Unrequited Engagement: Misadventures in Advocating for Medicaid Expansion

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Health reform in the United States is in peril. Although the Affordable Care Act (ACA) expanded health-care access to twenty million people, ongoing Republican attempts to dismantle the ACA make clear that these gains are extremely vulnerable. If the US Senate’s Better Care Reconciliation Act had passed in June 2017, for example, the Congressional Budget Office (CBO) estimated that fifteen million Americans would have lost their health insurance by 2018 and twenty-two million by 2026 (CBO 2017a). Likewise, the CBO estimated that if the recently passed tax reform bills—which would eliminate the individual mandate of the ACA—are signed into law, then thirteen million Americans would lose their health insurance (CBO 2017b), premiums would increase by approximately 10 percent per year (CBO 2017b), and the federal deficit would increase by 1.5 trillion dollars (CBO 2017c)—a move that many health advocates suggest would reduce Medicaid coverage over the long run as Republicans seek to cut so-called entitlement programs.

In this uncertain context, this essay is written with two primary aims. First, we turn an ethnographic gaze onto one of the major benefits of the Affordable Care Act: expanding Medicaid to low-income adults. Though the ACA is not perfect, and we analyze its faults at length in other places (Mulligan and Castañeda 2017), it is nonetheless important to take a public stand in favor of preserving the positive aspects of the law, including—and particularly—maintaining the expansion of Medicaid access to low-income adults. Based on our collective research experiences and the uniquely holistic approach of anthropology, we put human faces to the data to argue that Medicaid-facilitated access to health care saves lives. Conversely, we underscore that the absence of health coverage in the Medicaid “gap” leads to job loss, disability, and death.

Our second aim is to reflect on the role and limitations of a public anthropology in larger health-care debates through a consideration of our own unsuccessful attempts to publicize our ethnographic research in health-policy and clinical journals. In the past decades, anthropologists have largely abandoned previous disciplinary stances that celebrated neutrality. For many, advocacy and public engagement have become not simply an option but an ethical obligation. As practitioners both within and outside traditional academic institutions consider the role and commitments of anthropology in the twenty-first century, the concept of engagement has become increasingly central. In recent months, the American Anthropological Association has issued public statements advocating for science funding, opposing the repeal of the ACA, condemning the Trump administration’s travel ban, and defending research on climate change, among many other important issues (see AAA 2017).

As medical anthropologists studying the rollout of the ACA, we felt that it was important to advocate for the benefits of Medicaid expansion with policymakers and researchers from the more traditional policy disciplines who often serve as advisors to policymakers. We were (and still are) convinced that ethnographic stories have an important and compelling place in the wider polemics about the ACA, and so we decided to leave our own disciplinary and political echo chambers with the expectation that our perspective would be welcomed—or at least heard—by our interlocutors in other fields. Instead, journal after journal rejected the article, stating that the methodology and presentation of the data were not a “good fit” for their platform. Such rejections indicated that we were engaging in a very one-sided conversation where the alternative to the echo chamber wasn’t dialogue but silence. The difficulty we encountered in making our research public thus forced us to engage with long-standing—but perhaps never more salient—concerns about how ethnographic knowledge is perceived outside the discipline and what constitutes “data.”

Based on this experience of unrequited engagement, this essay undertakes an analytical postmortem that both revisits our arguments about the importance of Medicaid expansion and also explores why policymakers and policy scholars largely viewed this anthropological approach to health policy as unintelligible or unsuitable for scholarly discussions around the ACA. While admitting defeat is never easy, we
think it is critical to (publicly) think through our failure because it moves away from the easy, feel-good rhetoric celebrating public and engaged anthropology to instead explore the difficulties, challenges, and patterned rejections that frequently meet those who attempt to translate their work beyond the discipline.

**MEDICAID EXPANSION: A POLICY ISSUE IN NEED OF ANTHROPOLOGY?**

Our interest in writing an article on Medicaid expansion for a policy audience grew out of a workshop convened at the School of Advanced Research (SAR) in October 2015, which brought together nearly a dozen social scientists who were studying, ethnographically, the rollout of the ACA in fifteen research sites across nine states.

In the three years immediately preceding the workshop, one of the crucial points of contention in policy circles had been the expansion of Medicaid coverage in individual states. Medicaid is a complicated and much-maligned safety-net program that is currently the largest single source of insurance coverage in the United States. It provides long-term care for the elderly, coverage for children, aid to the disabled, prenatal care for babies and mothers, and, now, health coverage for sixteen million low-income adults (Gunja and Collins 2016). When the ACA was passed in 2010, a cornerstone of the bill was the federally subsidized expansion of Medicaid to adults with incomes below 138 percent of the poverty line. In 2012, however, the US Supreme Court decided that this Medicaid expansion was optional, devolving the decision about whether to expand coverage to individual states. This decision created what has come to be known as the coverage gap, whereby most low-income adults in states that decided not to expand Medicaid have no viable option for obtaining access to health coverage. As of December 2017, thirty-two states and Washington, DC, have pursued expansion, while eighteen states have continued to opt out, leaving uninsured some 3.1 million people who should have been covered by Medicaid according to the original mandates of the ACA (Garfield and Damico 2015).

Debates over Medicaid expansion have been acrimonious. Opponents of expansion—including citizen groups, state lawmakers, and politicians in Washington, DC—argue that Medicaid creates dependency and undermines personal responsibility (Frakt and Carroll 2012; Greenbaum 2015). They also question the health benefits of the program in light of the associated costs, including the ultimate fiscal impact on state budgets when federal funding for the program phases down to 90 percent by 2020 (ALEC 2013; Davis 2014). To counter these claims, advocates for Medicaid expansion have produced extensive quantitative evidence showing that expanded Medicaid coverage improves use of preventative care, results in more outpatient visits, and is associated with better blood-pressure control (Christopher et al. 2016).

Other studies have shown that expanded Medicaid coverage leads to improvements in the identification and control of chronic conditions like diabetes and high blood pressure (Hogan et al. 2015) and that it narrows disparities in health coverage for black and Hispanic adults (McMorrow et al. 2015). When the positive financial benefits of expansion are taken into account, along with the federal cuts to uncompensated care, proponents argue that the financial benefits that accrue to state governments clearly outweigh the costs (Frakt and Carroll 2012; Sommers and Gruber 2017).

As anthropologists engaged firsthand with subjects who are variously included or excluded from Medicaid, depending on their state of residence, we felt that these data, while rigorous and compelling, offered an incomplete picture. First, these studies were often based on narrowly defined research questions that, in turn, generated data points (and “answers”) that excluded or overlooked other lines of analysis that may have emerged in a more open-ended research approach. Second, because they were not contextualized within the actual lives of people living in the Medicaid gap, they failed to capture the “conjugated oppression” (Bourgois 1988) that illustrates the human costs of refusing Medicaid expansion. Conventional health-policy analyses document specific associations between Medicaid coverage and health outcomes, access to care, and household budgets. Yet such studies overlook how each of these isolated variables coalesces and combines to shape the lived experience of low-income adults. Families and individuals living in the Medicaid gap must contend with financial stress, chronic disease, acute health crises, and lack of access to care—all at the same time. Not surprisingly, the impact is greater than the sum of the parts.

When health-policy decisions are seen primarily through the prism of abstract, decontextualized data, it is easy to lose sight of the material, embodied consequences of health policy. It is in this area that we felt that our research, with its disciplinary focus on “peopled accounts” (Biehl and Petryna 2013), could make a contribution. Medical anthropologists have long played an important role in highlighting some of the shortcomings of Medicaid for low-income people and safety-net providers. Research has documented how privatizing Medicaid and moving to a managed-care model has made it more difficult for people to access care and has strained health-care safety nets (Horton et al. 2001; Horton et al. 2014; Lamphere 2005; Maskovsky 2000; Mulligan 2014; Wagner 2005; Waitzkin et al. 2002). Other work has argued that the stigma experienced by Medicaid recipients keeps the program from reaching its full potential, especially as stigma contributes to perceptions of second-class health citizenship and a lack of regard for poor people’s time (Andaya 2017; Martinez-Hume et al. 2017).

While these are important insights, in the context of the political debates over the ACA, we wanted to draw on our disciplinary expertise to provide a perspective that troubled prevailing views of Medicaid as hopelessly flawed and an engine of dependency. Our research consistently highlighted the intersection of poverty and sickness, demonstrating time and again not only that poor people are more likely to be sicker (a point well established in the quantitative literature)
but also that poorly managed sickness and chronic ill health were major contributors to ongoing poverty (Institute of Medicine 2009). By highlighting the Medicaid experiences of real people, we hoped to convince audiences outside our traditional arena—policymakers, policy researchers, and clinicians, for example—about the importance of advocating for Medicaid expansion in their states. Yet our attempt at engagement would prove far more difficult than we had perhaps naively imagined.

THE CASE FOR MEDICAID EXPANSION (AN ESSAY WITHIN AN ESSAY)
The argument of our policy article was simple. Drawing on illustrative cases from our comparative research, we called for closing the Medicaid gap, arguing that states that fail to expand Medicaid: (1) prevented people from obtaining the stable employment that might allow them to live better lives; (2) produced disability by keeping people from accessing acute, chronic, and preventative care; and (3) hastened death by providing only emergency care for otherwise manageable chronic conditions. As evidence for these points, we provided short vignettes that were extracted from our individual studies of health-care reform in the US (for details on the methods of the projects that contributed to these vignettes, see Appendix 1). These vignettes are reproduced in their original format below.

**Keeping People from Being Able to Work**
One of the most common motifs that occurred across our data was the association between being sick and being unable to work. Many of the people we spoke with, and particularly those with chronic conditions, were unable to work because of their health situations. Because they were unable to work, or at least work in full-time jobs that were likely to provide health insurance, they were also unable to obtain the treatment they so desperately needed. This situation more often than not resulted in a downward spiral in which impoverished people were placed at even greater risk for sickness and poverty (e.g., Sered and Fernandopulle 2005).

Consider fifty-eight-year-old Sharon from Texas. In 2009, Sharon was diagnosed with chronic sarcoidosis, which in her case led to scarring and thickening of the lung tissues, kidney damage, bone deterioration, and intense pain. These symptoms proved difficult to manage for Sharon, who was employed as a part-time home health aide, a job that did not offer health insurance. Every month, Sharon earned approximately $700. Out of this money she paid her rent, water and electricity bills, and a $10 payment toward the $250,000 she owed for two kidney-failure-related hospital stays. With whatever was left, usually $50 to $80, Sharon paid for groceries and the medications she could afford. She regularly received food from a local charity to supplement what she was able to buy, but even with this help she was sometimes forced to go without electricity in order to pay for partial refills of her medications. Sharon’s friends and relatives have asked her why she doesn’t change jobs in order to get health insurance. As she explained: “I feel I’m qualified [for other jobs], but right now I can take a break if I need to. I sweep and then I rest. I wash dishes and then I rest. . . . Things can be worked around my breathing and when I’m not hurting too bad.”

Like many sick Americans in similar circumstances, Sharon is caught in a catch-22. The severity of her illness means that she is only able to work part-time in a job that can accommodate frequent breaks to relieve her pain and shortness of breath but does not offer health insurance. Yet because she does not have health insurance, Sharon cannot manage the symptoms of her disease and is consequently unable to work full-time in a job that would offer health insurance. If Sharon had access to health care to manage her illness, her prospects for stable economic employment would be much brighter.

**Creating Disability**
In addition to preventing people from being able to work, we found that the coverage gap creates disability through a variety of mechanisms, including a lack of preventative care, inconsistent treatment for chronic conditions like diabetes, and a lack of care for acute injuries. The resulting disability, in turn, also has implications for employment, as the experience of sixty-two-year-old John from Idaho illustrates.

John’s disability was not a result of a single incident but arose through the gradual accretion of injury and ill health that occurred over decades of his life. As a young man, John worked in construction, a job that did not provide health insurance. During his time in this profession, he was pinned under a rig, hit in the head by a combine, and “whacked by a two-by-four.” These injuries, most of them untreated both at the time and later on, took their toll on John’s body. By his early fifties, John was no longer able to do outdoor work. Instead, he had turned to bartending, a job that paid the bills but, once again, offered no benefits. In order to manage the chronic pain from his untreated injuries, John typically took eight ibuprofen every two hours. When he needed something stronger, he turned to friends who were injured in the service and could obtain pain medication through the Veterans Health Administration.

When he was fifty-four years old, John suffered a stroke. He saw a doctor immediately after the event, but then received a letter stating that he would not receive additional care until he paid the initial medical bill. John, who was no longer able to bartend because of his stroke, was unable to pay. The doctor had given him a prescription during his one and only appointment, which he also could not afford to fill, so John was left to self-medicate with over-the-counter “aspirin-free stuff.” By the age of sixty-two, John still lacked health insurance, and decades of spotty and inadequate health care had taken their toll. Today, John walks with a cane, is unemployed, and can no longer fish or hunt, activities that once provided a large portion of the food he consumed. In spite of this, he was recently deemed not disabled enough to qualify for disability benefits. Because he has no income,
he was also ineligible for subsidized insurance through the ACA marketplace. If John had received care for the injuries he sustained early in life, as well as for the stroke he experienced later on, it is likely that his life would be very different. He almost certainly would not be as disabled as he is today.

**Letting People Die**

Finally, the coverage gap hastens death. This occurs when manageable chronic conditions, like diabetes and kidney disease, are not treated or are treated on an emergency basis only. Quantitative estimates put the number of avoidable deaths that can be attributed to states opting out of Medicaid expansion at 7,076 to 16,945 per year (Dickman et al. 2014).

If nothing changes, fifty-eight-year-old Carlos from Texas will soon number among those who died because of the Medicaid coverage gap. In 2013, Carlos was diagnosed with end-stage renal disease (ESRD) as a result of hypertension and Type II diabetes. ESRD requires regular dialysis treatment three times a week for three to four hours. Without dialysis, ESRD patients typically die within a matter of weeks. Without health insurance, however, the only way Carlos can receive dialysis is on an emergency basis, covered by Emergency Medicaid, when—and only if—his potassium reaches life-threatening levels. By the time Carlos presented at the emergency room, he was often unable to breathe due to the build-up of fluid in his lungs and was at imminent risk of heart failure or stroke. In spite of these life-threatening symptoms, Carlos was denied emergency dialysis if he was deemed not sick enough. This has happened multiple times. As Carlos explained, “If my potassium is not high enough, or they see that I am still able to breathe, the doctor will turn me away. They will tell me that it is not an emergency right now and that I can come back when I am sicker . . . when I am closer to death . . . like this, I am increasingly getting closer, week by week, to my end.” Because Carlos lives in Texas, a state that did not expand Medicaid, he is forced to face death on a weekly basis in order to have the chance to live.

While patients who receive regular dialysis and take care of themselves can live several decades on dialysis, patients like Carlos, who only receive emergency dialysis, have lower life expectancies and significantly poorer quality of life. One of the doctors who treated Carlos and other patients like him put it bluntly: “Receiving dialysis treatment only when you are on the verge of death is like a bizarre form of hospice. The health-care system provides just enough treatment to keep them barely alive . . . until it doesn’t.”

**The Impacts of Medicaid Expansion**

Based on our collective research, we concluded that the death, disability, and unemployment that directly result from a lack of health-care access are not inevitable. The ACA, and particularly Medicaid expansion, helped the poorest adults obtain access to care and thereby avoid premature death and disability. We found ample evidence for this in our research in states that expanded Medicaid. Consider the case of Paula, a fifty-eight-year-old woman from Rhode Island who had been uninsured for most of her adult life. Given her lack of health coverage, she did not see a doctor on a regular basis and generally treated herself for any medical complaints. When the ACA first went into effect in 2014, Paula became insured. She bought a highly subsidized health plan on the insurance exchange. Due to her unpredictable and low income, however, by 2017 she qualified for Medicaid. When she was informed of this, Paula was shocked. She felt guilty about not paying into the system, but her navigator explained that her income was too low to qualify for subsidized insurance. Paula accepted the Medicaid. At fifty-eight, she acknowledged that she needed it.

Although generally distrustful of insurance and doctors, since signing up for coverage, Paula has received routine health care for chronic conditions. She learned from lab work that her kidney function was worrisome to her doctor and that she was showing signs of prediabetes. Paula was also able to see a specialist about two recently fractured fingers that were not healing well and was considering seeing another specialist about hip pain if it persisted.

Although Medicaid skeptics and opponents of expansion often characterize the program as a handout, Paula, like most adults on Medicaid, worked. She moved between Medicaid and marketplace coverage, depending on her income. Unlike Sharon, John, and Carlos, who live in non-Medicaid-expanding states, she is able to get the basic preventative care that allows her to detect and manage chronic health conditions and offers protection if she has a health crisis. As Paula’s case demonstrates, investment in Medicaid has helped her remain healthy and productive. It allows her to work and to care for herself and her aging mother, and it prevents her from slipping further into the downward spiral of poverty and ill health that we found time and again in nonexpanding states.

**ENGAGED ANTHROPOLOGY AND INFLUENCING HEALTH POLICY**

After synthesizing the comparative data of the medical anthropologists who had participated in the SAR workshop, we felt that our findings on the additive burdens of poverty, ill health, and lack of health-care coverage would be of interest to policymakers and clinicians. We thought a fairly obvious but crucial conclusion from our work was that Medicaid had important benefits that were being overlooked in a political debate that often vilified the program and the people it served as well as in the existing literature that relied primarily on quantitative assessments of the program. At the same time, we recognized that our research would need translating for a policy audience. Accordingly, we adjusted the organization, length, style, and tone of our article. We penned a short and nontheoretical introduction, wrote the article in a direct style (which, among other things, allowed us to conform to the various journals’ low word-count criteria), avoided anthropology-specific jargon, and finished
with an actionable recommendation—advocate for closing the Medicaid gap—all of which are typical for policy articles.

Despite these attempts at translation, it was difficult to find interlocutors who felt that our qualitative data and methodology “fit” with their journal. Over the course of a year, desk reject after desk reject were accompanied by letters stating that while the editors found the material interesting, they did not find the methodology a good fit with their journal. The editors of one of the leading journals in the health-policy field even suggested that the article, if we could rework it, would be a better fit for the journal’s Narrative Matters section—a section of the journal published online that provides a venue for personal “stories” related to health and health care. It is not a research section of the journal and, among other things, is not peer reviewed and prohibits submissions that include academic citations, tables, or figures.

We had anticipated that we might experience problems with disciplinary differences around anthropological holism and theoretical underpinnings (or, perhaps more accurately, the unacknowledged theoretical commitment to positivism that underpins most policy scholarship), as well as the difficulty of reducing ethnographic data and analysis to fit within the limited word counts used in most health-policy and clinical journals. Yet the reduction of our research to mere “stories,” with the implication that our evidence was not robust and our work did not count as research, took us by surprise. We will be the first to admit that none of the many versions of our paper was perfect. What is concerning to us, and what should be of note to anthropologists who are interested in policy work but do not currently have a track record of publishing in policy journals, is that our paper was quickly and summarily rejected primarily because of its qualitative/ethnographic focus. While the readers of American Anthropologist surely need little convincing about the value of anthropology, it is worth considering why anthropological knowledge is often seen as invalid, impressionistic, or “soft” by other disciplines.

First, there is a strong preference in health-policy circles, as well as in medicine and public health, for quantitative research. This tendency is only strengthening as a growing number of researchers call for health-policy research modeled on clinical trials (Baicker and Finkelstein 2016). This clinical trialization of health-policy research leaves anthropological methods and ways of knowing far outside of the conversation (Newhouse and Normand 2017). Our qualitative methods, as became very clear, were woefully short on statistical analysis and convincing p-values. Anthropology’s open-ended ethnographic approach is substantially different with respect to recruitment, data collection, and analysis in ways that other disciplines—and journal editors—saw as lacking in rigor (for more detail on our argument against this perspective, see Mulligan and Brunson 2017).

For health-policy researchers, rigor is often the product of large representative surveys, experimental research designs with testable variables, and statistical confidence measures. In contrast, the methods used in our research emphasized depth of engagement with research sites and subjects, interpretive insights garnered from local actors, interviewing to saturation, and a focus on experience as a type of embodied knowledge about health policies.

Though we recognize these differences in methodological approaches, we reject the assertion that qualitative research, including ethnography, is somehow less rigorous, insightful, or valuable than quantitative studies. Thoughtful, well-organized, and disciplined qualitative research is not imprecise or fluffy, as some have claimed (Baicker and Finkelstein 2016). Moreover, a qualitative approach, which tends toward being inductive instead of deductive, provides an opportunity to consider questions that are often overlooked by other forms of inquiry, such as: Why do people hold conflicting assessments of the ACA and Medicaid expansion? How does the combination of poverty and ill health influence individuals’ experiences with new options for care? In this way, qualitative research has the capacity to expose epistemological blind spots, a critical issue in policy work.

Second, as we went through this process, we were confronted with how anthropological “ways of knowing” are made illegible outside the discipline, often resulting in the exclusion of anthropological data from politically consequential conversations. Though some have suggested that to remedy this situation anthropologists need to adopt the language (and epistemology?) of health researchers (Closser and Finley 2016), we are not entirely convinced. We do not want to lose what is distinctive about anthropology—in this case, our holism and commitment to understanding policy as experience—so that we can finally gain the ear of policy and medical practitioners, only to then find that our Faustian bargain effectively prohibits us from articulating the very insights that we think are critical.

Finally, because causation is treated in a more limited fashion among policy scholars, perhaps asserting that Medicaid improves lives was too grand a claim. A recent article in the New England Journal of Medicine is illustrative. Sommers, Gawande, and Baicker (2017) make very cautious conclusions from quantitative evidence about the benefits of insurance coverage, stating: “Overall, the evidence indicates that having health insurance is quite beneficial” (5). In contrast, looking more broadly at lived experience and focusing on the cumulative financial and health benefits of insurance coverage allowed us to document how high the stakes are in people’s everyday lives: stakes that we do not think an exaggeration to call life and death. When anthropologists look at experience and the ways in which people narrate the impact of access to health care, we see broader, more-significant connections than the anemic associations cautiously pointed to by quantitative researchers. There should be room in the journals that assess the impacts of health policy to incorporate this experiential knowledge. Otherwise, a major piece of the story will be missed, as will the explanatory power to make sense of how gaining access to Medicaid can transform people’s experiences of work, family, and well-being.
LESSONS LEARNED
Our failure to engage the attention of hoped-for interlocutors during our foray into engaged anthropology raises the question of what we could have done differently. Written a better article (or six)? Given up on trying to reach policy researchers or policymakers by publishing in their journals? Written free blog posts that, while likely to reach some of our targeted audience, don’t advance our careers? Focused more locally within our states where we have more cache? Dressed up our research as quantitative data that is more acceptable in policy circles? None of these seem very satisfactory.

While some anthropologists have struggled, as we did, to make their research “legible,” we also recognize that there are anthropologists who have had much success engaging policymakers in regards to health-care reform (see the work of Machledt [2017] and Willging [Kano et al. 2016] for a few examples). In many cases, these anthropologists conduct work in cross-disciplinary teams. While this inherently leads to fewer translation issues, it can entail other trade-offs, particularly in how we write about and convey our knowledge. This type of collaboration is also sometimes not an option, especially for anthropologists in traditional academic positions like ourselves.

As an alternative, we could have incorporated mixed methods into our studies. While not a traditional cornerstone of ethnographic research, surveys can provide important information that can contextualize ethnographic analyses and make results appear more robust compared to those with a strong quantitative bias. Although we continue to be uncomfortable with the underlying assumption that qualitative methodologies are “soft” or unreliable, we recognize that this could be a way to introduce other scholars to the unique insights that anthropological approaches can provide.

Yet another possibility was writing policy statements for the AAA or special interest groups like the Scholars Strategy Network in the hopes of leveraging the status of these organizations to promote our research findings. Given the circulation of online materials, it is possible that such statements could find their way into policy research conducted in other institutions and disciplines.

At this point, of course, arguing for Medicaid expansion has lost political urgency. Defending the benefits of the Medicaid program, however, has never been more important. The election of Donald Trump and the consequent bolstering of Republican attempts to repeal the ACA have transformed the policy landscape. Closing the gap now seems like a distant dream, as health advocates lobby their representatives to protect existing Medicaid from deep cuts in spending and eligibility. Indeed, the Senate health-care bill that was not passed last summer was widely described as an attack on Medicaid rather than a repeal of the ACA (Sanger-Katz 2017). Likewise, the tax reform bill that passed the Senate this winter has been criticized as a mechanism to ultimately limit Medicaid benefits to future enrollees (Wasik 2017). In this regressive context, anthropologists must draw on our disciplinary expertise and policy networks to advocate for the preservation of safety-net programs, most notably Medicaid and Medicare, but also Planned Parenthood and other essential programs that provide care to those we study. Without these programs, the lives of those we work with—of whom Sharon, John, Carlos, and Paula are only a sample—will be significantly more difficult.

CONCLUSION
As others have noted, engagement comes with dilemmas and challenges (Checker, Davis, and Schuller 2014). According to Checker (2014, 416) overestimating our powers is one such pitfall. She asks, “Are we glossing over our own limitations and overestimating or overstating the kinds of change we can effect, especially at this political-economic moment?” Such provocation has pushed us to ask at this point: What is our goal? To be part of policymaking processes? Or to be that incessant reminder to policymakers to think about the people who are impacted by their decisions? Are we any better equipped to do this than community and advocacy organizations? Is our goal simply to unsettle some of the hubris of policy wonks? President Trump and Congressional Republicans are not going to reverse their positions on Medicaid simply because they read our articles. Nonetheless, we feel compelled to act. Many of the people that we interviewed perceived us as being more powerful than them and vocally expressed their hope that we would be advocates on their behalf. More personally, our political and ethical commitments to trying to “give back” in some way are, for many of us, crucial reasons to try to make our knowledge visible to a wider audience who may have more political clout than we do.

While we are still muddling through the policy angle for our research, we have turned to other audiences and venues in the meantime. In addition to contributing to a book on health-care reform that was published in the fall of 2017 by NYU Press (Mulligan and Castañeda 2017), we have written blog posts (Brunson 2016; Brunson and Mulligan 2017; Castañeda, Mulligan, and Schuller 2017; Mulligan and Brunson 2017; Sered 2016) and are in the process of writing articles for anthropology and social science journals. We have and will present our findings at state and national conferences, inside and outside of anthropology. Of course, we will also continue to argue for the strengths of anthropology and to actively seek ways to promote our findings outside the discipline. Our experience has underscored that when anthropologists are successful inside the policy world, or any other nonanthropological world, we need to serve as vocal ambassadors to highlight the strengths and contributions of anthropological methodologies. In the age of big data and widespread skepticism about qualitative work, it is critical to continue to argue for the strengths of anthropology, particularly its ability to describe the complex cultural dynamics behind social processes and to demonstrate how social policies shape individual and collective lives.
REFERENCES CITED


**APPENDIX 1**

This study was the culmination of three years of collaborative work. The majority of the coauthors first met at a set of American Anthropological Association (AAA) conference panels in December 2014 organized by Emily K. Brunson, Jessica M. Mulligan, and Heide Castañeda. The following October, all of the coauthors came together at the School for Advanced Research (SAR) in Santa Fe to consider health care reform in the US more broadly. This paper is a direct result of conversations that occurred about Medicaid expansion at that seminar.

Data presented in this article derive from four independent projects that were conducted before the coauthors knew one another. The analysis here represents a synthetic qualitative, meta-analytic work. While at SAR, and afterwards as we wrote various iterations of this paper, we re-examined findings from each of our individual studies in regards to the impacts of not expanding Medicaid. This process involved beginning with the results of our individual analyses and from there iteratively reflecting and deliberating each other’s cases to make comparisons across and between samples.

All of the projects described above were approved by the Institutional Review Boards of our respective universities; accordingly, confidentiality and privacy were appropriately protected. Actual names of participants have been changed in this paper to protect their identities.

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**RESEARCH POPULATIONS AND DATA SOURCES**

**Central Texas Sample (Sharon’s Story, Emily K. Brunson)**

The central Texas sample was assembled specifically to examine the experiences of uninsured Texans living in a region...
of central Texas where rates of health insurance uptake mirrored the state averages. Interviews were limited to persons who were US citizens and who had been uninsured for at least six months in the past year. Participants were recruited through a variety of methods, including fliers posted at job centers and food banks, handouts provided at health clinics and WIC offices, and messages posted to online neighborhood message boards and Facebook pages. Thirty-one persons were interviewed in the first year of the study, 2013. In 2014, a subsample of ten participants was re-interviewed. These same participants were interviewed a third time in 2015. Interviews in all three years explored respondents’ health histories, past and current experiences with health care, and health-care access. All interviews were recorded and transcribed, and later were analyzed using the method of thematic analysis.

**Multistate US Sample (John’s Story, Susan Sered)**
From 2003 and 2004, interviews were conducted with individuals and families living without health insurance in Texas, Mississippi, Illinois, Idaho, and Massachusetts. Participants were met through local churches, community organizations, parks, pharmacies and supermarkets, and through local professors whose own research involved issues of poverty or health-care access. The initial 146 interviews—all with uninsured Americans who were in the workforce at the time—covered health and health-care status, job and family issues, and resources and tactics these individuals used to try to access health care. The initial 146 interviews—all with uninsured Americans who were in the workforce at the time—covered health and health-care status, job and family issues, and resources and tactics these individuals used to try to access health care. In 2015, eighty-two of the original participants were located and re-interviewed. This second round of interviews explored how individuals and families had managed their health and health care in the intervening thirteen years. All initial interviews with project participants were recorded and transcribed; the later set of interviews was noted by hand during the conversations. Interviews were analyzed thematically for across-the-board issues and also analyzed in subgroups based on location, race, and gender.

**Rio Grande Valleyo (South Texas) Sample (Carlos’s Story, Milena A. Melo)**
The Rio Grande Valley sample came from a dissertation project exploring the illness experiences of low-income Mexican immigrants undergoing dialysis for end-stage renal disease in south Texas. Over fourteen months in 2015 and 2016, dialysis patients were recruited directly through a local federally qualified health center and through snowball sampling. Interviews were conducted in English and Spanish with fifty undocumented and fifty documented (naturalized US citizens or lawful permanent residents) persons, all of whom were born in Mexico and were low income. Eight patients (four undocumented and four documented) were further recruited as case studies with whom bimonthly interviews and participant observation took place. In addition, interviews were conducted with forty-two health-care professionals, and additional participant observations were conducted in hospital emergency rooms, clinics, and dialysis patients’ homes. All interviews were recorded and transcribed and analyzed using ethnographic methods.

**Rhode Island Sample (Paula’s Story, Jessica M. Mulligan)**
The Rhode Island sample was assembled to examine the experiences of state residents who gained access to insurance coverage through health reform. Rhode Island is a Medicaid expanding state and so provides a counter case to the samples from states like Texas where Medicaid was not expanded. From 2014 to 2017, 185 health insurance enrollment interactions were observed at the state health insurance exchange and community enrollment events. Thirty-three interview participants were recruited from the individuals observed seeking enrollment assistance. Interviews with these persons took place several months after their observed enrollment transactions and considered their health needs, work histories, and experiences with health insurance. Interviews were recorded and transcribed and later were analyzed using the method of thematic analysis.