SARAH BALDWIN: Hi there, it's Sarah, host of *TrendingGlobally.* Before we start, I wanted to mention something. We're trying to learn more about our listeners. What you like about our podcasts at Watson, what you don't, and what you'd like to hear more of. So we created a survey and we'd love to hear from you.

It only takes a few minutes to fill out and it will really help us improve the show. And you'll be entered into a raffle for a pair of Bose noise canceling headphones. A link to the survey is in our show description. You can even go fill it out right now. We'll still be here when you get back. Thanks. Now, onto the show.

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As a graduate student in political science at the University of Chicago, Jamila Michener was unsure where to focus her interests in government, race, poverty and politics. So she did something that not all scholars do. She went out and talked to the people in the communities that she was studying. And one aspect of their lives kept coming up.

JAMILA MICHENER: Health care came up again and again. And because I was in neighborhoods that were composed of people who were living in poverty, Medicaid came up specifically.

SARAH BALDWIN: And it became clear to Michener-- Medicaid's effects go far beyond hospitals and health clinics. Her book, *Fragmented Democracy: Medicaid, Federalism, and Unequal Politics,* examines the role Medicaid plays, not only in its recipients lives, but in their perception of our democracy.

Michener is now an assistant professor of government at Cornell University. She spoke with Margaret Weir, a political scientist at the Watson Institute, about her book and research. They started by going back to her time as a grad student, and the people she interviewed who made her want to study this massive government program.

JAMILA MICHENER: The first conversation I remember is with the women-- and the names are all pseudonyms-- but with a woman I call Mabel, on the South Side of Chicago. I met Mabel outside of an unemployment office. And she had gone there to apply for unemployment, and was leaving, and I said, would you be willing to have a conversation with me? She said, sure. We sat down at a local McDonald's and we just talked.

One of the questions that I asked her which was super vague and broad-- and that was kind of the point just to get people talking-- was to tell me what she thought about the American dream. And Mabel was very cynical about the American dream. She said, I don't know what

that is. I know about the American nightmare. And she started to talk about the choices that she has to make between buying medicine and buying food.

And she said that she had at some point been on Medicaid and signed up for the program, but that her experiences with things like waiting in line, and dealing with the bureaucrats, and the agency caused her to no longer be a part of the program. And that she would rather just go to clinics and make do, and not have to interface with the government through Medicaid, even though she was a diabetic. And so she had this chronic illness that required that she had access to medication.

And by the end of the interview, she was she was nearly in tears. And so much of the conversation was about her health, and was about her struggle to get the resources that she needed in order to live a healthy life. So that was the first kind of conversation where I thought, man, I think health is something that's really important to people. I think medicine and medical care is really important.

And Medicaid didn't seem to be playing the role that I would have imagined it would. Going in I might have thought, most people who are poor enough are going to have health insurance through Medicaid. And when I started to have conversations like the one I had with Mabel, I realized that's not true, and there's a lot more to the story, and it's really about how people understand the role that the government plays in their lives.

MARGARET WEIR: And it sounds like their sense of the role that the government plays in their life is a pretty disempowering one, and one that makes them-- you used the word cynical. One of the key things in your book is about participation, and how the experience of policies affects people's participation. What did you learn about how people's experience of policy affects participation when you looked at Medicaid?

JAMILA MICHENER: I actually had my first inkling of this with Mabel. And when I asked her subsequently, later in the interview, what she thought about voting, she said, it's supposed to do something. We have Barack Obama. In her view as an African-American woman, we have this African-American president. Voting is supposed to be changing something. I'm still struggling to pay for medicine, and I'm still choosing between medicine and food. And so it's not clear to me that politics is really making a difference in my life.

And that theme that emerged initially with Mabel, emerged again and again for people. So people understand government, not through what they learn in-- or at least not solely through,

or primarily through what they learn in their social studies classes growing up, or in their civics classes in high school, or even through what they learn on television-- although some of that plays a role in how people understand politics. But for many people, they understand politics through what they learn in their everyday lives. Through the places and the spaces where they encounter the government in their daily lives, and especially for people who are on the economic or racial margins, they understand government through the resources that they can or cannot have access to.

A program like Medicaid is a kind of real life instantiation and representation of the government in people's day to day existence. And if that is failing you, even for with respect to providing the most basic resource that many of us understand everyone should have access to, if the government is failing you on that count, then it's not clear that investing and participating in democracy makes sense, right? That's not the best way to use your time. You may as well think about how to earn extra money, how to get that food that you need, how to get that medical care that you need, because investing your time and energy in the government isn't worthwhile. When the examples that you have in your daily life through programs like Medicaid are sending you messages and teaching you lessons about how insignificant and unimportant you are.

MARGARET WEIR: And it sounds like people have this experience that politicians come and go, but it doesn't have any impact on their access to critical resources. I mean, what can be more critical than access to health care? And even though Obama certainly was a politician that-- perhaps after 2010, in some states you would have found a more positive sense of what government can do-- did you find any sense where people felt like their interaction, or under some circumstances people felt like their interaction with the program actually made them feel more empowered?

JAMILA MICHENER: Yes, I think this is important. So one of the things that people say to me is, well, if this program is demobilizing people politically, then that means Medicaid's bad for democracy. And so maybe we should cut Medicaid. No, absolutely not.

Medicaid itself isn't bad for democracy. It's worth saying that. In interviews with Medicaid beneficiaries, when I ask them to tell me about their experiences with Medicaid, the first thing that nearly everyone said who actually had Medicaid-- who was actually enrolled-- was, I'm so grateful for the program. Many people told me stories about how Medicaid had saved their lives, how Medicaid had saved their children's lives, how crucial it was to them.

So for people who are benefiting from that resource, there's no doubt they recognize how crucial it is, that they're grateful for it, and that they appreciate it. But as the conversation continued, there were other factors that emerged that shaped their experiences with the program and the way that they understood it. And so Medicaid, on the whole, people told me stories about negative interactions, stigma and things like that, but not across the board. And that's important because it signals there's a possibility that this program can do something very different with respect to people's political lives than what it is doing now.

And so there were some people in some parts of the country, in places like Michigan, who relayed very positive experiences to me. And those folks are important to keep in mind, even if they were less common in my research than the folks who relayed negative experiences, because it means it is possible to structure these programs in ways that affirm people's dignity and incorporate them into the political process and the political system.

MARGARET WEIR: You mentioned waiting times, a sense that you don't matter. Tell us a little more about the experience of Medicaid that leads people to feel like there's just no point in getting involved, in trying to change things. Better to go find a way to earn more money. Don't waste your time on trying to change a public policy or change government in any way.

JAMILA MICHENER: I think that's a great question. And I think it's worth kind of delineating the nuts and bolts of how people come to these conclusions. So one thing is just the kind of arbitrariness of Medicaid as many people experience it. When states make decisions that change from one year to the next, or from one-- sometimes from one month to the next, right?

So recently, in Kentucky, for example, the governor decided that he was going to cut dental benefits, right? And then shortly thereafter that was rolled back and dental benefits were given back to Medicaid beneficiaries. That kind of process where one year you go to the doctor and you're able to get a service, and the next year you go back and that's no longer covered, that really stands out to Medicaid beneficiaries. When you get something that you didn't have before, or when you have something taken away that you had before, beneficiaries understand that they have no power. They have no control over what they'll get at any given time. They are completely at the, kind of, whims of the government.

And because of the political contestation that goes on with Medicaid on the kind of state level, there are a lot of changes in the program. Eligibility is constantly changing, which benefits people have access to is constantly changing, and there are some benefits in particular that

people care a lot about that are often taken away, like vision benefits and dental benefits, things like podiatry and physical therapy.

When you have an injury and you find out that you can't get physical therapy because it's not covered under Medicaid, but then you realize that your brother, or your sister, or whomever one state over can get it, there is this sense that the program is arbitrary. And that it's not about your needs. It's not even about how deserving you are. It's about things like what state you happen to live in, what year it happens to be, sometimes what county you live in and how near you are to the closest provider that is willing to give a certain service.

So there are all these elements built into the system that make it inconsistent and unreliable for beneficiaries, even as it's providing them with crucial, crucial resources. And that sends a clear message about the value of beneficiaries, and about the futility of even trying to change a system that is clearly kind of shifting with the winds in ways that most people don't understand, and don't believe they can control.

MARGARET WEIR: One of the subtitles of your book is federalism. And federalism sounds like one of those words that political science professors like to use, but when I just hear you talk, it's clear that people do have a sense of what federalism means. In this state you can get some dental benefits, and in a state where your sister lives or your aunt lives, you can't. Tell us a little bit about the role that this kind of variation across states-- and you go even down to the county level, and then really to the neighborhood, that all of these places matter a lot for how you experience Medicaid.

JAMILA MICHENER: Even though I'm a political science professor, I also can tend to think of federalism as this dusty, boring old term. It makes me think of the Federalist Papers, and I'm like, oh, James Madison. But what I found as I conducted this research, which I didn't originally envision as being about federalism, is that federalism is manifested on the ground in people's lives. So no one I interviewed said, man, federalism is the problem. That's not how people are articulating what's happening in their lives.

But many people that I interviewed said, well, I used to live in Georgia. And then I moved to Alabama, and then I moved to Mississippi, and then I moved to Chicago. And it turns out every place I went, Medicaid was completely different. And in some places I couldn't get services that I had gotten before. I didn't realize that's how the government worked I didn't realize that where I lived completely determined what I had access to. But I'm the same person with the

same needs. Why should it matter if I cross the state border?

And so people are mobile. Even people who aren't mobile have friends, have family members in other states, and they start to be able to get a sense of the differences in these programs. That is striking to people. It's kind of part of the narrative that emerges again and again as I'm talking to Medicaid beneficiaries. And one of the reasons why every place I went, Medicaid was completely different, and in some places I couldn't get services that I had gotten before. I didn't realize that's how the government worked. I didn't realize that where I lived completely determined what I had access to. But I'm the same person with the same needs. Why should it matter if I crossed the state border?

And so people are mobile. Even people who aren't mobile have friends, have family members in other states, and they start to be able to get a sense of the differences in these programs. That is striking to people. It's a part of the narrative that emerges again and again as I'm talking to Medicaid beneficiaries.

And one of the reasons why it really struck me is because I didn't start this project off thinking that that was going to be the story. So I wasn't asking people to tell me about differences across places. And some of the more kind of fine-grained differences on the county level and the neighborhood level, I even less so expected. And so I knew Medicaid was different in different states, and I expected that some differences in people's experiences would emerge. I didn't expect them to be as deep and significant as they were, but even my lens were trained at the state level at most.

And then I started having conversations with people talking to them about Medicaid. And they're talking about their neighborhoods. They're talking about the Medicaid clinic and the neighborhood it's in, and why they don't like going there, and how that affects the way they understand the program and who gets what. So people who live in this neighborhood, their Medicaid is like this. And people who live on the other side of the tracks have better Medicaid.

There was this sense that people had that there was good Medicaid and there was better Medicaid. And that which you had was dependent on where you lived on the neighborhood level. And that was something that, honestly before I talked to people, had never occurred to me. Similarly with counties, especially in places like Georgia, I would talk to people and they would say, well, in DFCS County you get this, and the bureaucrats are really mean because there just so many people. And so they're frustrated. And if you move a few counties over you

might be able to get more attention.

Even Mabel, who I began this conversation talking about, I didn't realize when I interviewed Mabel-- so what stood out to me was how much medicine mattered in her life, and how much medical care mattered. And that was part of what prompted me to pursue this project. But after I was, like, several years into the project and I realized how much place mattered, I went back to some of these initial interviews to see if there were things I had missed.

And I realized in Mabel's interview that she had told me a story that I completely didn't pick up on at the time. That for a year, she had moved from the inner city part of Chicago to the suburbs, because her son lived in the suburbs, and she had been doing well financially then, or better financially, then, so she moved to the suburbs. She was doing better financially, but she was still low income.

And so she applied for Medicaid when she was in the suburbs, and Mabel talked about how easy it was. And she was really struck by the fact that what she called the Medicaid building wasn't a Medicaid building. It was in a bank. And you went into a bank, you went into an office in a bank, you signed up for your benefits, everyone was nice to you. There was no stigmatizing-- this is the building all the Medicaid beneficiaries go to.

And so for her, it was a great year of Medicaid in the suburbs. And she talks about moving back to the city and standing on a line that went around the block to get Medicaid, and deciding she wasn't going to stand in the line, and just no longer being a part of the program. And so even from the initial time that I started talking to people, they were talking about place, they were talking about in terms of states, but they were also talking about it much more granularly in terms of where they lived, in the city, in the suburbs, in what county.

And so that's how people experience policy. They experience it as differentiated across place. And there are so many ways for them to find that out. Folks who are Medicaid beneficiaries are not indifferent or unaware of the way that policies are structured. They don't think federalism, but they know it's different in different places.

MARGARET WEIR: In your story that you tell about Mabel, it's based in Chicago. And one of the things we know about Chicago is that it's one of the most racially segregated cities in the country. So how does race play a role in your story? What is the difference that people of color experience with regard to Medicaid?

JAMILA MICHENER: So race was something that came up again and again. In particular, when I interviewed African-American Medicaid beneficiaries. And it was just-- it was part of the background of how they understood Medicaid, that often they referred to and talked about in a really casual way. And so they would say things like, well, there's a hierarchy of Medicaid, there's a racial hierarchy. And white folks are at the top, black folks are at the bottom, or the polls. And in the middle are Latinos.

And so if I walk into the office, I'm going to get treated with the least respect. I'm going to be looked at as someone who's just there for a handout. If a white woman walks in she's going to be viewed as someone who must be having a hard time and just needs a little bit of help. And so again and again, beneficiaries, especially African-American beneficiaries, relayed the kind of sense that racial inequalities and racial hierarchies were built into the system of Medicaid.

Now even further than that, this place-based differentiation also brings race into the picture, because place is structured in the United States, at least, largely around kind of racial disparities, and racial segregation as you noted. And so some of the people that I interviewed, like a young woman who's featured in the book quite a bit, named Daphne, who lived in hyper segregated neighborhoods in Syracuse for her whole life, and understood that people in those neighborhoods got a certain kind of Medicaid.

There was black people's Medicaid, the Medicaid that black people got, and then there were kinds of Medicaid that you got when you lived in other parts of town that were predominantly white. And so a lot of how people made sense of the arbitrariness and capriciousness of Medicaid was through the lens of race, right? So race was a way for them to understand why things were the way that they were. White beneficiaries for the most part, just didn't see that. Race just didn't come up when I interviewed them or even when I had other interviewers who were also white interview them, right? Because I'm an African-American woman, so maybe white people just wouldn't bring up race with me, right?

And so to make sure that wasn't going on, I trained some other research assistants to interview white beneficiaries. And they didn't bring it up then, either. And so I think it's just not a kind of primary consideration for them. I think there was one interview that I had with a white woman in upstate New York, in a rural part of upstate New York, and she talked about how great her experiences were with Medicaid. And then said, but I bet it wouldn't be like that for everybody. It'd probably be worse for black people, right?

So every once in a while you encounter someone who is not a person of color who's aware of that possibility. But certainly in interviews that I had with African-Americans, and to a slightly lesser extent, but still much more with Latinos there was an awareness that their racial status mattered. And for Latinos this sense that there are going to potentially be perceived as illegal, or have to go through more hoops to provide paperwork. So race is at play in many different ways here.

MARGARET WEIR: We've seen a lot of problems with Medicaid from your research. The capriciousness of the Medicaid bureaucracy, the differences across place, the perceptions of arbitrariness, unfairness. Let's talk a little bit about what might be done to make Medicaid better.

You talk some about advocacy in your book. Tell us a little bit about that, and about what you see in terms of possibilities for advocacy.

JAMILA MICHENER: Yeah, so I'll say a little bit about what comes up in the book. And then it might be worth also adding a lot of what I've learned in the last few months since the book has been published, because I've been able to connect in a much more kind of deep way with the advocacy community around Medicaid. And so maybe I'm a little more hopeful than I was when I wrote the book. Which is-- hopeful is not my specialty. So that's a good thing.

But one of the things that I was interested in toward the end of the book was understanding how Medicaid beneficiaries who are engaged, who are active, who are sort of standing up and trying to change things, how they get there. What helps them to be able to take that kind of position, and what is the potential role that federalism plays in structuring those possibilities?

So one thing I found is that federalism can provide opportunities, right? And a lot of what I focus on in the book are the kind of constraints of federalism. I think those are real and those are important to kind of acknowledge, and think through, and confront. But federalism also does some other things, right?

So for beneficiaries who are interested in advocacy and activism, federalism provides them with lots of models and different places they can look around and say, well, that happened in Kansas, we really don't want it to happen in Iowa. Let's work. Let's mobilize. So there can be that motivation. Or it can be, well, that happened in California. Why can't we have that here? Let's mobilize, right?

So place-based differentiation can provide people with negative and positive examples that

spur mobilization. And this is a lot of how the kind of activist beneficiaries that I interviewed worked. They saw what was going on in different places and thought why not here? Why not Iowa? Why not Michigan?

Since publishing the book, I've actually been engaging with a lot of Medicaid advocates and organizations that kind of advocate on behalf of and mobilize and organize Medicaid beneficiaries. And that has given me a sense of the role of organizations, of civic organizations. And I think that there's some hope there. I think if we develop the civic infrastructure in low income communities and communities of color more broadly, but specifically around health care, there's a lot of room for mobilizing Medicaid beneficiaries as a kind of antidote to the demobilization that I talk about in the book.

MARGARET WEIR: It seems like people would want to be mobilized around this policy in particular because it is so personal for their own well-being and for the well-being of their loved ones, that it would be-- if there were some ability to connect with people and give them a path towards feeling efficacy, that, of all policies, this one would be one that people would be motivated by.

JAMILA MICHENER: I think that's exactly right. I think that the folks that rely most heavily on Medicaid do have lots of barriers in their lives that prevent them from participating more deeply in general. But like anyone else, they care about these issues. They recognize what's at stake.

And so if we have the structures in place that actually reach them, and mobilize and catalyze their action, I think it's entirely possible to bring them in to the political community. For Medicaid to be a springboard for political incorporation, it's possible, and I think it's the vision that I have, right, and a vision that ultimately gets us to a system where everyone has health insurance.

And I think that only happens, though, if we recognize where we are now. And I think-- so the book is not a happy one, but it's one that helps us to confront the present so that we can envision a brighter, and better, and more democratic future.

MARGARET WEIR: Well, Jamila Michener, thank you so much for talking to us about your book, *Fragmented Democracy,* and helping us to make sense of Medicaid and citizenship. Thank you.

JAMILA MICHENER: Thank you for having me.

SARAH BALDWIN: This episode of *Trending Globally* was produced by Dan Richards, Jon Maza and Alex

Laferriere. Our theme music is by Henry Bloomfield. I'm your host Sarah Baldwin. Before you go, don't forget to fill out our listener survey. There's a link in the show description for this episode. You can fill it out on your phone right now. It's really short, and we'd really appreciate it. And you'll be enter to win a pair of Bose noise canceling headphones, which will make all your podcasts sound even better.

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