise, patients should not have to worry about receiving confusing bills.

“In general, I think things need to be more clearly defined in laypeople’s terms so people actually understand what they’re paying for,” said Jackson, who spent much of her professional career as an officer in the fund accounting department of a leading financial institution. “There were some bills that would come in for $500 and I wouldn’t even know what they were for. They’re marked in medical jargon and you don’t even know what that means. We tried to be proactive, but we never got the answers.”

Rare inflammatory disease leads to $10,000 in medical bills
Still reeling from a prostate cancer diagnosis a month earlier, Ronald Boisvert was stunned to receive a $1,900 bill for lab services. When he called his employer-sponsored insurance plan to find out why, he learned that his in-network urologist had sent a biopsy specimen to an out-of-network facility.

“She was in my network. I would never, never in my wildest dreams think she’s gonna send it to a different affiliated hospital,” the 57-year-old said about his doctor. “That’s her fault, her doing, but it’s gonna cost me.”

Boisvert thought he did everything right. He chose a primary care doctor affiliated with the hospital in his insurance company’s network. That primary care doctor referred him to a urologist who had an office in the same hospital. But when a high prostate-specific antigen test led to a biopsy in May, Boisvert went to the doctor’s Newburyport office. The biopsy was sent to a lab at another hospital with which the doctor had a relationship, not the one in his insurance company’s network.

“I would never question it … I was sent to her by my primary care physician,” the Newbury resident said. “I would have figured she would have sent the biopsy to an affiliated facility.”

It was June when Boisvert received the bill, and he was frustrated and worried. He was scheduled to undergo surgery in just a few weeks. He had already planned a three-month leave from his job as a land management assistant at a farm in Essex. The leave would be unpaid because he has no disability insurance. Boisvert is self-employed but is covered by his wife’s employer-sponsored health insurance.

“It’s awful. I got rent to pay. I got bills to pay, and here’s a bill for almost two grand. It’s like what do I do? I gotta pay my bills or I end up on the street. How am I gonna do it?” Boisvert said.

Boisvert filed a grievance with the insurance company arguing that he should not be responsible for what he considers a physician mistake. The insurance company denied the grievance because the bill was submitted properly.

The denial letter included paperwork about Health Law Advocates, a law firm that provides free legal assistance to Massachusetts residents with low incomes. An attorney at the firm took on Boisvert’s case, but as of October 30, 2014, the bill was not resolved and a collection agency had classified the payment as delinquent. The bill was still in dispute in March 2015.

Being out of work without pay because of his cancer was a struggle emotionally and financially for Boisvert. He had to withdraw $6,000 from his retirement account and sell $3,000 worth of personal items. That unpaid medical bill was constantly on his mind.

While the nearly $2,000 lab bill is the largest and most surprising, it is not the only one Boisvert must pay as part of his cancer diagnosis and treatment. There was a $250 co-pay for the initial surgery, $250 in charges he doesn’t understand for X-rays to check if the catheter could be removed, a $250 deductible to cover an emergency room visit and a hospital admission to treat a blood clot in his lung, and two $50 co-pays for one appointment with a urologist for a second opinion.

Boisvert doesn’t argue that he shouldn’t pay for a portion of his health care. But he feels as if his health insurance is failing him when he needs it most. “I think, I’m okay, I’m covered,” Boisvert said. The premiums alone cost his wife more than $130 a week for the lowest-cost plan.

The experience has left Boisvert wary of the medical choices he makes and concerned that he could unwittingly make a decision that will lead to more bills he can’t afford. The next steps in Boisvert’s cancer treatment are hormone therapy and radiation. Boisvert is scared that the best treatment may have the highest cost.

“Like I need another bill,” Boisvert said. “Everything else I can deal with, but when you get a bill when you don’t have the money—that is tough.”
There was only one way Marisabel Melendez could afford to cover the high cost of managing her diabetes and send her daughter to college: give up her apartment and move into her mother’s Lawrence home. She initially balked at the idea of forfeiting her independence, but repeated number crunching and a failed attempt at cutting her insulin use revealed there was no other safe way to trim the budget.

“My expenses were just too much. I had to give up some things in the budget. I had to choose where to cut, so Mother having an extra room made it easy,” Melendez said. “I had choices. A lot of people don’t have those avenues, and it’s tough.”

Melendez had been struggling with her high medical expenses since January 2012, when she enrolled in health insurance through her employer, an urban community assistance agency. Melendez was previously covered by MassHealth after her management position at an adult day health center was eliminated.

“I thought, Wow, now I’m going to have private health insurance. You always think it’s going to be better. It was a lot harder,” said Melendez, who laughed remembering how happy she was to enroll in private health insurance. “My first co-pay started at $20, and went up to $30.”

Melendez had two plans to choose from, and both came with high prescription co-pays. She looked into the Massachusetts health insurance marketplace, the Health Connector, but realized that because she does not qualify for a subsidy, the monthly premium would be substantially higher than the $100.40 she currently pays.

Diagnosed with Type 1 diabetes 20 years ago, Melendez manages her disease by checking her sugar levels four to eight times a day. She also requires prescriptions for two types of insulin, two types of syringes, test strips, and a blood pressure medication. At her doctor’s recommendation, Melendez also takes over-the-counter iron, vitamin D, and biotin supplements. The price tag for all those medications is about $200 a month.

After six months of struggling to pay $200 a month for her medications, Melendez decided to take a creative approach to trimming costs. In the summer of 2012 Melendez started eating less because it caused her blood sugar to drop, which meant she didn’t need to take as much insulin.

That ended in the fall, when Melendez’s endocrinologist saw lab results that were part of a routine checkup.

“She asked me what I was doing. I told her. She said, ‘You can’t do that!’ I said, something’s gotta give, and it’s not going to be my health. So I got back on track,” Melendez said. “I know that I need my insulin every month. I need my syringes every month. I need my test strips every month. If you have a disease like diabetes, it’s not like you can say, this month I’m not going to take care of it. I have no choice.”

Giving up her rental and moving into her mother’s Lawrence home in November 2012 became the only choice Melendez could make without jeopardizing her health. It would come at the right time because her daughter, Yarisa Carrasco, had just started her freshman year at Broward College in Florida. Melendez was helping with Yarisa’s expenses, including tuition, transportation costs, books, and supplies.

Her experience with high medical costs and hard choices has influenced how Melendez handles the clients she works with as a community organization program director. In her role, Melendez supervises a navigator program that assists individuals with acquiring health insurance.

“If I’m struggling—and I’m making good money—you can imagine how they are struggling,” Melendez said.

The cost that comes with carrying private health insurance is a topic that Melendez stresses with clients. They need to understand the financial impact of their monthly insurance premiums and annual deductible as well as co-pays for doctor’s visits and prescriptions.

“It’s something we can discuss with our clients: If you’re getting your own health insurance, you’re going to have to budget more money toward your health care needs,” Melendez said. “So does it affect how I deal with people? Yes, because of my own personal experience. I know that some people are experiencing the same thing in more dire situations than mine.”

Melendez is just one of the dozens of women in her family who are managing adult-onset Type 1 diabetes. Knowing that her relatives are sharing similar financial struggles makes Melendez wish all insurance companies could make exceptions for chronic diseases.
Unemployed man with Crohn’s disease skips pills to save money and triggers a flare-up

Skipping two pills a day saved Stephen Slaten more than $35 a month for four months. But the decision would end up costing him more in the long run when it triggered a serious flare-up of his Crohn’s disease that required treatment.

“How do I manage my money so that I can pay my living expenses? What do I cut back on? The medication was an easy risk,” said Slaten, a licensed psychologist. “I can’t cut back on my mortgage and utilities. It was one of the few controllable things.”

The medication, Pentasa, was prescribed by Slaten’s doctors to keep his Crohn’s under control and in remission. He was directed to take the medication four times a day, and he did so faithfully for more than 23 years. But in October 2012, Slaten cut his pill intake to twice a day. His monthly prescription costs of $75 were now cut in half.

Slaten said that the small cut in expenses was necessary because it was a tough time financially for his family. The single father had been laid off from his position as a nonprofit’s executive director in Worcester two months earlier and was struggling to keep up with his expenses. His son had just graduated from high school and was living at home; his daughter was out of the house but still on the family health insurance.

Unemployment compensation provided just half of Slaten’s previous salary, and initially there was only $500 left over after paying for a family health insurance plan under COBRA. When Slaten qualified for a state subsidy four months later, his COBRA premium payment dropped to $800 a month. But that was still too much.

“It was a big financial challenge,” Slaten said. “The premium cost was overwhelming.”

So he emptied his savings account and dipped into his retirement savings to cover the difference. But Slaten also thought about where he could cut back. The Pentasa prescription seemed like an obvious choice.

“I had been very stable,” said Slaten, who was diagnosed with Crohn’s 25 years ago and had only a couple of minor flare-ups over the years due to stress or antibiotic use.

That stability came to an end in the winter of 2013, when he had a major flare-up of his Crohn’s. He called his doctor, who put him on a new medication. A checkup with the doctor and blood tests revealed that Slaten was anemic. He was prescribed prednisone for three months and told to go back on the full dose of Pentasa.

“It was clear I have to get treatment. I’m not doing well. It’s not going to go away. It’s only going to get worse,” Slaten said. “So now spending the money on the prednisone and seeing the doctor was necessary. It was no longer discretionary.”

Slaten now has a full-time job and has vowed never again to cut back on his preventive medication, but that doesn’t mean he’s free from worries about his health care costs. He’s been putting off having a colonoscopy and been living with a degenerating hip for several years because of the high co-pays and deductibles for those medical procedures.

The Affordable Care Act requires health plans to cover the cost of colonoscopy screening tests, but Slaten’s insurance company informed him the test will be considered diagnostic if it reveals a problem. Members must pay a deductible for diagnostic colonoscopies.

“If my colonoscopy was clean, I wouldn’t have to pay for it … If I had a condition, I would have to use my deductible,” Slaten said.

Slaten said he also must consider that his salary is based on how many clients he sees, and taking six weeks off work to get his hip replaced will mean substantially less income. He wears high arches in his shoe and exercises to strengthen his muscles in an effort to diminish pain and increase mobility.

“I’m compensating with things that make it livable. It would be nice to get it replaced,” he said. “There’s a financial consideration for why I’m putting that off.”