

## Data Brief Report

“No One Asked Me”: Latinos’ experiences with Massachusetts Health Care Reform

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### **Abstract**

*This report presents accounts from a qualitative study funded by the Robert Wood Johnson Foundation (RWJF) that examined the personal experiences and financial impact of the 2006 Massachusetts Health Care Reform law (Chapter 58 of the Acts of 2006) among low-income Latinos. Twenty interviews were conducted with Latinos who had obtained health insurance coverage after the law’s enactment. Data from the interviews indicates that once informed about the insurance law, participants became active agents seeking affordable health insurance coverage. However, they felt intimidated by the health insurance enrollment process; and thus sought assistance from a community-based multiservice organization or program that provides case management-like services. Although affordable monthly insurance premiums for low-income residents can be determined by simply using an affordability scale, participants’ views of affordable insurance involved a more complex calculus. Due to changes in their day-to-day financial circumstances, participants continued to reconsider whether their health insurance premiums were affordable. Findings indicate that the health insurance enrollment process is notably complicated for low-income Latinos, and more so for those who face language barriers and lack of familiarity with use of health insurance. Without the help of community based organizations, participants’ success at obtaining health insurance coverage was unlikely. As a model for future national health reform, the enrollment experience of Latino residents in Massachusetts described in this report suggests the need to implement communication strategies to inform linguistically diverse populations about the steps to follow to comply with health insurance mandates. Also, findings point to the need to equip community based organizations with the necessary tools to assist individuals with limited experience with health insurance during their process of obtaining affordable health insurance.*

### **Introduction**

Last year, the Robert Wood Johnson Foundation’s New Connections initiative funded a qualitative study designed to better understand the personal financial impact of the 2006 Massachusetts Health Care Reform law (Chapter 58 of the Acts of 2006) among low-income Latinos. The study’s aims were to examine the pathways they followed to comply with the law; whether they could or could not afford the subsidized health insurance premiums established by the government; and what they did when they deemed their insurance premium unaffordable.

## **Background**

In 2006, the Commonwealth of Massachusetts passed Chapter 58 of the Acts of 2006 of the Massachusetts General Court (entitled “An Act Providing Access to Affordable, Quality, Accountable Health Care”). One of the goals of the law (Chapter 58) was to expand affordable health insurance coverage to about 530,000 uninsured residents within three years<sup>1</sup>, and thus provide near-universal health insurance coverage to the Commonwealth’s residents. The expansion was to be achieved through a combination of Medicaid expansions, subsidized private insurance programs, insurance market reforms, and employer sponsored insurance.

Chapter 58 contains an individual mandate which requires that residents who can afford health insurance pay for it. The consequences of not securing health insurance are tax penalties, unless coverage is deemed unaffordable by a government entity. This individual mandate is predicated on important principles: (1) taxpayers pay for the care of uninsured individuals and emergency care; (2) it is fair to ask people who can afford health insurance to pay for their own coverage; (3) voluntary measures are not enough; and (4) healthy uninsured individuals should contribute to the insurance risk pool. In order to facilitate the purchasing of affordable health insurance, Massachusetts established an independent quasi-public authority— the Commonwealth Health Insurance Connector— created to serve as a clearinghouse to connect individuals and small businesses with health insurance products. The legislation also created a subsidized health insurance program, the Commonwealth Care Health Insurance Program, for residents who earn less than 300% federal poverty level (FPL) and are ineligible for MassHealth (Medicaid).

Since the very early stages of Massachusetts health reform, the public dialogue has focused almost exclusively on the reform’s impact on government, businesses and health care

institutions. Although advocates have voiced concerns about the personal experiences of low-income individuals who are required to purchase affordable health insurance coverage, consumers' voices have been minimally included in the dominant public discourse. With the exception of household survey studies<sup>2,3,4,5</sup> that have focused on the effect of the Massachusetts health reform on residents' insurance status, access to care, out-of-pocket health care costs, medical debt, and general financial problems consumers, no in-depth accounts of low-income residents' experiences with the process of health insurance enrollment have been documented. Within the current public discourse, two contrasting outcomes have captured the public's attention in recent times: 97 percent of Massachusetts residents now have health insurance coverage; and state and federal health care spending will increase from \$1 billion in fiscal year 2006 to a projected cost of \$1.7 billion for fiscal year 2010. More recently, and in light of the current national health reform debate, there is a continued emphasis on directing attention to the fiscal burden that the reform has created on the state government. A case in point is the recent announcement of benefit reductions for legal immigrants as a money-saving tactic to address a budget deficit.

Even when the government provides adequate resources to achieve the goal of providing the mechanisms through which its uninsured residents could obtain health insurance, the process of figuring out the most suitable health insurance coverage is complex due to its myriad of requirements, regulations, and technical language. For those uninsured residents with limited English proficiency (LEP), this adds an additional burden to the process of obtaining health insurance, and it is further complicated by the fact that the diffusion process, by design, is seldom geared to inform individuals with LEP, and their likelihood of not been familiar with the process of health insurance enrollment and use.

This report presents accounts from a qualitative study funded by the Robert Wood Johnson Foundation (RWJF) designed to examine the personal experiences and financial impact of Chapter 58 from the perspective of a group of Latino residents. The study focused on Latinos because: (1) it was the group with the highest proportion of uninsured adults in Massachusetts prior to the enactment of the law; (2) information to facilitate compliance with Chapter 58 was available in Spanish since the early stages of the implementation process; (3) there was no documentation of the health insurance enrollment experience of members of ethnic and linguistically diverse groups who are more likely to be unfamiliar with the bureaucratic process of enrollment, have limited English proficiency, are low income and have minimal or no experience dealing with health insurance programs. The lessons learned from this study provide important insights that could be applied to the current national health reform debate.

### **Data and Methods**

Twenty interviews were conducted from October 2008 to January 2009 with individuals between 150-300% of the FPL who had obtained health insurance coverage after the law's enactment. Participants were recruited through community based organizations and key informants who identified individuals who fulfilled the following inclusion criteria: (1) Latino men and women ages 18 and older; (2) English or Spanish as first language; (3) enrolled in health insurance program in compliance with Chapter 58; and (4) family or individual income between 150-300 % FPL.

The twenty study's participants were legal U.S. residents born in: Dominican Republic, Guatemala, El Salvador, Puerto Rico, Colombia, Venezuela, Honduras, Mexico, and the United States. The participants' average age was 44 (ranging from 21-59) and the number of years residing in the United States for those born elsewhere was 17 (ranging from 2-34). The interviews focused on the following areas: knowledge about Chapter 58; steps taken to comply with the health insurance coverage mandate; experiences related to health insurance enrollment process; perceptions of health insurance affordability; strategies to cope with unaffordable

premiums; and perceptions about the benefits of having health insurance coverage. Participants received a \$50 incentive upon completion of the interview. The interviews lasted approximately one hour.

This report focuses on three themes that emerged from the narratives collected from Latino residents: (1) their awareness and understanding of the individual mandate; (2) the role of community-based organizations during the enrollment process; and (3) residents' perceptions of the affordability of health insurance.

### *The individual mandate*

Data from the interviews indicate that Massachusetts has done an effective job at communicating to its residents about the need to comply with the mandate of obtaining health insurance coverage. All participants knew about the reform and the individual mandate. However, the channels through which they learned about the law varied. Most participants learned about it through the media; others learned about it through word of mouth; and a few others became aware of the law when they were dropped from “free care” or the uncompensated health insurance pool as the result of new eligibility requirements. Once informed about the insurance law and its individual mandate, participants became active agents seeking affordable health insurance coverage. According to the data collected, two ethical responsibilities propelled participants to seek health insurance coverage: their responsibilities as law abiding residents with a strong sense of civic duty, and— for those who are heads of households— their familial responsibilities.

As law abiding residents of the United States, participants viewed their compliance as an exercise in civic participation that is emblematic of a democratic and highly regulated society. It is their understanding that the state government wants individuals to participate and share

responsibility, and they are willing to act accordingly. For participants who are heads of households, there is an additional motivation to seek health insurance coverage: their moral obligation of providing for their families. For these individuals, health insurance coverage provides special protections to them and their families in the event they experience illness. Participants worry about their families' health, but also about the importance of preserving their own health for the sake of their families. One participant reported feeling distressed and frustrated as he was unsuccessful at seeking affordable health insurance coverage for his family. He spent sleepless nights worrying about the fact that he was unable to neither provide for his family nor comply with the mandate.

Participants also reported that having health insurance provides a sense of security that will allow them to not delay care when needed, something that has happened in the past when they did not have health insurance coverage. A participant expressed this view as follows: *“We have peace of mind knowing that we have health insurance...Security, more than anything else...and in the event that something happens, I feel secure enough that they [providers] will check it out [the health problem].”* Another participant said: *“Because when you have it [health insurance coverage] you feel protected...Is like having \$10 in your purse. You go to the store to buy something, you know you have it [the money], and that you are going to pay for it. That is what it is, feeling that you have a protection.”*

The prospect of paying a tax penalty— that went from the loss of the personal tax exemption (\$219) in 2007 to up to half the cost of the lowest available yearly premium (up to \$912) beginning in 2008— for not having health insurance coverage was another key incentive for participants to seek health insurance coverage. They figured that if they were to pay up to half of their yearly premium they would rather pay for full coverage, even at the risk of great

financial sacrifice. However, in instances in which the prospects of finding affordable health insurance coverage looked unpromising, participants felt that paying the tax penalty was their only recourse.

It is important to note that compliance with the individual mandate did not necessarily mean that participants supported the mandate, particularly as it related to the notion of shared individual responsibility. In this regard, participants viewed the government's requirement of purchasing health insurance as unfairly applied to low-income residents who struggle to make ends meet every month, and who tend to not seek health care services indiscriminately. This stand appeared to be driven by a combination of misconceptions of the most fundamental aspects of the mandate: fairness and pooled risk. Even though the subsidies provided by the government are considered modest by some and generous by others<sup>6</sup>, many participants deemed the established subsidized insurance premium rates above what they can comfortably afford. In addition, only one of the twenty residents interviewed understood the concept of pooled risk. This quote illustrates one participant's limited understanding of this concept: *"I am giving my money away to other people and I am not using it [health insurance]. Huh? I do not use it because I have to pay for my medication. You have to buy it [medication] apart from your insurance. So, what does that mean? I am giving my money away to someone I do not know."* The one participant who understood the concept of pooled risk still opposed the notion of requiring healthy individuals to purchase health insurance coverage. Instead, he proposed the alternative of calculating health insurance cost based on a formula— similar to a car insurance policy— that takes into account an individuals' health risks, medical history and amount of health care services used in the past.

*The role of community-based organizations*

Participants felt intimidated by the health insurance enrollment process. They described it as challenging, and thus they all sought assistance from a community-based multiservice organization or program that provided case management-like services. Spanish-speakers needed more help than those who spoke English. Specifically, Spanish-speakers needed help finding basic information such as where to look for health insurance, how to apply for subsidized coverage, and how to determine affordable insurance premiums. One Spanish-speaker indicated that without the help from the community based organization it would have been impossible for her to obtain health insurance: *“I would not have been able to do it [obtain health insurance coverage] on my own.”*

English-speakers were able to find sources of information (such as web sites) and identify subsidized health insurance coverage they were eligible for, but still they were confused: *“It’s confusing. Some of it is confusing. You don’t know which way to go because it’s too much information, and if you click on one link, it’ll send you back to another, and then, another.”* They sought assistance from community-based organizations they were familiar with or from programs recommended by others, when their independent efforts to obtain affordable coverage failed. The assistance they needed included: help filling out forms; obtaining basic information about subsidized coverage; figuring out ways to qualify for less expensive coverage; and exploring health insurance alternatives that they were not familiar with, such as government-funded health insurance coverage for their children and changes in eligibility based on marital status. In short, both Spanish- and English-speakers sought advice to choose their health insurance plan from the community based organization’s staff assisting them during the enrollment process. However, Spanish-speakers— who typically had less experience with health

insurance bureaucratic procedures– needed more assistance from community-based organizations throughout all the enrollment steps.

The tasks performed by staff at community-based organizations included orientation meetings to explain the application process for subsidized health insurance; filling out forms, making follow-up calls to the Connector; visiting the homes of participants who needed to apply for health insurance coverage but could not make it to the organization’s facility; resubmitting paperwork when subsidized coverage was denied; and offering advice to participants about what level of health insurance coverage to choose as well as legal strategies to reduce cost (i.e., apply for separate insurance coverage for children; report legal marital separation; consider marrying partner to obtain coverage through partner’s insurance policy, etc.).

*How affordable is “affordable” health insurance coverage?*

Although affordable monthly insurance premiums for low-income residents can be determined by simply using the Commonwealth’s Connector’s affordability scale, participants’ views of what is affordable involved a more complex calculus that takes into account their ever-changing financial situation. Participants continued to reconsider whether their health insurance premiums were affordable even after they have already joined a health insurance plan due to changes in their day-to-day financial circumstances: changes in job status, limited budget, unexpected expenses, high premiums, and copayments. For example, participants reported that reductions or increases in the number of hours worked impacted directly their eligibility for subsidized health insurance coverage, as well as their ability to pay their monthly premiums. A reduction in hours worked strained their ability to make ends meet, whereas an increase in hours worked could result in a monthly premium increase. Most participants experienced financial events (e.g., reductions in hours of work, changes in mortgage payments, unexpected expenses)

that affected their ability to pay their monthly bills, including their health insurance premium. When this occurred, participants made the necessary budgetary adjustments in order to continue paying their premiums. The adjustments included prioritizing payments of certain monthly bills over others; disconnecting cable TV and cell phone services; buying less food (e.g., meat, milk, and chicken); sending fewer remittances to their families residing in their countries of origin, and even contemplating discontinuation of their health insurance premium payments. The following quotes illustrate some of these coping strategies:

*“If you used to buy two gallons of milk, you then buy only one instead of two because you have to save money to be able to pay that money [to cover health insurance premium].”*

*“We hardly ever go to the stores to buy clothes, shoes, hardly ever.”*

*“I have to use my credit card to buy food. We cannot even buy take-out food, because we do not have enough money.”*

*“We used to buy corn flakes, but now we cannot afford it.”*

*“We wanted to pay for the health insurance plan, but did not have enough. We were in a double bind: we wanted to pay for it, but we did not have enough money, and we did not even know how we were going to be able to pay the [tax] penalty.”*

Other strategies that participants used to cope with health insurance cost were taking steps to avoid illness, sharing medications, having medical procedures performed in their countries of origin, and claiming to be legally separated from a spouse, among others. The participant who claimed to be legally separated to reduce his premium payments voiced uneasiness about following that course of action: *“There should be a way. I wish I could pay an amount for the whole family, so that I do not have to... because if we formalize [our relationship] again, the insurance is going to say, ‘you do not qualify.’ That’s a problem. Then, what do we do? Do what we are not supposed to? We do not like to do that...say that we are not together...”*

It is important to note that the key factor that participants considered at the time of choosing their health insurance plan was the cost of monthly premiums, without necessarily conducting a thorough review of the plan's coverage and copayment rates. As a result, participants who ended up with high copayment rates for medical visits and medication perceived that their health insurance coverage left them in a state of underinsurance and thus reported foregoing routine preventive care. This quote illustrates this situation: *“This is what is happening to me [not being able to afford copayments]. I have to buy the medication in addition to what I am already paying, because I believe that is “buying” the medication. I say, look, I want that medication. I order it, but I know that I have to have money in my purse, because if I don’t, they are not going to give me the medication.”* In addition to facing difficulties meeting copayments, some participants had not chosen a primary care provider because they do not know how to do that.

## **Conclusion**

As noted by others<sup>6</sup> this study confirms positive outcomes regarding the implementation of Massachusetts' health reform to the extent that the mandate was compelling enough to mobilize Latino residents to seek health insurance coverage, even when it was deemed unfair and they faced challenges figuring out the enrollment process. The enrollment process appears to be difficult and confusing for both English- and Spanish-speaking low-income Latinos. The health insurance enrollment process was notably complicated for those who face language barriers and lack of familiarity with use of health insurance.

Findings from this study suggest that disseminating information— about the individual's civic responsibilities to comply with the law— clearly in all languages is key, but not sufficient. Latinos' connection with community based organizations was instrumental for their successful

health insurance enrollment. As a model for future national health reform, the enrollment experience of Latino residents in Massachusetts described in this report suggests the need to implement specific communication strategies to inform linguistically diverse populations about the steps to follow to comply with health insurance mandates. In addition, findings point to the need to equip community based organizations with the necessary tools to assist individuals with limited experience with health insurance during their process of obtaining affordable health insurance. Specifically, since staff from community-based organizations played an instrumental role in connecting individuals with health insurance, they could be trained to communicate complex information and concepts—such as pooled risk and affordability—to the residents they serve, as well as how to use their health insurance effectively such as the use preventive care services.

This study also uncovered first-person accounts of what happens after implementation. Chapter 58 was created to guarantee access to health insurance to most residents in Massachusetts in order to facilitate access to health care services. Quantitative studies<sup>2,3,4</sup> have documented a general improvement in access to care after the reform's implementation. However, more recent studies have identified differences in access to care among adults across racial/ethnic lines<sup>5</sup> and enrollment experiences<sup>7</sup>. In one study<sup>5</sup>, Latinos were found to be less likely to have had a doctor visit in the last year and more likely to report unmet need for doctor care, specialist care, medical tests, treatment or follow-up care, preventive care screening, and prescription drugs. Similarly, most participants interviewed for this qualitative study felt that their access to care is limited—even with health insurance coverage—due to the difficulties they face affording copayments for both medical visits and medications, as well as by the fact that they have not figured out how to choose a primary care doctor.

Although Latinos interviewed for this study became active agents seeking information about health insurance coverage in order to comply with the law, they faced many challenges exercising personal choice and making informed decisions about their health insurance coverage. The challenges appear to be the byproducts of several factors: communication gaps, misunderstandings, and limited options. Instead of making informed decisions about their health insurance based on risk and needs, participants chose their plans based on affordable monthly premiums. This course of action resulted in limited access to care since most participants deemed their copayments unaffordable.

Findings from this study suggest that lessons learned from Massachusetts' experience could be used to inform the current national debate on health reform. As a model, it demonstrates that Massachusetts has done an effective job communicating the civic duty of complying with the law. Secondly, the use of an individual mandate that carries tax penalties as consequences for non-compliance has been an effective strategy to mobilize residents to obtain health insurance coverage. Thirdly, findings from this study suggest that even with subsidies, affordability hampers residents' ability to fully access care as intended by the Massachusetts health reform. Language barriers and lack of familiarity with bureaucratic processes further compound people's ability to fully exercise personal choice in the process of seeking affordable health insurance. As noted earlier, in order for individuals across linguistic and socioeconomic lines to fully participate and make informed choices, wide-reaching health care reform initiatives need to include strategies to facilitate the enrollment process. A seamless enrollment process could prevent consumer's ill feelings and frustration such as the ones expressed by one participant: *"I'm not too happy about it. Yeah, it's very necessary that all of us have health*

*insurance, but it's not accessible. I was born American. I have every single right. I'm covered under the Constitution, but I still don't qualify [for affordable health insurance]."*

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