

## I

## Medicaid, Political Life, and Fragmented Democracy

*“No one can travel the length and breadth of the United States without the conviction of its inexpugnable variety. East and West, South and North, its regions are real and different, and each has problems real and different too. The temptation is profound to insist that here, if ever, is the classic place for a federal experiment ... This kind of argument is familiar in a hundred forms. I believe that, more than any other philosophic pattern, it is responsible for the malaise of American democracy.”*

– Harold Laski, 1939

*“I’ve worked in Ohio, I’ve worked in California, I’ve worked in Washington and as a single parent I have always had Medicaid. Now here in Georgia in 2012 they cut me off because I have a part-time job ... This is the only state that has ever cut me off Medicaid because I have a job, a part-time job that does not allow me to afford insurance. Why cut off someone for that? You know I have to be healthy to work right? You want me to be a functioning, self-sufficient adult. So why take away the very thing that keeps me functioning, self-sufficient, and able to provide?”*

– Terrie, 2012

One warm August day I sat in a burger joint on the outskirts of Atlanta and spoke with Terrie, a middle-aged black woman.<sup>1</sup> I treated Terrie to a banana milkshake and she gave me the scoop on Medicaid. Because of her limited income, Terrie had been on and off Medicaid for more than seventeen years. Over this period of time she lived in Ohio, California, Washington, Illinois, and Georgia. Of everything she divulged about her experiences, Terrie’s most emphatic observation was that Medicaid varied dramatically from place to place. Before we sat down to talk, I told her that the purpose of my research was to understand what it

was like to be insured through Medicaid. Then, I began with a very open question: “Tell me a little about yourself?” In response, Terrie portentously broached the core issue that she would dwell on throughout our conversation:

My name is [Terrie] and I have a sixteen-year-old son; he’ll be seventeen soon. I have traveled a lot so the difference between state to state with Medicaid and what it offers and the programs and how consistent they are; I have a lot of experience with that. Being in [Medicaid] seventeen years, you know, it has just been a whirlwind with keeping [my son] safe and healthy.

I was struck by the prominence of geographic variation in Terrie’s first words. Her emphasis on this proved persistent and pointed. She soon offered details about the merits of various state Medicaid programs: “Ohio is the easiest, they do care about their people.” “California, their process is probably faster, but there are so many people and it’s so rapid that it is out of control.” “In Georgia, there are limitations in everything that they offer ... you either can get this and can’t have that, or you can have this and can’t get that ... you can only go to this doctor on this day at this time.”

Foremost on Terrie’s mind was how the intergovernmental design of Medicaid affected interstate travel. She shared this:

When I knew I was going to meet you, I got upset a little bit thinking about it, because I’ve got a lot to say about Medicaid. Like, for instance, my grandmother was here from Chicago just this past week. She went to the doctor and to the hospital. We got some prescriptions we needed to fill for her. So we go to the pharmacy and we can’t fill this prescription because Medicaid is non-transferable state to state ... and her prescription was \$190, so we really had to find \$190 for her prescription. That was amazing ... and for something that’s provided by the government ... you’re limiting the use of something meant to make people better.

As our conversation progressed, Terrie elaborated on the (state-specific) political lessons that she drew from such geographic discontinuities:

If it was about helping people, you would say yes, let *my state* be more productive and healthy so that we do not have people losing their lives [and] so that they can be productive citizens ... These types of people are here serving you food when you go out ... wouldn’t you like to know that they are healthy? These are the people that you want to give Medicaid, the very people who are serving your food ... you do not want to insure the very people that are serving you food? (emphasis added)

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Toward the end of the interview, I asked Terrie whether politics might be an avenue for changing some of the things we had talked about. She stared at me in what seemed like disbelief and sardonically uttered, “white noise.” I looked back at her, confused. Again, she reiterated, “white noise.” After a few seconds of awkward silence, I asked her what she meant. She explained by saying,

White noise is the people that choose to say well, if they give it to me, they give it to me, if they don't, they don't ... white noise also means that you feel like in your world, *you have no say, no say in the process if you don't agree with what is going on in Medicaid*. It's demeaning, you know, the process. So when you want to, you can't get through that door and you are wondering how can you possibly get through the magic door to get people to understand ... I have never seen anyone really stand up about Medicaid. We fight a little bit ... politically we fight a little over welfare reform and Medicaid reform and all that, but in general as people, I don't know why we don't fight (emphasis mine).

Terrie was among those who did not fight. Most of her time was spent working grueling low-wage jobs while taking care of her son, and she simply did not believe Georgia was a place where one could make a difference on issues like Medicaid. Throughout our conversation, she would recount some feature of how Georgia's Medicaid program operated, compare it to another place she had lived (often Ohio), sigh audibly, and say, “that's Georgia.”

Terrie recognized that Georgia was not the only “headache when it comes to Medicaid.” She named other culprits, like Louisiana, a state that “doesn't give a toss about Medicaid whatsoever.” She thought this was an injustice, reasoning that “Everyone in America needs to be covered so America is covered.” Still, Terrie saw little hope for change. She was mostly resigned to a life of second-class citizenship. She even admitted being “amazed” that I cared enough to talk to her, much less write an entire book about people on Medicaid.

Terrie's contextually inflected experiences with Medicaid were accompanied by feelings of political inefficacy and powerlessness, “white noise” as she dubbed it. She was not exceptional in this regard. Though the details differed in rich and revealing ways, nearly all of the Medicaid beneficiaries I interviewed for this book described program experiences that varied across states, counties, and even neighborhoods – critically shaping political life along the way. John, Fiona, and Daphne provide additional examples. Before I proffer a single word about academic literature or scholarship, I present their stories. I lead with the voices of

Medicaid beneficiaries because their experiences paint a compelling and multitone portrait of the largely veiled operations of federalism in the everyday lives of economically and (disproportionately) racially marginal Americans. The ensuing narratives exemplify the profound implications of federalism for democratic citizenship and provide a springboard for the scholarly inquiry taken up in this book.

#### JOHN: “MARRIED” TO MICHIGAN MEDICAID

John is a white man from Michigan who was diagnosed with a life-threatening chronic illness in early childhood. He expressed gratitude for Medicaid, but he also admitted feeling as though he was “married to Michigan” medically, without “the option of really going other places.” Like Terrie, John described an out-of-state trip gone wrong: “I actually hurt my leg and I got like a patch of gout down in my ankle and [Michigan] refused the bill and I got a whopping bill in the mail that I am still paying.” Further underscoring his weddedness to Michigan, John discussed his dashed hopes of relocating to Arizona to start a new life.<sup>2</sup> After speaking to caseworkers and friends in Arizona, John learned that the Arizona Healthcare Cost Containment System (that is the name of the state Medicaid agency) had meager home health care provisions that would not cover the services he required. “I got some other friends [who] live down [in Arizona] who have the same disease I do and ... they’re stuck over there with what they got and it just kind of becomes a struggle.” Reluctant to jeopardize his life-sustaining benefits, John decided not to move. He explained that “beggars can’t be choosers,” and declared that he would “live on Mars” if he had to. John also pointed out that if the government “just did like a federal insurance and everybody had their insurance card regardless of who we are, where you are, I think it would solve a lot of problems for people, but I don’t think that’s going to happen.” Incredulous about the possibility of change, John noted that Medicaid beneficiaries were politically lackluster because “it does kind of feel like you just reach a fork in the road where you just give up, you just lose.” Throughout our conversation, he continually referenced his thwarted aspirations: “I wanted to venture off and go try to do something different for myself ... seeing other family and friends and they’re able to move on ... it is tough.” When I finally asked him what he thought about “politics,” he assured me that he was not the least bit “interested in that.” I return to John in

subsequent chapters because it turns out that when mobilized by a cause proximate to his life, health, and community, he cares quite a bit about “politics” (which, as I make clear throughout this book, extends far beyond voting and elections). Still, separate from the concrete political outcomes I detail later on, the snapshot of John offered here speaks to how profoundly a federal political system conditions life for those who find themselves in need of assistance from the government to secure vital resources.

FIONA: “MEDICAID SAVED MY BABY’S LIFE”  
(BUT ALMOST DIDN’T)

Fiona’s story was more heartening, but the challenges she encountered are nonetheless instructive. Fiona was unexpectedly thrust into the world of health care policy when her son Jack was born with a potentially fatal tumor on his leg. With her partner in school, the family lost health coverage when she quit her job to care for Jack. Sympathetic and supportive hospital employees in North Carolina helped to sign Jack up for Medicaid. The program paid for everything and even covered expenses retroactively from a period before he was enrolled. Fiona had great things to say about Medicaid because it met her family’s most dire need during a perilous time. Nonetheless, she recounted a disconcerting problem. After about a year, the treatment that Jack’s physicians in North Carolina were providing stopped working. Fiona sought care from experts in Boston who were more knowledgeable about the rare condition that Jack suffered from. But North Carolina’s Medicaid program refused to cover that care, cautioning Fiona that if she pursued treatment in Massachusetts, she would have to do so on her own dime. At a devastating loss, Fiona waited and hoped. She soon noticed that Jack’s tumor was shrinking. Doctors said that the treatment he received in North Carolina had kept him alive long enough for his body to mount its own defense against the illness. Fiona avowed, “Medicaid saved my son’s life!” I relished in her happy ending, but wondered what would have happened if Jack’s body had not taken over. Fiona rightly spent little time pondering this. Instead, her experience with Medicaid motivated a new career: she now works for a grassroots organization advocating “health care for all.” In this role, Fiona coordinates with activists in Florida, Texas, and North Carolina to spearhead the fight for Medicaid expansion in the states that have refused it.

DAPHNE: MEDICAID AS THE BURGER KING OF  
 THE HOOD

At the time we initially spoke, Daphne – a young black woman in her early twenties – had been insured through Medicaid for her entire life. She grew up in a high-poverty, high-crime, hyper-segregated neighborhood in Syracuse, New York. She was living at home, attending community college, and desperately trying to “get out of the hood.” Her life had been so deeply defined by where she lived, that when I asked her about Medicaid, the overbearing power of place lurked in the subtext of nearly all that she relayed to me. For Daphne, Medicaid meant the scary clinic downtown where only the most indigent beneficiaries ventured. It meant being treated in “ridiculous” ways by health care practitioners who surely would not do the same to (white) people from nicer neighborhoods like “Fayetteville or Cicero or North Syracuse.” Medicaid meant missing out on high-quality care, not (only) because the program itself was inadequate, but because the *places* where poor people utilized the benefits were lacking. As far as the practical application of Medicaid services, Daphne told me that “it is different in different places ... [like] say if you’re at an Olive Garden or you go to a Burger King, they treat you really different.” Daphne and those who lived in communities like hers were relegated to the medical equivalent of the cheapest junk food.

Daphne was savvy enough to know that this was politically meaningful. Her politics – like most politics, perhaps – were local.<sup>3</sup> No matter the direction our conversation veered, the specter of the neighborhood loomed. What’s more: Daphne mapped the local to places beyond it, and she developed her ideas about policy and politics accordingly. For example, when I raised the topic of Medicaid expansion, Daphne confessed that she was glad New York had expanded the program, but deeply uncomfortable with that decision being left in the hands of any particular state:

I don’t really like the state choosing things ... *I don’t really trust the state* ... I just think everybody having the same access and it being the same everywhere ... would be more helpful instead of having all these rules and here and there ... I wish it was just nationwide ... I just wish it was the same nationwide and not just the state, because *I don’t think the state could be trusted, honestly. We can’t even trust our police force* (emphasis added).

At the root of Daphne’s mistrust of the state, there was something more proximate: her mistrust of local police. Extrapolating from one level/

institution (neighborhood/police) to another (state/Medicaid), Daphne deduced that policy decisions should be uniform across the nation. In doing so, she unknowingly foreshadowed her own struggles.

A few months after our initial interview I caught up with Daphne and learned that she had come to experience the consequences of federalism more acutely than she ever wanted to. Her long-held dream had come true: she was accepted to a college in North Carolina and given sufficient financial aid to actually go. Exultantly, she had made it out of “the hood.” Distressingly, her Medicaid could not go with her. Since North Carolina had stricter eligibility criteria, Daphne could not qualify and had to remain signed up for Medicaid in New York. Her plan was to visit her doctors when she came home over breaks. So when she tore a major muscle in an accident, she could not immediately see a doctor in North Carolina. Instead, she aggravated her injury by waiting until she could arrange travel home for treatment. As Daphne finished her first year in a bachelors degree program, her move south represented her purest aspirations for upward mobility, but it imperiled her health.

### Political Life: Participation and Citizenship

The political lives of Terrie, John, Fiona, and Daphne bear the imprint of Medicaid’s federated structure. By invoking political “life” in this way, I am being intentionally capacious. I mean for this to include “political behavior” as traditionally understood by political scientists (which encapsulates activities such as voting, contacting an official, and protesting). Going further, political life also involves more mundane actions taken by denizens seeking resources, redress, or protection from national, state, or municipal governments (such as filing a complaint within a local bureaucracy or requesting a fair hearing). Extending beyond the realm of participatory action, political life is also about how a person experiences democratic citizenship. Citizenship includes the “rights, duties and obligations imposed by government, as well as citizens’ responses to them” (Mettler and SoRelle 2014: 156).<sup>4</sup> Folks who cannot recall participating in any political activity at all nonetheless have political lives worth recognizing. Some of the people featured in this book exemplify that. They returned only blank stares when I asked them how, if at all, they “participated” in politics. But when I probed their experiences with Medicaid, they surprised themselves by having more to say than they had thought possible. And despite their disconnection from “politics” in the formal sense, they captivantly articulated

how they were actually *living* politics off the record. This is what Terrie, John, Fiona, and Daphne voice to us. While I will demonstrate why and how people like them take political action, I will also describe how they *live in and make sense of* a polity that is fragmented by the powerful force of federalism.

This book thus illuminates a pressing question: *how do Americans understand and respond to a political system that confers (or withholds) access to resources for the most indigent – not on the basis of needs or rights – but on the basis of geographic location?* To tackle this inquiry, I investigate whether, how, and under what conditions Medicaid influences political life. I find that it has varied effects across states, counties, and neighborhoods. In this way, federalism produces geographically differentiated political capacity across its population of beneficiaries and federalist<sup>9</sup> social policy is a key purveyor of political inequality.

### Why Medicaid?

The design of Medicaid is one reason for its central place in this book. The intergovernmental configuration of the program allows for wide discretion across state and local levels, which facilitates the policy fragmentation that I seek to understand. Still, Medicaid is not merely a useful case for investigating larger questions; it is substantively important in its own right.

Medicaid is the largest source of public health insurance in the United States and the primary mechanism for providing health coverage to low-income Americans. It is the third most costly domestic program in the federal budget (following Social Security and Medicare) and the biggest source of federal revenue in state budgets, accounting for one out of every six dollars spent on health care (Paradise 2015; Snyder and Rudowitz 2015). Recognizing Medicaid's immense significance, scholars have studied it carefully. Among other things, they have found that Medicaid has (positive) effects on mortality, mental health, financial security, and educational outcomes (Baicker et al. 2013; Cohodes et al. 2016; Finkelstein et al. 2012; Sommers, Baicker, and Epstein 2012a). In this book, I assess its effects on democratic citizenship and political participation.

With growing ensemble of academics, pundits, and ordinary people stridently pronouncing (and denouncing) the economic stratification of political life in America, tracing the conduits of political inequality remains a first-order task. Given that charge, Medicaid is especially



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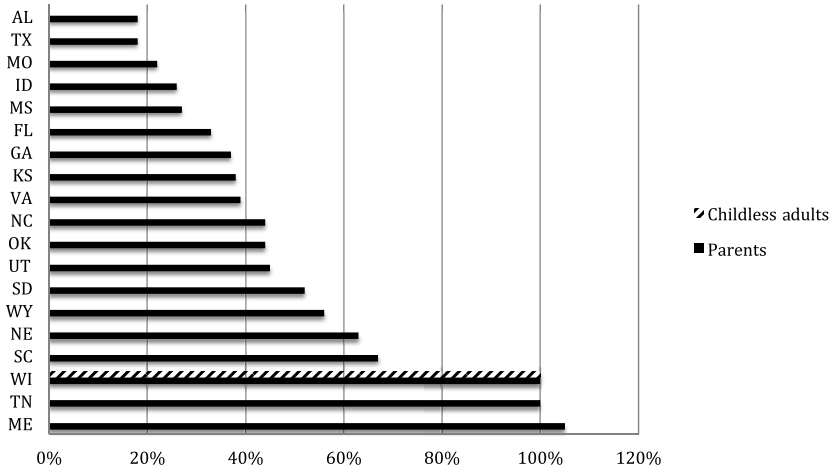


FIGURE 1.1 Income eligibility limits for adults in non-expansion states (2016)  
 Data from Henry J. Kaiser Family Foundation, 2016

significant. Its beneficiaries are overwhelmingly poor, disproportionately people of color, and unduly prone to health troubles. As such, Medicaid policy brings government directly into the lives of the most marginal citizens (Hernández-Cancio, Bailey, and Mahan 2011; Manchanda 2011).

Foremost among such persons are the economically marginal. Income is the chief criterion of Medicaid eligibility, especially for able-bodied adult beneficiaries.<sup>6</sup> In the wake of the 2010 Patient Protection and Affordable Care Act (commonly called the Affordable Care Act, or the ACA), non-elderly adults became eligible for Medicaid in states that implemented expansion so long as their income fell below 138 percent of the federal poverty line (FPL). In Wisconsin (a state that did not expand Medicaid) the cutoff is 100 percent of the FPL. The remaining (non-expansion) states have varied income requirements that mostly exclude non-disabled adults; when parents with dependent children qualify, they must fall (on average) below 44 percent of the FPL (see Figure 1.1).

The larger point is this: though Medicaid plays many important roles in our health care system,<sup>7</sup> the overall picture suggests that it is a primary resource for those who are living in or near poverty. In 2015, more than 90 percent of non-elderly beneficiaries were either poor or low-income: 54 percent were officially below the FPL (accounting for

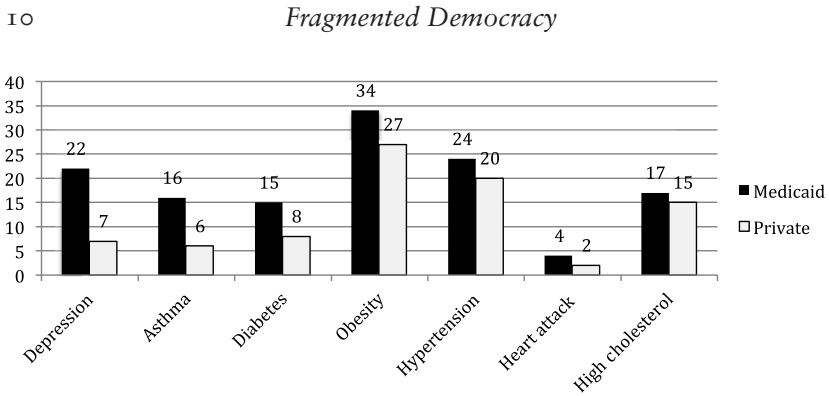


FIGURE 1.2 Percent of Medicaid insured and private insured with health conditions  
 Data from on Gallup-Healthways Well-Being Index, 2013

36 percent of all Americans in poverty), while an additional 38 percent hovered between 100 percent and 199 percent of the FPL (comprising roughly 30 percent of all low-income Americans).<sup>8</sup>

The tethering of class to race in the United States means that the penury of beneficiaries has racial repercussions. People of color are disproportionately represented in Medicaid: 32 percent of African-Americans and 34 percent of Latinos were enrolled in 2015 compared to only 16 percent of whites. Though blacks and Latinos (combined) composed 30 percent of the U.S. population in 2015, they accounted for 50 percent of Medicaid enrollees.

Not surprisingly, given well-documented racial and economic health disparities, Medicaid beneficiaries are also more likely to suffer from illnesses like diabetes, asthma, obesity, high cholesterol, and high blood pressure (Mendes 2013). Figure 1.2 contrasts people insured through Medicaid to those with employer-sponsored insurance.<sup>9</sup> The ailments of beneficiaries are particularly worrisome in light of mounting evidence that health can affect both electoral participation and democratic representation (Gollust and Rahn 2013; Pacheco 2013; Pacheco and Fletcher 2015; Pacheco and Ojeda 2015; Schur et al. 2002).

The trifecta of race, class, and health puts Medicaid beneficiaries among the most politically vulnerable persons in the country. Discerning the democratic corollaries of Medicaid is therefore essential for an accurate picture of political (in)equality in the United States. Relatedly, comprehending the political consequences of Medicaid policy requires attentiveness to its defining institutional facilitator: federalism (more on that in Chapter 2).