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## An ethnographic study of enrollment obstacles in Rhode Island, USA: struggling to get covered on an Affordable Care Act insurance marketplace

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### ABSTRACT

The Affordable Care Act (ACA) of 2010 expanded access to health insurance coverage in the United States through online marketplaces that provided subsidized insurance coverage. Nonetheless, many obstacles made it difficult to enroll in and maintain ACA insurance coverage. In this article, we analyze obstacles to enrollment and continuous coverage based on an ethnography of ACA insurance enrollment in Rhode Island. We foreground consumers' experiences and highlight the time and effort that people invested into getting covered. Unlike studies that focus on individual choices and employ a deficit perspective to understand gaps in coverage, this article argues that structural problems related to the organization of the American health insurance system, economic instability and bureaucratic eligibility criteria shaped the experiences of individuals and families seeking coverage. We found that people actively and intensely struggled to enroll and were met with multiple obstacles, most of which were beyond their control. In some cases, these obstacles resulted in gaps in coverage. In almost all cases, they created additional stress, were time consuming and frustrating. The most significant obstacles to enrolling in coverage were bureaucratic barriers, affordability, changes in personal or family status, and knowledge about health insurance and ACA program rules. We end by questioning the ethical basis of a health coverage system structured on 'churn' and offer policy recommendations to design programs that respect people's time, avoid verification redundancies and are motivated by a mission to expand coverage.

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## Introduction

Unlike all other high-income countries, the United States does not guarantee universal access to health coverage. The Affordable Care Act (ACA) of 2010 addressed this deficiency by creating new consumer protections and online insurance marketplaces that offer subsidized insurance coverage. Nonetheless, many obstacles made it difficult to enroll in and maintain ACA insurance coverage. In this article, we analyze obstacles to enrollment and continuous coverage based on an ethnography of ACA insurance enrollment in Rhode Island. We foreground consumers' experiences and highlight the time and effort that people invested into getting covered.

The ACA created new pathways to coverage through expanded access to Medicaid for those earning less than 138 percent of poverty and means-tested tax credits and cost-sharing reductions for those near the poverty line. The ACA also penalized individuals and families who did not enroll in coverage through a penalty, known

as the individual mandate that imposed a fine (tax) on people who experienced a coverage gap of more than two months.<sup>1</sup> The law included exemptions to the mandate for people who could not afford coverage or who experienced a special circumstance.

This combination of incentives and penalties led to record increases in insurance coverage and lowered the uninsured rate by 2016 to 10 percent for persons under age 65 (Garfield, Majerol, Damico, & Foutz, 2016). In Rhode Island, where this study was conducted, the figures are even better: the uninsured rate declined from 11 percent in 2012 to 5 percent in 2015 (Rhode Island Health Information Survey, 2015). Interestingly, of those who remained uninsured, most were eligible for some form of public insurance or tax credits and cost-sharing reductions to purchase coverage on the marketplace (Rhode Island Health Information Survey, 2015).

Despite the success of the ACA in lowering the uninsured rate, enrollment on insurance exchanges has been lower than expected (CBO 2017a, 6); 12.2 million people were enrolled in a marketplace plan at the start of the 2017 plan year (CMS 2017) and that number has dropped slightly for 2018. The elimination of the individual mandate in 2019 as part of the recently passed Republican tax bill is projected to further erode enrollment (CBO 2017b).

What is known about why people have enrolled in smaller numbers than anticipated? Most health policy experts agree that enrollment has been negatively impacted by the unaffordability of coverage for some (Giovenelli and Curran 2016), the complicated nature of the law and partisan politics (Haeder & Weimer, 2013; Morone, 2016). For many, premiums and out of pocket costs are too expensive, even with tax credits. The law also has many rules about when and how to enroll that are difficult to understand and follow. Concerted opposition to the law by Republicans has impeded implementation, created uncertainty and focused attention on the negative aspects of the law.

In-person assister programs are supposed to provide a remedy to many of these problems, including the challenges of price and complexity, by providing objective, technical assistance and education to consumers (Goodell, 2015). Research on consumer choice in health care has repeatedly shown that consumers need supports such as decision tools, in-person assistance and involved state regulators in order to choose wisely on insurance exchanges (Nadash & Day, 2014). In-person assister programs helped over 5.3 million consumers get connected to coverage in 2016 (Pollitz, Tolbert, & Semasnee, 2016). Nonetheless, survey research of in-person assister program leadership paints a picture of enrollment systems that are far from perfect: taking 1–2 hours to enroll, difficulty reconciling information and coverage still too expensive for many (Giovenelli & Curran, 2016; Pollitz et al., 2016). These studies rely on survey methodologies and query high-level leadership. While these studies provide valuable information for understanding the scope, performance and strategies employed by in-person assister programs, they are prone to presenting a more positive take on performance and do not include the viewpoints of frontline workers or consumers. Our findings reveal a system where the rule, not the exception, is that consumers will encounter multiple barriers to enrollment, experience frustration and become disillusioned with the health law.<sup>2</sup> Other studies that employ qualitative methods and focus on enrollment assisters have found that assisters are most successful when they employ cultural repertoires that build common interest and establish trust (Vargas, 2016) and that ‘move toward’ clients with strategies such as learning about the law, bending rules, using personal resources and collaborating to solve problems (Tummers & Rocco, 2015, 821). Less effective strategies include insisting and informing without building trust (Vargas, 2016).

We argue that any effort to reform existing health insurance enrollment policies should be based in a thorough, qualitative understanding of the barriers to maintaining continuous coverage that are experienced by low- and middle-income individuals. In our study, the most significant obstacles to enrolling in coverage were bureaucratic barriers, affordability, changes in personal or family status, and knowledge about health insurance and the ACA. When viewed from the consumer’s perspective, the choice of whether or not to get covered was

much less important than the many obstacles that consumers had to overcome to complete the enrollment process (Mulligan, 2017). As such, our study highlights how problems related to the organization of the American health insurance system, economic instability and bureaucratic eligibility criteria structured the experiences of individuals and families seeking coverage. We found that people actively and intensely struggled to enroll and were met with multiple obstacles, most of which were beyond their control. In some cases, these obstacles resulted in gaps in coverage. In almost all cases, they created additional stress, were time consuming and frustrating. We end with policy recommendations to design programs that respect people's time, avoid verification redundancies and are motivated by a mission to expand coverage.

## Methodology

This article presents research from a qualitative study of health insurance enrollment that was conducted in the state of Rhode Island. Rhode Island is particularly interesting because the state expanded Medicaid, created its own insurance marketplace and launched a statewide effort to promote insurance enrollment that leveraged community partnerships. Unlike many Republican-led states that pursued a path of 'absolute non-collaboration' (Jones, Bradley, & Oberlander, 2014, 119), the executive and legislative branches in Rhode Island supported health reform and promulgated policies with the explicit intention of enrolling as many people as possible in insurance coverage. Enrollment assistance was available at the exchange contact center (in all years except 2016) and also at navigator-led community enrollment events located at convenient locations throughout the state such as libraries and churches. Navigators were employed by the exchange, community health centers and other contracted organizations that provided consumer assistance such as the United Way and the Rhode Island Parent Information Network. The exchange also maintained a navigator directory on its website that instructed consumers to call community organizations and make appointments for in-person assistance. In addition to enrollment help available by phone and at the contact center, Rhode Island had a network of 152 (2017) and 185 (2016) trained and certified enrollment assisters serving an exchange that enrolled 84,000 people in 2017 and 107,000 in 2016 (HSRI 2016, 2017). And yet, we found that significant barriers to enrollment persisted, some of which were the product of flaws in policy implementation and others were artifacts of how the ACA was designed.

The examples discussed in this article were selected from a larger ethnographic project in which the PI (principal investigator) observed 188 households attempt to enroll in insurance coverage in Rhode Island at the customer service center of the health insurance marketplace (also referred to as the exchange) and at community enrollment events. The project was approved by the IRB at Providence College and the PI entered into a research agreement with the exchange as well as a community organization that employed navigators and hosted community enrollment events. Informed consent was obtained from enrollment assisters and people attempting to enroll. Field notes documented the observations immediately following the enrollment transaction and did not include any personal identifying information. During observations, subjects were asked to complete a contact form for a future interview. Thirty subsequent interviews were conducted. Interviews were semi-structured and open ended; they focused on family background, work and education history, insurance coverage and health status.

Inductive and open-ended methods were also utilized in the data analysis – the goal was to document enrollment experiences from the perspective of enrollment assisters and applicants and to generate analytic categories from these data. Most studies of enrollment are based on institutional data generated from enrollment systems or surveys of marketplace leadership rather than attending to the perspectives of applicants. We begin with the premise that applicants are knowledge producers and are therefore the best source of data and analysis

regarding their own barriers to enrollment. Furthermore, applicants' experiences are underappreciated in the broader policy literature that tends to be driven by institutional and managerial concerns.

Field notes and interviews were transcribed, coded and subjected to thematic analysis using the mixed-methods software, Dedoose. The authors used a grounded theory approach to generate codes from the data by looking for patterns and themes in the observations. A provisional list of codes was developed and then applied to a subset of the field notes. The authors then met to compare their codes, identify discrepancies and refine the codes.

This study suffers from several limitations. First, the subject recruitment procedures skew the study results toward people who encountered problems in the enrollment process. People who enrolled successfully at home or over the phone are not part of this study. Based on call center data, the need was considerable for enrollment help by phone and in-person. During a 17-week open enrollment period, the call center received an average of 17,000 calls a week in 2015 and 12,500 calls a week in 2016 (HSRI, 2016, 15), suggesting that most people needed assistance in order to complete their enrollment. Considering that only 107,000 people were determined eligible to sign up for coverage through the exchange in 2016, this is a ratio of almost two calls for every one person found eligible for coverage. Second, since Rhode Island created a state-run exchange and expanded Medicaid, the results from this study are difficult to generalize to other states, especially those with more hostile implementation environments. Nonetheless, the findings are significant because they show that even in a state that tried to maximize enrollment, multiple barriers persisted. In states that obstructed ACA enrollment or used the federal exchange, the barriers were likely more severe as access to in-person assistance was more limited (Goodell, 2015).

## Enrollment obstacles

We define enrollment obstacles as any barrier or delay in processing a health coverage enrollment for otherwise eligible individuals. Obstacles can lead to lapses in coverage, but they do not always. Delays in processing prolong the time spent enrolling (so that it was not uncommon for enrollments to take two hours) or necessitate help on multiple occasions before the problem was solved. Enrollment obstacles represent a cost in terms of time and often money for those who must take time off from work to address these issues or continue to make premium payments on insurance policies that they cannot actually use. Enrollment obstacles are also emotionally taxing, leading to frustration and ultimately disillusionment with health reform and state agencies. Only 20 out of the 188 enrollments that we observed involved no discernable obstacle to enrollment. Obstacles varied in severity, but most people sought in-person enrollment assistance because they were unable to complete the enrollment on their own. The major categories of obstacles that we identified were bureaucratic barriers, affordability, changes in household characteristics, and health insurance and program literacy. [Table 1](#) contains definitions of each of these obstacles and lists the frequency with which they occurred in our study sample.

**Table 1.** Enrollment obstacles: definitions and frequency. ([Table view](#))

Enrollment obstacles	Definition	Frequency from study % (N=188)
Bureaucratic Barriers	Receiving inaccurate or inconsistent Information, having to submit paperwork multiple times, document verification delays, difficulty calling the contact center, long waits, system errors	50.5

Enrollment obstacles	Definition	Frequency from study % (N=188)
Affordability	Difficulty paying for coverage due to unstable employment, unaffordable premiums, difficulty estimating income	46.8
Changes in household characteristics	Obstacles relating to immigration status, place of residency, family composition, aging out of household and aging into Medicare	48.9
Health insurance and program literacy	Unclear understanding of enrollment rules and requirements; confusion regarding plan structure, costs and tax implications of the law; or a lack of comfort signing up alone online	41.4

Enrollment obstacles are an example of what Michael Lipsky has termed ‘disentitlement’ and others studying Medicaid enrollment processes have termed ‘de facto disenrollment’ (López, 2005; see also Joseph, 2018).<sup>3</sup> According to Lipsky, rationing access to benefits happens in many forms and is often indirect by imposing costs and inconvenience on clients (1984, 8). Forms of disenrollment include making it difficult to ‘establish and maintain eligibility’, non action to resolve issues, low staffing, inability to resolve administrative issues and decreasing workers’ discretion (1984, 8–12). Perhaps most striking in our observations was the perception on the part of clients that their time didn’t matter to the exchange and that frontline service workers were nice, but largely unable to resolve their issues. The enrollment obstacles framework is important because it shifts responsibility for enrollment lapses from individuals onto the bureaucratic systems that are supposed to make coverage easily accessible. In each of the sections below, we describe the major enrollment obstacles encountered by applicants and illustrate how people experienced them.

### ***Bureaucratic barriers and system issues***

In our observations and interviews, we documented that exchange applicants encountered multiple bureaucratic obstacles to enrollment: customers waited months for their issues to be resolved, received inconsistent information and experienced disruptions to their health care (which might not have been recorded as official instances of ‘churn’ if the enrollments were eventually backdated). We define bureaucratic obstacles to include receiving inaccurate or inconsistent information, making multiple trips for help or to submit paperwork, document verification delays, difficulty getting through on the phone line or long waits.

The following examples are typical of the bureaucratic delays experienced by many. A mother tried to enroll her uninsured son in Medicaid in 2017. She repeatedly brought in the same income documents to be verified. With exasperation, she explained: ‘I come back. I come back. Over and over like that. They need to verify and verify’. Another family struggled to ensure that their account included the correct family members. In January 2017, the family’s account erroneously showed that the Medicare eligible father was applying for coverage. The mother and 23-year-old daughter’s insurance was not active, even though they made their monthly premium payments. The elder daughter came in over a dozen times to get this issue resolved beginning in November. Months later, the case had been ‘escalated’ and the exchange was still trying to remove the father from the coverage, enroll the family in the correct plan and apply the tax credits. In 2015, a woman visited the contact center about a billing issue. Her tax credits had disappeared as of October and her account had a balance of

\$1150. No one was clear why. When her husband went to the doctor for his chronic health issue and medications, his insurance didn't work. Customer service assured her that the effective date would be retroactive. The woman paid her \$123 monthly bill before she left. Customer service representatives often counseled applicants with bureaucratic delays to keep paying their premiums even though they were unable to access health care services with their insurance.

Many people reported waiting hours on the phone during open enrollment, only to then be disconnected. It was not uncommon for the wait at the contact center to reach 90 minutes or more. Bureaucratic obstacles relate to the quality, accuracy and speed of service that customers received from the health exchange. Bureaucratic obstacles created frustration, prolonged the time it took to complete an enrollment and in each of the cases discussed here led to gaps in coverage. Bureaucratic obstacles also created more work for exchange staff because many phone calls and visits consisted of repeat and follow-up inquiries. One reason for the lengthy resolution times was that exchange staff were not empowered to resolve many common customer issues, but instead transferred the case to 'escalation', another backlogged area.

Bureaucratic obstacles were often intermixed with system errors. A customer service representative in 2017 explained it this way: 'The system has its own personality, sometimes it will work for people and sometimes it won't for no particular reason'. One family was upset because the information kept changing in their account. It would say, they were active and then that they weren't, sometimes during the same session. The wife printed out screen shots and had them with her for proof. 'I thought you wouldn't believe me if I didn't have these', she said. The CSR opened the customer's account and found that the wife was active on Medicaid, the son had disappeared from the account, and she could not determine the husband's status. At just one single community enrollment event in 2016, we observed multiple technical issues: One of the several navigators could not access accounts, because the system said they were locked. Someone was put in Medicaid even though their income was too high. Another navigator said that not all of the plans were showing up.

Enrollment in ACA insurance coverage takes place through an online application that is supposed to simplify and streamline the process. As these examples demonstrate, however, the electronic system has been the source of many enrollment obstacles. Common system errors that we observed included receiving an error message, not being able to login or reset a password, system just not working, will not go to next task such as processing the application, tax credit not showing up, incorrect eligibility determination such as being put in Medicaid when not Medicaid eligible, and identity mix ups resulting in beneficiaries being mistaken for dead or the recipient of some other benefits like social security payments. System errors were particularly frustrating for enrollees because they were very difficult to resolve and seemed totally illogical. Fixing many of these system errors required high levels of technical expertise and communication with the subcontracted technology provider, Deloitte.

The problems on Rhode Island's state run exchange are not wholly unique; technology issues have plagued exchanges nationally. The federal Healthcare.gov had a very rocky rollout and has since improved. Even so, it is still prone to slow downs, error messages during high volume periods and glitches. Some state exchanges folded because of administrative and technological challenges. Nonetheless, Rhode Island decision makers exacerbated the exchange's technology challenges by implementing a controversial Unified Health Infrastructure Project (UHIP) in 2016 (for the 2017 open enrollment season). UHIP led to widespread enrollment difficulties and backlogs across social services agencies in the state. Top administrators resigned, federal audits were conducted, and the governor issued many apologies (Nesi, 2017). In this context, it is not surprising that system errors spiked for the 2017 enrollment period. However, our data show that system issues have always been one of the leading obstacles to enrollment.

## ***Affordability and difficulty estimating income***

We define an affordability-of-coverage obstacle as straining to pay for or opting not to enroll in coverage due to unaffordable premiums and/or out of pocket costs such as deductibles. Given what we learned from consumers' experiences trying to qualify for and pay for coverage, we use a broader definition of affordability that includes unstable employment that disrupts the ability to pay premiums and difficulties estimating income which impacts eligibility and pricing determinations. Affordability-of-coverage obstacles created stress for consumers as they negotiated the mandate to get covered with their own financial constraints. It also led people to skip treatments, forego medication and opt out of coverage. Take for example the case of a 64-year old man who earned \$21,000 a year. He encountered multiple bureaucratic barriers to reenrolling in his marketplace plan for 2016 coverage, leading him to describe enrollment as a 'job'. After qualifying for a tax credit and cost-sharing reduction, his plan cost \$92 a month with a \$500 deductible. However, his \$21,000 annual income did not leave him with enough discretionary income to cover his out of pocket costs. Therefore, even though he was technically covered, he opted not to fill his prostate medication prescription. To cope with symptoms, he avoided activities where he could not be close to a restroom.

In 2016, the vast majority of uninsured persons were low- or middle-income earners: 89 percent of uninsured individuals nationally earned less than 400 percent of poverty (Garfield et al. 2017, 7). For people who earn too much to qualify for Medicaid but are still relatively low income, ACA coverage was often difficult to afford. For some, their status as 'covered' masked deep financial strain. Take for example, the case of a 41-year-old man in 2014 with an income of \$27,000 (approximately 225 percent of the poverty level). He struggled to pay his insurance premium of \$178 a month with a \$2100 deductible. 'What is this?' he kept asking. 'This is terrible'. He asked his enrollment assister several times how he was supposed to pay so much. 'This is a terrible system', he said. He was just one unexpected bill away from not being able to afford his coverage. In these two examples, the enrollees were able to enroll in and maintain coverage, though their coverage added financial stress onto their already overburdened household budgets. For others, they stopped being able to pay the premium at some point during the year and so lost coverage or opted to go without coverage for periods to save money. Some people optimistically assumed they would gain employer coverage soon, were anticipating qualifying for Medicare, or stocked up on health care before their insurance lapsed by booking multiple appointments during the same month.

Though the financial strain on some was considerable, affordability obstacles were less common in our study in Rhode Island than in national data where affordability was the main obstacle to coverage (Sommers, 2015). In 17 percent of the enrolments we observed, affordability of premiums was an obstacle to health insurance coverage. This is partially because Rhode Island is a Medicaid expansion state and Medicaid enrollees comprised 42 percent of the observations. In Rhode Island, Medicaid enrollees do not pay premiums and have zero out of pocket cost sharing for covered services.

Our study did find, however, that a less appreciated factor greatly influenced people's ability to enroll in affordable coverage: accurately estimating income. Though affordability of coverage seems like a purely financial issue, when viewed in the context of people's lives, it is clear that affordability was exacerbated by bureaucratic and policy obstacles as well as insecure, unstable, temporary and part-time employment. Receiving help paying for coverage – which for most meant the difference between affordable and unaffordable coverage – required successfully navigating the enrollment bureaucracy and providing an accurate estimate of future income. However, this task was difficult for many potential enrollees.

In 2015 a single male who worked in landscaping for 8 months of the year sought coverage. Annually, he earned \$16,000, but his monthly income varied depending on the season. Open enrollment occurs in the late fall and he was not currently working. Therefore, he was placed in Medicaid based on his monthly earnings but told

that his yearly earnings would qualify him for marketplace coverage. When his hours pick up in the spring, the assister explained, he would need to report the change. He was concerned about this solution because he planned to work seven days a week and knew he would not have time to deal with health insurance. Others also found that changes in employment and unpredictable hours made enrollment very difficult. In 2017, an uninsured woman who had recently separated from her husband sought coverage for herself and her 13-year-old daughter. The family's marketplace coverage had lapsed at the end of the year due to nonpayment of premiums. The woman's income was difficult to calculate. She had just started a job driving a school bus and her hours varied between 20 and 25 weekly, but only when school was in session. After entering her most recent pay stubs, the system determined the family qualified for Medicaid. But the woman worried that she did not really qualify because she had missed a week of work in the past month to handle issues related to her divorce. She anticipated churning out of Medicaid soon into marketplace coverage only to re-qualify for Medicaid in the summer.

These are just three examples from the 46.8 percent of the enrollments that we observed where the household encountered difficulty estimating income or anticipated major changes in income over the year. The ACA is a means-tested program. Because tax credits, cost-sharing reductions and eligibility for Medicaid are linked to income, entering income information is a major component of enrollment. Accurately predicting one's income for the coming year, providing income documentation and ensuring that reported income matches other records and databases (like the IRS) can all cause major barriers for low- and middle-income people. Higher income earners are exempted from this hassle – once income tops 400 percent of poverty, the enrollee pays the full price for coverage and means testing is not necessary. The ACA was designed for people who did not already have coverage through an employer, and so, ACA enrollees are more likely to own small businesses and be engaged in work that is part time, has unpredictable hours, is temporary, seasonal, or subject to downsizing, as in all of the examples above. Changes in income and difficulty estimating the coming year's income created stress for enrollees, had tax implications and often led to delays in processing enrollments as documentation and verifications had to be completed. Inaccurate estimates also resulted in enrollees paying too much or too little for their coverage which impacted the affordability of the plans.

### ***Changes in household characteristics***

It was very common for changes in household characteristics to impact enrollment eligibility and processing. Examples include: aging out of a parents' household; aging in to Medicare coverage; moving out of state or changing residence; change in immigration status; and adding or losing family members due to birth, death, adoption, divorce or legal separation. Out of the 188 observations, changes in household characteristics obstacles appeared in 48.9 percent of the cases.

In the following examples, applicants encountered obstacles in getting coverage for their family beyond income and employment. It is common for family configurations to change through separation or divorce that can be particularly challenging for insurance enrollment. In 2014, a man sought health insurance for himself and his two children under his divorce agreement. He was not in contact with his daughter and son so he was unsure of their insurance status. The man was only able to enroll himself and his daughter but was worried that he was not fully complying with the terms of his divorce settlement. Other times, the family composition stays the same, but members age into new eligibility categories. In 2015, a family of three (father, daughter and son) visited the contact center because the daughter was told at the pharmacy that she no longer had coverage. The family learned that the daughter's coverage lapsed because she had just turned 26 and was no longer on the family's account. During the visit, the father reported that he recently had a small increase of income that pushed him out of Medicaid and into a marketplace plan. He was worried that his medication would be too

expensive on this new plan. The family left with everyone on a different account and different plans even though they all lived in the same household.

Immigration status, in particular, impacts eligibility in complicated ways (Castañeda, 2018; Joseph & Marrow, 2017). Unauthorized immigrants and some who are lawfully present are ineligible for ACA insurance coverage. Immigrants in some statuses who have been in the country for five years are eligible for Medicaid, those who have not yet met the five-year bar are only eligible for marketplace coverage. Many times, although an individual may have been lawfully present, they encountered immigrant related obstacles throughout the enrollment process. For example, individuals who had previously given all of their documentation found that their paperwork was lost in the application and they had to resubmit it or the authenticity of their documents was called into question.

In 2017, a husband and wife sought health insurance. The husband was a citizen and his wife was a legal permanent resident but had been in the country for less than five years. Recently, the wife had stopped working making her unable to pay for their health insurance plan that cost over \$300 a month leading to a gap in coverage. With the decrease in income, the household fell below the Medicaid eligibility level. However, since only the husband was a citizen, he was enrolled in Medicaid and the wife had to continue to purchase a marketplace plan. They had waited too long after the income change to qualify for a special enrollment period and so had to wait for open enrollment to make the coverage change. The husband could have enrolled in Medicaid earlier because it is always open enrollment, but he was not aware of this.

The ACA anticipated the challenges posed by changes in personal characteristics and requires individuals to update the marketplace when they move, change income, divorce/marry, have a baby or lose health coverage. These changes in life situation prompt 'special enrollment events', which give households 60 days to make a change in their coverage. Otherwise, households must wait until open enrollment to make a change. Despite being given two months to address the change in a family situation, many individuals miss the special enrollment period or are unable to change their health plans. Two such reasons are that other events have taken priority, or the event has not actually happened at the time a person is trying to report it. To report a change to the marketplace, the event must have already occurred and proof must be available of it. Based on observations and interviews, this left many individuals stuck in unaffordable health plans, leading some to miss payments and lose their health insurance. A change in family situation often intersects with other obstacles including the affordability of health insurance plans, bureaucratic barriers and system errors.

### ***Health insurance and program literacy***

We define health insurance and program literacy obstacles as not understanding enrollment rules and requirements; confusion regarding plan structure, costs and tax implications of the law; and a lack of comfort signing up alone online. As can be seen in the examples below, many people experienced multiple overlapping obstacles simultaneously. And yet, they used the resources at their disposal such as in-person help, friends and family members to overcome these obstacles.

In 2014, a 47-year-old white male who was just discharged from addiction treatment sought coverage. The enrollment specialist explained copays, coinsurance and deductibles, but he struggled to follow as she scrolled up and down the screen, moving on before it was possible to focus and digest what she said. Confused, he decided to go back to his friend's house where he was temporarily staying and read through the plans on his phone; the contact center was paperless so he had no printed information about his options. In 2015, a 29-year-old college educated woman complained, 'it's impossible to sign up online'. She was overwhelmed and didn't want to make a mistake. She lost coverage in May when she stopped being a full-time student. She had just quit her job but wasn't able to enroll in Medicaid yet because she was still working for another week. After many

system freeze ups, she was told to come back in a week. She could do it herself online, but she said, 'no, I need help'. In one of the more extreme illustrations of difficulties navigating the complicated enrollment process, we met a 68-year-old man who received a notice in 2016 that his plan was canceled. He was not eligible for Medicare because he did not have sufficient working quarters; he had no income and lived on savings. His tax credit did not show up because he had not filed taxes since the 1970s. He described himself as a dinosaur who does not have a computer and never worked on one. He was uninsured for 30 years. He said that he called to resolve his problem, but only heard one human voice in days. He will need to file his 2015 taxes before he is eligible for a tax credit for 2017. In each of these examples, people confronted obstacles related to knowledge of insurance and enrollment rules. In the first example, the applicant was confused about insurance terminology. In the second, the applicant was not comfortable applying alone without help. In the third, computer literacy and knowledge of tax rules impeded the enrollment.

Health insurance in general and the ACA in particular are difficult to understand. Insurance in the United States relies on multiple payment mechanisms such as premiums, copays, coinsurance and deductibles that make the total cost of a plan difficult to predict. Each plan limits its provider networks and covered prescription medications. In addition, the ACA has a whole set of rules about eligibility, when enrollments can take place, when payments must be received, and how taxes must be filed that are challenging to understand. Add to this that the enrollment system is online and some people are not comfortable with or do not have access to the internet, and the knowledge challenges mount. The results of a recent health insurance literacy quiz administered by the Kaiser Family Foundation shows that about half of Americans can answer 7 out of 10 basic health insurance questions correctly. However, people who are younger, less educated and uninsured tend to score more poorly on the quiz (Norton, Hamel, & Brodie, 2014). Survey research has also shown that higher financial and health insurance literacy is associated with higher rates of Medicaid and marketplace insurance enrollment (Hoerl 2017). This is concerning because populations with low levels of financial and health literacy are exactly the populations who use ACA insurance exchanges. In our research, we found that knowledge of insurance and ACA enrollment rules, the tax implications of coverage subsidies and lack of comfort with the online enrollment system all posed obstacles for people in search of coverage. Rather than seeing insurance literacy obstacles as a lack or deficit on the part of applicants, we see this as the product of policy choices to construct very complicated plan designs and program rules that rely on, rather than trying to eliminate, frequent changes in coverage. Designing policy that calls on everyone to become experts in insurance is fundamentally flawed.

## Discussion and conclusions

In this study, people encountered difficulties enrolling in coverage because of bureaucratic barriers, system issues, affordability, difficulty calculating their income, changes in household status, and confusion about insurance and program rules. We did not find 'free riders' who were taking advantage of the system and skipping coverage until they got sick. Instead, we found people with complicated families and work situations who were actively struggling to enroll in health insurance. The system put multiple obstacles in their way that they tried to overcome.

Our study adds to the existing literature on in-person assistance and barriers to insurance enrollment in several ways. First, we provide a four-year long study, not just a snap shot of challenges during the first year of open enrollment, which shows that maintaining continuous enrollment is a major challenge for enrollees. Second, we use consumer experiences both as a form of data, but also of analysis about what is working and not working on insurance exchanges. Unlike much survey research, we don't rely exclusively on elite or managerial accounts. As such, we identified far more problems with the enrollment system than those who are more

distanced from the frontlines of enrollment. Our main finding is that the vast majority of enrollees experienced one or more obstacles to enrollment. What's more, bureaucratic and system obstacles interacted with the other obstacles (affordability, change in family characteristics and health insurance literacy) to place multiple barriers between applicants and affordable coverage.

Critical medical anthropologists have approached the issue of chronic uninsurance and instability in coverage as an example of how the health system produces marginality and conscripts low income and minority individuals to substandard care (Becker, 2007; Sered & Fernandopulle, 2005). We follow this analytical tradition by arguing that means testing, program fragmentation, complicated eligibility rules, malfunctioning technology and insufficient accountability created enrollment obstacles that prospective enrollees struggled to overcome. Rather than alleviating these problems, recent health reform efforts in the United States institutionalize and normalize frequent changes in coverage as a feature of the health care system. Health coverage eligibility is determined by employment, income, age, immigration status and household composition – all characteristics that are subject to change. Importantly, churning disproportionately impacts low-income individuals and families.

A better policy would create a health system that makes it easy to enroll in affordable coverage and stay covered. The best solution would be to create an integrated, universal health system to replace our stitched together patchwork of inadequate and partial programs. Many countries have health systems where annual enrollment in coverage is simply unheard of. But short of a total overhaul, there are still practical policy interventions that can reduce frequent changes in eligibility and cumbersome, malfunctioning enrollment processes. Some researchers recommend using automatic enrollment, extending Medicaid eligibility for one year (Swartz, 2015) and creating plans that allow individuals close to the Medicaid cutoff to seamlessly transition between marketplace and Medicaid coverage (Sommers, Graves, Swartz, & Rosenbaum, 2014). Our research suggests that a crucial place to start would be to simplify the application process and require fewer redundant verifications. The current five layers of identity checking is excessive: Department of Homeland Security; the IRS, Experion credit; Social Security Administration and RI DHS. In addition to all of these databases, people have to submit their identity documents and paystubs and often other documentation as well. Documentation review approval bottlenecks greatly slowed down the enrollment system in Rhode Island. While in-person enrollment help is crucial, frontline enrollment assisters also need to be trained and empowered to actually resolve common issues – the practice of escalating complicated cases did not lead to effective and timely resolutions. The policy choice of using health insurance eligibility as a tool of immigration policy is also flawed and leads to slow processing and many gaps in coverage for citizens and non-citizens alike, especially in mixed status families (Castañeda, 2018; Joseph & Marrow, 2017). Finally, public agencies and private contractors must be held to account for the bureaucratic and system errors that have proven so difficult to overcome.

Though the largest source of obstacles in our study was systems issues and bureaucratic barriers, we want to resist understanding the problem as simply a technocratic one that can be fixed by new enrollment policies, different management methods or a better technology contractor (though these might be helpful!). Underneath the systems and bureaucratic obstacles lies a problematic idea: that a health system built on churn is acceptable. The unspoken assumption here is that it is okay if poor and near poor families regularly gain and lose coverage based on changes in their income, household composition, immigration status, or difficulty understanding and navigating through byzantine program rules and recertification processes. Current health reform trends to add work requirements to Medicaid and increase consumer cost sharing, promise to further erode continuity of coverage. This is why it is urgent to recenter the academic study of health policy around the experiences and

analysis of the poor and near poor individuals whose attempts to maintain coverage show us where to find the flaws in the system.

## Notes

1. The 2012 Supreme Court decision in *National Federation of Independent Businesses v Sebelius* made the expansion of Medicaid optional; the upshot is that residents of 18 states still do not have access to expanded Medicaid.
2. For a review of the contribution of behavioral economics to understanding enrollment behavior, see Baicker and colleagues (2012). We find the theoretical premises and assumptions problematic in this work as it usually approaches non-enrollment from an individualized deficit perspective that assumes that people don't want coverage or don't have the wherewithal to get it. For example, Baicker and colleagues employ explanations such as 'lack of understanding', choice overload, misperceptions and limited self-control that implies that people who are uninsured lack the capacity, self-control and efficacy to make the right choice to enroll in coverage. Rather than looking for the reasons for low take up in assumptions about the psychological make-up of the uninsured or based on evidence from decontextualized laboratory experiments, we employed the anthropological methods of observation and interviewing to learn how actual people attempted to get covered.
3. Joseph studied immigrants in the Boston area and found that the most common barriers to insurance coverage 'fit into three main overlapping categories: (1) immigration-related, (2) bureaucratic, and (3) health care system' (2017, 106).

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