

Building Power for Health: The Grassroots Politics of Sustaining and Strengthening Medicaid

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Abstract

Context: Notwithstanding an impressive corpus charting the politics of Medicaid, there is still much to learn about the contemporary politics of sustaining, expanding, and protecting the program. There is especially scant scholarly evidence on the significance and function of grassroots political actors (i.e., the communities and groups most directly affected by health policy). This article explores the role such groups play in the politics of Medicaid.

Methods: This research is based on qualitative interviews with organizers and advocates working in the domain of health policy.

Findings: The power of grassroots actors in Medicaid politics is constrained by political and structural forces, including philanthropic funding practices, racism, and partisan polarization. Nevertheless, when bottom-up actors effectively exercise power, their involvement in Medicaid politics can transform policy processes and outcomes.

Conclusions: Grassroots actors—those who are part of, represent, organize, or mobilize the people most affected by Medicaid policy—can play pivotal roles within Medicaid politics. Although they do not yet have sufficient political wherewithal to consistently advance transformational policy change, ongoing political processes suggest that they hold promise for being an increasingly important political force.

Keywords Medicaid, grassroots, organizing, advocacy, power

As a pillar of US health policy, Medicaid serves more than 80 million Americans (CMS 2024). A large share of Medicaid beneficiaries live in or near poverty, with more than 65 percent at or below 200 percent of the federal poverty line (KFF 2022a). Additionally, Black, Latinx, Native American, Asian American, and multiracial people account for more than

60 percent of Medicaid beneficiaries (KFF 2022b). These demographic patterns underscore Medicaid's role as a pivotally important lever for health equity (Donohue et al. 2022). As the program approaches 60 years performing this and other critical functions, it is an apt time to reflect on its political status and sustainability.

There is abundant evidence that the design and administration of Medicaid policies are fundamentally contingent on politics. A substantial body of research reveals a dynamic interplay of political actors and institutions that shape Medicaid (Barnes, Michener, and Rains 2023; Barrilleaux and Miller 1988; Grogan 1994; Grogan and Patashnik 2003; Hanson 1984; Haselswerdt 2017; Huberfeld 2011; Moynihan, Herd, and Rigby 2016; Michener 2018, 2019; Olson 2010; Smith and Moore 2015; Sparer 1996, 2015; Thompson 2012). Notwithstanding its range and depth, most of this scholarship is oriented toward political elites and top-down processes. Relatively little research on Medicaid has examined the relevance of grassroots organizing, broadly defined as strategic collective action driven by communities and groups with shared experiences and mutual interests in advancing common political goals.¹ Neglect of bottom-up processes like grassroots organizing attenuates our understanding of the welfare state, undermines our ability to accurately chart paths of political change, and decenters the very populations that are most affected by Medicaid policy (Michener 2019; Michener 2023b; Michener, SoRelle, and Thurston 2022).

This article explores the role of grassroots organizing in the political processes that sustain and strengthen Medicaid.² Drawing on insights from qualitative interviews with leaders of organizing and advocacy groups across the United States, I illuminate how the political power of grassroots actors (i.e., the communities and groups most directly affected by health inequity) can be hampered by underinvestment and stymied by political elites. I highlight philanthropic practices, partisan polarization, and racism as three core barriers to building and exercising power among the economically and racially marginalized communities whose interests

1. The definition of grassroots organizing offered in this article aligns with a related definition of "community organizing" as "the process by which people who have a common identity or purpose unite to identify shared issues, develop collective goals, and implement strategies and tactics to reach those goals" (NCCDH 2022). This article's specific emphasis on "grassroots" organizing is meant to highlight organizing that is centered on the people most affected by health inequity, who have the most direct interest in advancing equity.

2. This article does not focus on elite or grassroots organizing aimed at weakening or eliminating Medicaid. Organizing efforts by opponents of Medicaid are worth identifying and understanding; nevertheless, they are not the emphasis of this work.

and experiences make them a crucial base for grassroots organizing efforts. Despite these barriers, the evidence presented in this article underscores that organizing grassroots actors to strategically advance their collective interests holds promise for transforming Medicaid in ways that make it better at meeting the needs of the people and communities it serves.

Medicaid and the Political Logic of Grassroots Power

Even as Medicaid has been on a consistently expansionary trajectory—far exceeding initial expectations in terms of enrollment, expenditures, scope, and place in the landscape of American social policy—it has also faced enduring threats and perennial retrenchment (Brown and Sparer 2003; Engel 2006; Grogan and Park 2018; Haselswerdt and Michener 2019; Kogan 2022; Olson 2010; Thompson 2012). As the program has grown, it has become a target for budget hawks who balk at its cost, conservatives who seek to shrink the footprint of the welfare state, and a range of other political actors with interests or ideas that compel opposition to a well-resourced, equitable, and sustainable Medicaid program (Levitt 2022). Stark and interrelated dynamics of partisan polarization, racialized health politics, nationalized state politics, and a political economy of scarcity have converged to push Medicaid to the front lines of political battles over reducing the national deficit, reforming “entitlement” programs, reproductive rights, work requirements, and much more (Fording and Patton 2019; Grogan and Park 2017b; Grumbach 2022; Hertel-Fernandez, Skocpol, and Lynch 2016; Lanford and Quadagno 2016; Michener 2020, 2021, 2023a; Pacheco, Haselswerdt, and Michener 2020). In a policy environment inhibited by gridlock at the federal level, grassroots actors are potentially pivotal tie breakers, power brokers, and sources of influence. The people most affected by policies struggle mightily to influence them at the national level, but as political centers of gravity shift to other levels of government, there are manifold (if constrained) opportunities to influence state and local policies around choices such as Medicaid expansion, eligibility requirements, scope of benefits, administrative burdens, and much more (Grumbach 2022; Grumbach and Michener 2022; Miller 2008). Moreover, achieving long-term transformative political goals (e.g., equitable, stable, and expansive funding for Medicaid; universal access to high-quality health care) requires strengthening Medicaid constituencies (see Grogan, this issue). Deepening the involvement of grassroots actors aligns with this prerogative.

Grassroots Organizing and Medicaid Politics Research

Notwithstanding the political logic of grassroots power, social scientists have been relatively silent about its role in Medicaid politics. Consider one of the most widely studied policies over the last decade: Medicaid expansion. The Supreme Court's decision in *National Federation of Independent Business v. Sebelius* (2012) curtailed federal leverage for enforcing the mandate that every state expand Medicaid to those at or below 138 percent of the federal poverty line. In the dozen years that followed, states made a range of choices about the adoption and design of Medicaid expansion. Researchers fastidiously assessed the political determinants of these choices. Existing scholarship suggests that expansion decisions have not been primarily driven by need (Barrilleaux and Rainey 2014). Instead, Medicaid expansion has stemmed from a complex mix of state politics and inter-governmental relationships shaped by governors, legislators, public opinion, interest groups, partisanship, ideology, institutional mechanisms (e.g., ballot initiatives), judicial developments, and bureaucratic administrators (Bradley and Haselswerdt 2018; Callaghan and Jacobs 2016; Camobreco 1996; Fording and Patton 2019; Grogan and Park 2017b, 2018; Haselswerdt 2021; Hertel-Fernandez, Skocpol, and Lynch 2016; Jacobs and Callaghan 2013; Lanford and Quadagno 2016; Olson 2015; Richardson 2019; Rocco 2020; Rocco, Keller, and Kelly 2020; Rose 2013, 2015; Shor 2018; Skinner 2015).

Within this substantial and important body of research on Medicaid expansion, a handful of studies have considered the role of state and local advocacy organizations (Callaghan and Jacobs 2016; Haselswerdt 2021). A key finding from these studies is that advocacy groups engaging in coalitional politics and lobbying can shape Medicaid policy. Drawing on quantitative state lobbying data, Callaghan and Jacobs (2016) find that lobbyists for public interest groups (e.g., public interest advocates who work on behalf of people who are uninsured) can significantly increase the likelihood of Medicaid expansion, even after accounting for a wide range of other factors. Complementing this finding via in-depth qualitative interviews with people involved in Medicaid expansion advocacy, Haselswerdt (2021) finds that "activists" can leverage state coalitions and ballot initiatives to circumvent the barriers to Medicaid expansion posed by "fractious federalism" in Republican-controlled states.

While these studies are valuable, they shed little light on grassroots political organizing driven by people and communities directly affected by Medicaid policy. At best, existing research emphasizes the "mediated advocacy" of professional lobbyists and other kinds of advocates

(Michener 2018).³ Although advocates are important, most are not directly accountable to a grassroots membership (i.e., a base of people from the most affected groups or communities), so their actions do not necessarily reflect the preferences or perspectives of grassroots actors (Grogan and Gusmano 2007; Mosley 2016). Instead, many advocacy organizations operate in relation to what some people in and beyond the Medicaid ecosystem call the *grasstops*. This means they focus on how to influence the trajectory of Medicaid through channels that flow primarily through political elites or the mass public.⁴

Table 1 details the goals, tactics, structures, and activities of grasstops advocacy organizations. As shown, grasstops approaches focus on influencing policy outcomes through connections to government officials and/or mass communications strategies.⁵ They are usually led by a limited number of advocates or lobbyists who are paid professional staff. The primary activities of grasstops advocacy organizations include lobbying, building relationships with political elites, and media campaigns. Importantly, however, advocacy groups are not indifferent to the people and communities most affected by policy. To the contrary, advocates often work to educate and/or mobilize such denizens. Education efforts entail sharing information meant to facilitate better access to resources, change societal narratives (e.g., altering public opinion in hopes that doing so will influence political elites), or enable political engagement. Mobilizing involves incorporating more people into the work of the organization, often for the purpose of short-term, episodic political action targeted toward specific ends such as voting in an election, testifying at a legislative hearing, or writing a letter to a public official. Advocacy groups taking a

3. Michener (2018: 136) defines mediated advocacy as “Medicaid policy advocacy [that] most often depends on the interventions of professional employees of nonprofit organizations tasked with representing the interests of Medicaid beneficiaries.” The crux of such advocacy is that it is indirect (e.g., not led or driven by the people and communities most directly affected by Medicaid policy).

4. The characterizations of advocacy and organizing approaches offered in this article are stylized for the sake of clarity and simplicity. Importantly, these approaches are not always as clearly bifurcated as table 1 conveys. Some organizations pursue both advocacy and organizing. Others shift from one approach to another over time. It is analytically and practically useful to understand the differences between grasstops advocacy and grassroots organizing approaches. Still, we should be cognizant of the blending and blurring of these distinctions that happens in practice.

5. The distinctions drawn in table 1 are primarily based on insights distilled by the author via the empirical analysis described in this article. There is also a sizable literature on advocacy (for an overview, see Mosely, Suarez, and Hwang 2023) and a growing literature on organizing (for an overview, see Han, Baggetta, and Oser 2024). Both sets of concepts and activities are variably defined, with no conceptual consensus on their precise content or boundaries. For the purposes of this article, I do not adjudicate conceptual disagreements or linger on definitional disagreements. Instead, I contrast organizing and advocacy based on the empirical evidence collected for the purpose of better understanding how grassroots actors engage Medicaid politics.

Table 1 Grasstops Advocacy and Grassroots Organizing

	Grasstops Advocacy	Grassroots Organizing
Goals	<ul style="list-style-type: none">▪ Policy change▪ Influence brokering	<ul style="list-style-type: none">▪ Policy change▪ Power building
Theory of change (i.e., operating assumptions about how change happens)	<ul style="list-style-type: none">▪ Persuading political elites▪ Shaping narrative/discourse▪ Shaping public opinion	<ul style="list-style-type: none">▪ Persuading political elites▪ Pressuring political elites▪ Shaping narrative/discourse▪ Shaping public opinion▪ Building social movements
Key actors and decision makers	<ul style="list-style-type: none">▪ Lobbyists▪ Policy advocates▪ Paid/professional staff	<ul style="list-style-type: none">▪ Community organizers▪ Community members
Key activities	<ul style="list-style-type: none">▪ Lobbying elites▪ Building relationships with elites▪ Mass media/communications▪ Education▪ Mobilization	<ul style="list-style-type: none">▪ Affected populations▪ Organizing people and communities▪ Building relationships with members▪ Developing leaders from within affected communities▪ Political education▪ Direct action▪ Engaging political elites via persuasion, confrontation, and negotiation

grasstops approach deploy mobilization and education to directly help those they advocate for and to indirectly influence political outcomes. Nonetheless, the bulk of their efforts remain targeted toward elites, and the lion’s share of organizational decision making is dictated by professional staff, with little direct accountability to a specific base. For these reasons, grasstops advocacy, even when it involves mobilizing or educating large numbers of people, is different from grassroots organizing.

Grassroots organizing has elements that overlap with grasstops advocacy as well as those that are distinct from it (table 1). The chief objective of organizing is power building: the strategic development of political formations (groups, networks, coalitions) that equip people and communities to exercise collective power over the processes that affect their lives.⁶

6. The distinctions between organizing, mobilizing, and advocacy are too numerous to fully capture in this article. An apt distillation of one element of contrast is found in Han, Baggetta, and Oser (2024: 246), who describe organizing as “an approach to collective action that seeks to change individuals and groups into effective actors in the public sphere,” and who juxtapose it with mobilizing as “an approach that conceptualizes collective action as a process of aggregating and expressing preferences without an explicit focus on changing individuals or groups.”

While any group of people can be organized (including elites), grassroots organizing entails building power via the direct and central involvement of the most affected constituencies, especially those that are marginalized and otherwise lacking substantial political influence (Beckwith and Lopez 2011).

As table 1 underscores, the concrete work of grassroots organizing is multifaceted. It may involve protest or other forms of direct action, engagement with political institutions (e.g., legislatures, courts), negotiation or confrontation with political elites, media communication, and more. Across this range of activities, grassroots organizing generally reflects at least three common practices:⁷

1. Relationality—the people being organized have substantive medium- to long-term relationships with organizing groups and with one another.
2. Power sharing—the people being organized have voice and influence within the organizing institutions.
3. Strategy—organizing activities are tactically selected based on political knowledge/ideas related to a shared understanding of how to drive political change.

Organizing is generally understudied in political science (Han, Baggetta, and Oser 2024). Nevertheless, grassroots organizing is especially germane to efforts to advance health equity (Heller et al. 2024; Michener 2022; NCCDH 2022). The weight of health inequity is disproportionately borne by communities facing obstacles to collective action (Michener 2023b). Organizing helps people to overcome such hurdles by equipping them to identify the systemic failures underlying their individual problems and to channel their collective influence (Han, McKenna, and Oyakawa 2021; Heller et al. 2024; Michener 2023b).

Grassroots organizing is also particularly pertinent to Medicaid. Evidence suggests that Medicaid shapes the contours of democratic participation, sometimes motivating people to deepen their engagement with politics and other times generating experiences that attenuate their relationship to the polity (Clinton and Sances 2018; Haselswerdt 2017; Haselswerdt and Michener 2019; Kogan 2022). The fact that Medicaid

7. Not all grassroots organizing reflects each of these practices to the same degree. There is variation across organizations (based on such factors as geography, structure, and organizational history) as well as within organizations over time and across issue domains. I offer a stylized rendering of organizing that is clarifying in terms of broad strokes but limited in terms of elaborating the complexities underlying organizing practices.

can cause “feedback” effects in the political system continues to be an important focus of social scientists (see Campbell, this issue). Yet, most studies of Medicaid feedback emphasize voting or other individual level political outcomes, while neglecting collective action and community-level processes (Michener 2017). And while understanding individual political choices is vital, scholars know comparably little about the community-based or organizational politics of Medicaid. Medicaid beneficiaries are not just individual voters whose decisions may shape elections; they are also a potential political constituency that can be strategically organized to leverage the strength of their people-driven power. Per this logic, a focus on grassroots organizing usefully complements standard policy feedback research on Medicaid.

In the pages to follow, I investigate whether and how grassroots organizing is part of Medicaid politics. Culling the qualitative insights of advocates and organizers across the country, I find a consensus around the belief that grassroots power is valuable. Yet, I also observe immense heterogeneity in the application of this belief to decisions regarding organizations’ practices, structures, and resource allocations. Key institutional barriers to grassroots organizing in health care include funding limitations, partisan polarization, and racism. Even in the face of those obstacles, when state and local organizations make concerted efforts to organize within racially and economically marginalized communities, they can make headway. Although grassroots power is not yet a dominant force in Medicaid politics, it holds promise to bring our health care systems toward a more equitable, just, and transformative future.

Data and Methods

To understand the role of grassroots organizing in Medicaid politics, I conducted semistructured interviews with 17 advocates and organizers across 13 states. The states represented in this study span a geographic range including seven southern states, two states in the Northeast, and four states in the Midwest. I also interviewed several organizers and advocates who worked at the regional or national level. Table 2 summarizes key details about each organization included in this study.⁸

8. To minimize the risk of identifying specific organizations or people, I do not directly name states. Many states have relatively few organizations that engage in health policy work and thus relatively few advocates and organizers. This small network of people know one another well and are often well known within their states. To protect confidentiality and maintain anonymity, I withhold state-specific information. I also sometimes omit or alter trivial details related to location.

Table 2 Characteristics of Organizations in the Study

Organization Type	Region	Primary Modality	State Expansion Status
Multi-issue	South	Grassroots	Nonexpansion
Health care	Multistate	Grasstops	Both
Multi-issue	Midwest	Grassroots	Expansion
Multi-issue	Multistate	Both	Both
Multi-issue	Northeast	Grassroots	Expansion
Multi-issue	South	Grasstops	Expansion
Health care	South	Grasstops	Nonexpansion
Multi-issue	Midwest	Grasstops	Expansion
Health care	South	Grasstops	Nonexpansion
Multi-issue	South	Grasstops	Nonexpansion
Multi-issue	South	Grassroots	Nonexpansion
Multi-issue	Midwest	Grassroots	Expansion
Health care	Midwest	Grasstops	Nonexpansion
Multi-issue	South	Grassroots	Expansion
Multi-issue	Northeast	Grassroots	Expansion
Multi-issue	Multistate	Grassroots	Both
Health care	South	Grasstops	Expansion

Case Selection

The selection of organizations for this research was dictated by theoretical and empirical imperatives. My primary aim was to achieve range in both the states and types of organizations represented in the study. At the state level, I sought variation in terms of Medicaid expansion status, region, and racial composition of the beneficiary population. At the organizational level, I sought heterogeneity in organizational modality (grassroots vs. grasstops). Table 2 presents the details on these dimensions.⁹

Including both expansion and nonexpansion states enabled me to understand how politics unfolded in relation to expansion as well as other aspects of Medicaid policy (e.g., Medicaid cuts, postpartum benefits, etc.). In expansion states, interviewees explained how expansion happened, but they also discussed what they had done to protect and advance Medicaid in a postexpansion era. In nonexpansion states, interviewees delineated the barriers to expansion, but they also detailed efforts to strengthen Medicaid and build power among relevant constituencies, even during times

9. Table 2 does not include data on the racial composition of the state Medicaid population because this information (combined with the other information in the table) would make it possible to identify the states in the study.

when expansion was not on the table as a political possibility. Relatedly, in many nonexpansion states, grassroots organizing was less common and less widely accepted than grassroots advocacy tactics (of the six organizations in the study that were in nonexpansion states, four of them were grassroots focused). This gave organizations in nonexpansion states a distinct and instructive vantage point on the challenges of grassroots approaches and ensured informative variation in understandings of the core phenomena of interest. A similar dynamic held in terms of region. Grassroots organizing as an approach to political change was less extensive, less common, and (perceived as) riskier in southern states. Thus, the substantial inclusion of organizations from this region offered important insights into the challenges and barriers emphasized in the rest of the article.

The racial composition of state Medicaid beneficiaries was a significant selection consideration because existing research suggests that racial dynamics are a fundamental element of Medicaid politics (Fording and Patton 2019; Grogan and Park 2017a; Lanford and Quadagno 2016; Michener 2018, 2020, 2021). Some of the states selected have large and dominant white populations, with relatively few Black, Latinx, Native American, or Asian American state residents and/or Medicaid beneficiaries. Others have significant populations of racially marginalized groups (more than 40 percent of state residents or Medicaid beneficiaries). Others still are in the middle range, with nontrivial numbers of state residents or Medicaid beneficiaries who are people of color (more than 25 percent).

Heterogeneity in organizational modality (grassstops vs. grassroots) was important because health policy organizations across the country take myriad forms, and perspectives on grassroots actors within Medicaid politics can vary accordingly. Organizations that engage in grassstops political advocacy have different relationships to grassroots actors than those who do not (and vice versa). Finally, table 2 notes whether organizations are health care–focused or multi-issue. This is pertinent because many grassroots organizations have a multi-issue approach that parallels the range of challenges facing people within economically and racially marginalized communities. While single-issue groups sometimes also take a grassroots approach, including multi-issue organizations allowed for a wider spectrum of vantage points on grassroots political constituencies.¹⁰

10. Despite having much to focus on, health care was not drowned out in multi-issue organizations. To the contrary, many multi-issue groups had health care as a central aspect of their work and could speak extensively to their work related to Medicaid and health policy.

Data Collection and Analysis

With these selection criteria in view, I identified 22 organizations of interest.¹¹ I then reached out to those organizations via email and requested an interview.¹² Staff from 17 of the organizations responded and agreed to be interviewed. The interviews occurred in the summer and fall of 2023; each interview lasted approximately one hour.¹³ They were all conducted by the author via Zoom (with cameras on).

The interviews were very loosely structured. They began with interviewees talking about the organization they worked for and their role within it. The conversations flowed organically from there. As the interview progressed, I asked each interviewee (1) how they believed policy change occurred with the Medicaid program, and more generally with health policy; (2) what role Medicaid beneficiaries or other directly affected communities played in change processes; and (3) what barriers prevented the expansion, reform, or improvement of Medicaid.

I recorded the interviews and had them transcribed. I then coded the data via Dedoose, a web-based coding platform. I developed an initial set of broad codes (e.g., organizing, advocacy, barriers) based on observations that emerged while conducting the interviews. I then conducted a round of open coding to confirm and expand on the initial codes. This involved reading through the transcripts with an eye toward detecting additional themes. Once I finalized the codes, I conducted a round of thematic coding aimed at capturing how interviewees described the role of grassroots actors in Medicaid policy processes and what they viewed as barriers to more substantive incorporation of such actors.

Strengths and Limits of This Study's Qualitative Approach

It is worth taking a moment to explain why findings based on 17 interviews can make an important contribution. There is no obvious or predefined number of cases necessary for informative qualitative research (Small 2009).

11. I did so by drawing on my professional knowledge of health policy organizations, doing basic internet research, and soliciting recommendations from actors within the health policy space. Through these varied channels I was able to identify organizations that were familiar to me as well as many that were not (thus ensuring that my own blind spots did not unduly limit the scope of organizations included).

12. Of the 22 organizations I reached out to, I ultimately interviewed people from 17 organizations, for an organizational response rate of 77 percent.

13. I offered to compensate interviewees \$50 for their time (some interviewees accepted this offer; others did not).

Yet, several indicators suggest that I spoke to enough people. First, even though there are tens of millions of Medicaid beneficiaries across the country, only a small number of organizations play a primary role in organizing and advocacy in any given state.¹⁴ This means there are relatively few people who possess the knowledge I was seeking to gain. Thus, having a small number of interview cases is appropriate. Another relevant indication of the sufficiency of the number of interviews was that I reached saturation—the point where each new interview yielded little new information (Small 2009).

Notwithstanding sound reasoning for the qualitative methods deployed here, there are limits to this empirical strategy. First, I did not contact or interview the full universe of organizations doing work related to Medicaid policy. It is difficult to even grasp the scope of that universe of cases, so there are most certainly organizations that I did not identify. These organizations might have offered distinct perspectives on the phenomena of interest. Admittedly, it is tough to gauge the extent and direction of such selection bias. I suspect it is minimal given the high response rate and careful selection of a wide range of organizations. However, it is important to acknowledge the possibility that I could have learned more and/or different information had I interviewed a more comprehensive set of organizations.

More generally, the scope and nature of the claims the data can support are limited. This article offers descriptive evidence, emphasizing *how* grassroots actors play a role (or fail to play a role) in Medicaid politics and *how* organizational actors perceive barriers to them doing so. The data neither aims at nor allows for strong claims about effects, causal relationships, or statistical correlations. So, for example, while I can say that key people involved in Medicaid organizing and advocacy believe that racism is a barrier to the involvement of grassroots actors in Medicaid politics, I cannot say with confidence that racism causes the exclusion of grassroots actors. This is not simply a matter of semantics or splitting hairs. Acknowledging what kind of information we can garner from the qualitative evidence (e.g., descriptive evidence on how grassroots actors engage in Medicaid policy processes and how organizers and advocates make sense of such processes) enables us to discern what knowledge remains to be discovered.

14. Although organizing necessarily involves and includes many people and does so in ways that center their voices and allows for their leadership, the work of initiating, coordinating, and funding organizing activity is generally spearheaded by a much smaller number of people.

Qualitative Findings: The Role of Grassroots Actors

Strikingly, everyone interviewed for this study—both advocates and organizers—expressed a belief in the fundamental importance of grassroots actors. Nevertheless, the interviews revealed clear divergence in whether and how organizations were structured in alignment with this belief. Despite widespread expressed enthusiasm for grassroots political approaches, many organizations advance change in Medicaid policy via advocacy-based approaches that leverage grassroots relationships, narrative change strategies, and top-down educational initiatives. Across the full spectrum of interviews, distinct organizational tacks with respect to advocacy versus organizing mapped onto a contrast between robustly including grassroots actors and lacking the capacity to do so. Notably, some organizations took both grassroots and grassroots approaches, attempting to leverage the best of both modes. Instructively, both organizers and advocates spoke extensively about the barriers that made grassroots organizing a challenging strategy.

Contrasting Advocacy Organizing through the Lens of Storytelling

To illustrate relevant tensions between grassroots advocacy and grassroots organizing, it's illuminating to examine storytelling, a tool used within both approaches but for different reasons and in different ways. Storytelling was a way for advocates to demonstrate genuine regard for grassroots actors while circumventing their deeper inclusion in political processes. Alternatively, it was only one of many ways for grassroots organizers to amplify the voices of their members. Organizations that were equipped for advocacy (e.g., those that had only lobbyists and advocates on staff but no organizers) but that aspired to grassroots inclusion were drawn to storytelling as a communication tool meant to fill the gaps between advocacy and community. To understand this more clearly, consider Jill, an advocate from a midwestern expansion state. In describing the work of her organization, Jill emphasized advocacy and service provision over organizing. Jill's organization was primarily oriented around providing legal services and offering education (including antiracism workshops, "bystander to upstander" training, voter registration, and COVID vaccination campaigns). Jill's organization was asked to work on the Medicaid expansion ballot initiative because the services they offered brought them into contact with low-income and

racially marginalized communities. So, even though they had not done much work on Medicaid before (hardly anyone in the state did), they got involved in the Medicaid expansion effort. As a 501(c)(3) organization, they were careful to remain nonpartisan, with the vast amount of their efforts geared toward educating and informing. Jill describes this work as follows:

We were asked to work on Medicaid expansion. And so, in coalition with [state and national health organizations], we went out to educate communities on passing Medicaid expansion, as it showed up on the ballot as a constitutional amendment. . . . We translated [thousands of] ballots and mailed them out to [immigrant-] focused zip codes. . . . We also talked about voters' rights. . . . of course, we couldn't go out there and say, "Absolutely, vote for Medicaid expansion." We could just only educate.

This work was not within the realm of organizing, because Jill's group did not seek to build long-term power or develop sustained relationships in marginalized communities to support consistent and effective collective action. Instead, they sought to educate (make sure people knew about expansion) and mobilize (enable them to show up and vote for the ballot initiative) in a more episodic way. To be fair, Jill's organization educated communities creatively and thoroughly: "We were able to bring Medicaid expansion information [to communities]. . . . While the kids are playing soccer, we're talking to the adults about Medicaid expansion. So, it's even just sitting around a soccer practice. . . . We try to get our foot in the door. We have a partnership with the school district. . . . So when we're there talking to the parents at parent-teacher conferences . . . we're also talking about Medicaid expansion."

Perhaps most instructively, when I asked Jill whether or how the communities that were targeted in such educational and mobilization efforts were integrated more deeply into her organization's work, she cited storytelling as a key linkage between communities and advocacy. Specifically, she made this observation:

That's where storytelling comes in. . . . That's where we take the anecdotal information and use that on the advocacy side. That's where we gather stories and share with legislators who are on our side so that when there is discussion . . . lobbyists, other coalition partners . . . have that information so that they can share those direct stories. . . . *It's primarily*

that storytelling. That story collection is what unifies community education and advocacy. (emphasis added)

Jill was not unique in this perspective. Storytelling emerged as a theme across many interviews. However, the logic and practice of storytelling differed depending on whether organizations were grasstops or grassroots. For example, Joan was an organizer with a multi-issue grassroots organization in a northeastern expansion state. Her organization engaged in community-based work focused on building power relationally through sustained collective action, and they found it valuable to bring together members of their base who were “in need of Medicaid” to “be storytellers, talk to the press, give trainings across the state.” In a different part of the country, working at a large multi-issue organization that did both grassroots and grasstops work, Faye’s entire job oriented around gathering stories and deploying them in political processes. She offered a sophisticated account of storytelling as a tool for advocacy as well as organizing. On the advocacy front, she describes having “storytellers speak to local media, speak to national media, go to the White House, testifying in Congress. . . . We really do have a full, robust storytelling program.” At the same time, Faye emphasized that stories can be used for both grassroots and grasstops engagement:

There are a lot of stories that are really good for building [community] support, and you need that support to be able to influence the lawmaker. But the stories that you use to build support in a community . . . stories that you amplify out in the community, you include them in what you bring to the lawmaker, but you might highlight different ones. . . . The story that I put on the news isn’t always the story that I put in front of the lawmaker . . . You have to consider your audience. The story that gets people riled up in the news isn’t necessarily going to be the story that resonates with the lawmaker. And so, you have to be thoughtful and think about that.

Most of the organizations included in this study emphasized the strategic value of stories in larger policy campaigns. Nevertheless, an important difference between advocacy groups like Jill’s and organizing groups like Joan’s concerned whether storytelling was the primary means of incorporating marginalized communities into policy work (as it was for Jill’s organization) or whether storytelling was instead one of numerous modes the organization used to engage communities (as it was for Joan’s). The former was more often the case.

The Challenges and Possibilities of Grassroots Organizing

Extensive community-based organizing is resource intensive in terms of both people and money. Comparatively, it is more feasible to select a limited number of people with “lived experience” to act as a stand-in for communities by telling their stories. It is precisely because organizing is difficult and expensive that storytelling has taken on more prominence within advocacy organizations. Nora is a leader within a salient health advocacy organization in a southern Medicaid expansion state. Her organization played a visible role in the expansion process. When I asked her about organizing, she described the distinction between organizing and advocacy quite clearly, and she referenced the mediating role of storytelling: “[Grassroots organizing is] really hard. We really don’t have an organizer. . . . We’re probably gonna have to get [one]. But you know, our storyteller, she was the person who was on the road more doing that because that was really more her role. But I promoted her more recently to a policy advocate position. So we really need to get someone else more on the ground.”

Nora recognized organizing as a form of being “on the ground.” The primary person her group had who could approximate such closeness to community was a storyteller, and even that person had recently been shifted to a role focused on advocacy.

The absence of organizing that transcended storytelling from much of the work happening within state-level health policy spaces was arresting, especially because advocacy groups unequivocally recognized its importance. Efforts to address this gap in the field were varied. Using storytellers as a stand-in for community was one tactic, as noted above. Forging coalitions with more community-connected groups was another. Clara, a leader within an advocacy-focused organization in a nonexpansion southern state, described the latter strategy:

We don’t have an on-the-ground presence. We’re not organizers. We don’t have a group of organizers, so we are at the mercy of identifying community partners who trust us, who we trust to do what we can’t do. One of the ways that we are trying to make this easier is that we’ve identified statewide organizations who are known for the particular work that they do. One of the groups that we identified is . . . known for their ability to knock on doors, to go out and mobilize local communities. They conducted a survey. They got 100,000 signatures in six months, so they are known for being able to do that. Another organization, they have

been recognized nationally for their ability to mobilize churches around health justice issues. So we have identified people who are righteous in the work that they do to say, this is what we see that you do really well. Can you show us and other people across the state how to do that?

On the other end of the spectrum, Blake was the director of a large multi-issue grassroots organization in the South. His organization was where grasstops advocates would turn when they needed stories or sought to leverage people power. Yet, for several years, Blake's group had hired a lobbyist and attempted to straddle both advocacy and organizing work. Eventually, however, his organization decided to let their lobbyist go as a result of misalignment with their grassroots organizing work:

We had a paid lobbyist for five or six years . . . and he was well respected. . . . But he was often in the [legislature], and [the reason] why we ended up parting ways [was him] saying, "Hey, you all can't do that action, or you all shouldn't do this." He was part of what we call the "good old boy" system in that state legislature. . . . So even though he was really well connected and knew a lot of legislators, he could never figure out how to convey [the benefits of] those relationships to directly affected people.

Like Blake, but from the vantage point of the grasstops, Clara thought it best that more well-resourced advocacy organizations stay out of the business of organizing and instead support the groups who had been doing organizing historically and were best positioned to do it well. Clara strikingly observed that such community-based groups were more trusted within communities of color, while advocacy groups were not, which made coalitional work a more equitable approach than the expansion of advocacy groups into the organizing realm. As a Black woman in a mostly white-led advocacy organization, Clara articulated the logic as follows:

I've had conversations with leadership about this. And they're like, "well, why wouldn't we [hire an organizer]?" Because if we do that, then what about organizations of color who don't feel like [our organization] should be in this space? What they will say is that this white organization had the power and the resources to hire all of these people to come in and snatch up resources from people who have been doing the work for years. That will not be us. So, we'll contract with the people who have been doing the work already, and we will glean from what they learn. We're gonna stay in our lane. *Our lane is . . . advocacy.* We'll use the power of our communications teams for folks who don't have

communications, and we'll use the power of our attorneys for people who don't have access. *Everybody's gonna stay in their own lanes.* . . . It seems so logical and so straightforward, but it also is very different than the way many organizations pursue. (emphasis added)

Notwithstanding Clara and Blake's differentiation between organizing and advocacy, several of the organizations included in this study had joint organizing and advocacy strategies and emphasized the effectiveness of such a dual model. Rita, from a multi-issue organization in a southern nonexpansion state, offers another example of an organization that does both. Rita notes that her organization has "always viewed grassroots engagement, civic engagement as driving our work. . . . So our policy agenda is always informed by grassroots and member engagement. . . . It takes a lot of work to maintain. But it was a part of our founding DNA, and I think it makes us really unique."

Precisely as Rita intimates, organizations that robustly incorporate both organizing and advocacy are rare. Indeed, most of the people interviewed for this research came from advocacy-based institutions and were only slowly beginning to place value on organizing. This did not appear to be a matter of biased interviewee selection, especially given that many interviewees talked about the broader dynamics of health policy work beyond their own organizations. Rather, it reflected the approaches that were most widely represented within the health policy ecosystem. Nevertheless, whether organizing was a foundational element of a group's work, something they leveraged by forming coalitions, or something they were early in the process of embracing, every interviewee acknowledged the pivotal importance of grassroots actors in the Medicaid policy landscape. Alana, an advocate who supported regional Medicaid policy campaigns across the South, articulated this most clearly in making this assertion:

In recent years I've been encouraged by the leaning into the power building work and the recognition that you can't do it without . . . communities that are historically left out. There's no place for them. There's no voice for them if they're not in those conversations. So, I feel like more and more people get that and understand the need and importance of those voices, and therefore have been figuring out how they can drive their work in that way.

Similarly, Sam, the leader of an advocacy group in a southern non-expansion state, notes the shifting trajectory of his organization. After

describing their roots primarily in grassroots advocacy, he notes how their growth has brought changes:

Each year we've grown and have taken different steps as part of our vision for the work. And now we're at a place where it's about centering the voices of people who have been impacted. I think somewhere along that line in that journey I realized that's what it was about. . . . Our value is kind of being in the middle, like being part of this feedback loop to get to the people in power and have them hear what's going on. . . . The most important relationships we hold . . . are with community members and people who have been directly impacted and their stories, and giving them a chance . . . holding the door open for them to go do the thing for themselves.

Barriers to Grassroots Power

This consensus around the importance of grassroots organizing was belied by significant headwinds that prevented deeper inclusion of grassroots actors. Interviewees identified three primary obstacles to advancing grassroots power in Medicaid policy work: philanthropic funding, racism, and partisan polarization.

Funding

Consistent with scholarly research on misaligned goals between funders and grantees, every interviewee mentioned funding as a perennial challenge to their work, and often they did so in the context of explaining why grassroots organizing, though vital, is not feasible (Shank and SoRelle 2021). For instance, Alana made a pointed case for why grassroots work is lagging in the health policy field:

I really feel like resources drive a lot of what happens here. . . . 'Cause you know, push comes to shove [with] more limited resources, we had to focus on grassroots. We just did not have the infrastructure to have the time and commitment that it takes to do that power building and that work in community. That was always a goal, and that was something that we struggled with, you know, we should be doing this organizationally. We need to be out there in the communities. Well, that's great. We don't have the funds to support someone doing that. You know what I mean?

This was a theme that emerged often among the advocacy-based groups included in this study. It was common for advocates to note the importance

of grassroots actors, regretfully observe their absence, and point to funding as an explanation. Even beyond what interviewees said, the structure of their organizations did its own talking. Many of the organizations interviewed for this study mentioned having a full-time lobbyist on staff. Fewer had full-time organizers on staff.

Crucially, the rarity of organizing approaches meant that the groups that did organizing work (such as those led by Rita and Joan) were able to leverage their distinctiveness to secure funding. Although not all funders invest in cultivating bottom-up actors, when they do, organizing-based groups benefit and thrive. As Rita explained:

We have benefited from funders who acknowledge that you need grassroots and grassstops. . . . Funders who normally never would fund health care work [will fund us]. . . . Not necessarily because it's health policy, it's just that they like our model. . . . We still get a lot of foundation funds that are dedicated for lobbying, [and] disease groups will give us lobbying dollars because they know how critical it is, and they have that in their national model.

Overall, the funding norms that undergird the activities of advocacy and grassroots actors within Medicaid politics are aligned (implicitly or explicitly) with the theories of change espoused by foundations or donors. If funders believe that bottom-up processes are important for changing Medicaid policy, they direct their resources toward that end. This enables institutions that take an organizing approach to increase their capacity, which is essential given the resource-intensive nature of working in communities. It is also vital given the remarkable heterogeneity of constituencies served by a program like Medicaid. Some people receive Medicaid during short stints of economic precarity; others have illnesses or disabilities that make them reliant on the program indefinitely; and others still are living in or near poverty for long stretches that require use of Medicaid. These and other sources of variation among Medicaid beneficiaries mean that they are not a clearly defined political group. Although there are tens of millions of people enrolled in Medicaid, these numbers cannot translate into political power unless beneficiaries are organized in ways that leverage their shared interests, common struggles, and interdependence. Organizing in this vein requires building relationships in a range of communities, around an array of issues, and in relation to disparate constituencies. Such strategic organizing that meets the unique challenge of the political landscape for Medicaid is expensive.

If funders do not believe that bottom-up actors are central to advancing health policy, then they fund lobbyists—the more traditional, common route to securing policy change.¹⁵

Of course, these are not mutually exclusive options. Some funders support both lobbying and organizing. The overarching point is that the preferences of funders are critical in structuring the approaches of nonprofit organizations within the Medicaid politics ecosystem. Such preferences are neither static nor binary; they are instead dynamic and nuanced. For example, some funders believe in the importance of grassroots actors but have an emphasis on storytelling (over and above building power on the ground in communities). Such priorities then get refracted through organizations, influencing their tactics. Sam, the leader of an advocacy group in a southern nonexpansion state, explains how his organization was influenced by funders. He also explains the development of their work and the critical ways that it diverged from the direction of funders (as he perceived them):

We had this one woman . . . who joined us as a story banker. *We have funders . . . who are asking for stories . . . [from] like directly impacted people and stuff. So we started focusing on how to build that capacity. And it was because of funders thinking it was a commodity.* That initial thinking is what brought us into doing that work. . . . Our story banker, we paid her per story she would collect. But as we spent more time, I'll say it like this . . . if you tell us a sad story, we're gonna cry, and we're gonna become emotionally invested. And I think the more that we did that it started to really sit with us that [stories] are not commodities; these stories aren't commodities; these are people who are impacted in very real ways. So we started to do the thing better . . . building relationships with partners on the ground who could connect us to their people. . . . At first it was just collecting the stories. Then it was like, oh, these are our people, how do we build relationships with them? . . . Instead of, "hey, we need a thousand stories." . . . What are they telling us they need? How

15. Of course, some funders do not fund explicitly political work at all. Such funders may focus instead on supporting service-based organizations, legal advocacy, educational campaigns, and other nonpartisan activity. Community organizing itself can be considered a nonpartisan activity, depending on how it is implemented and to what ends. Some organizations (advocacy-based and organizing-based) have tactics and/or an institutional structure that allows them to leverage both c3 funding (for nonprofit organizations that only engage in nonpartisan advocacy) and c4 funding (for nonprofit organizations that engage in some partisan activity). Others pick one status and tailor their approaches based on that choice. In any case, whether through c3 or c4 routes, my focus here is on work that is political in the broad sense—that is, seeking to influence policy processes. This can happen via different routes of nonprofit status, each of which entails its own constraints and challenges.

do we strengthen them . . . and start to get them in the process? . . . If anything's changed for me in terms of how I think of power, I think it's that you have to get real granular down to the person. . . . Sometimes you need a critical mass to make a difference, but it doesn't have to be a huge number, doesn't have to be a thousand people, or at least that's not where it has to start. It can definitely just start with a group of dedicated folks who feel it in a deep way and are willing to do the things. And now we're at a stage where after years of developing those relationships and getting people to trust us, now we are mobilizing them and giving them a chance to go do the thing. So earlier this year . . . was our first time taking those teams of people to the capital . . . and everyone led with their own stories . . . and it was pretty powerful. (emphasis added)

Sam's group was motivated to collect stories because funders expressed a desire for them. In Sam's view, funders treated stories like a commodity, even subsidizing the collection of stories on a per story basis. But as Sam and his team heard the stories, their own perspectives changed and seemed to diverge from those of the funders. They began to focus on dimensions of political work that are more squarely in the realm of organizing (e.g., building power by cultivating relationships on a granular level). Notably, however, Sam's group did not make a full-scale transition into organizing; nor do they have an organizer on staff. This is due in part to funding constraints. It is also because of the background and training of Sam and his staff (in advocacy) and the difficulty of gaining an organizing-based foothold in the difficult political terrain of the southern state Sam's organization operated in. Despite all of this, funders' push toward "stories" changed the course of Sam's thinking and practices, even if that played out in ways that funders did not seem to intend.

Racism

Racism was also frequently named as a barrier to incorporating grassroots actors into Medicaid policy work. Interviewees pointed out that advocates and lobbyists—the main grassroots players—were disproportionately white. Alternatively, the communities implicated in bottom-up processes were much more multiracial. This racial configuration of actors produced tensions. Rita, a white woman from the South, describes these dynamics: "There have been, for the most part, white lobbyists coming to these [Medicaid expansion coalition] meetings. . . . [The coalition has] a steering committee that's still unfortunately, mostly lobbyists, because

they're the ones who are paid to have an hour every few weeks to just sit and talk about strategy, even though these meetings are open to grassroots partners."

In addition to the racial composition of the lobbyists, Rita also notes the larger racialized environment within the statehouse: "The statehouse is a very racist, toxic environment. And we see that in who is working there, who has these insider relationships, and how they're moving. I would say the majority of our steering committee, who are lobbyists for health care groups, are mostly white women who work for advocacy orgs. . . . My policy director and some of the other lobbying staff are Black women, and they find it to be a really oppressive environment."

Similar perspectives emerged throughout the interviews, especially for advocates in states where conservative legislators held significant power. Becca, a leader within a health-focused advocacy organization in a conservative nonexpansion state, explained a specific situation that brought into sharp relief the challenge of incorporating racial equity into political conversations related to Medicaid:

We have a Medicaid Oversight Committee, and it's really important for advocates to be at those meetings to testify because that is the opportunity to inform legislators on that committee about what's working and what's not working . . . It's an opportunity for advocates to actually get up to the podium and provide testimony. So that's been a very powerful way [to incorporate people with lived experiences]. But it's not been without problems, because we are interested in equity and calling out where there [is] systemic racism. And we had—oh, it's a painful recording to watch—but we had an advocate that spoke to that Medicaid Oversight Committee and said that there is systemic racism in Medicaid, and she was torn apart by the chair of that committee, who heard systemic racism and said, "Tell me where? Tell me, tell me who's doing that? I see no evidence of that. And if you use that word again in my committee, you're going to be barred from testifying in my committee again, because we don't talk about folks that way, and nobody in Medicaid is racist." . . . So we have to tread very carefully when it comes to talking about equity. We don't shy away from it . . . we say "rural" and "race" as we talk about equity. And so that it's both, it's not solely about race. . . . When possible, we lift up racism and systemic racism as a contributing factor to the health outcomes in our state.

These harsh political realities generate conflicts over whether and how racial equity should be centered in Medicaid policy work. One the one hand, grassroots actors talk about racism overtly, as Rita describes here:

The grassroots folks and our organizers actually talk about [race] a lot more explicitly. . . . When we're out in community and out doing town hall meetings, meeting with our constituents, we do listening sessions, we do all kinds of things [and] there's really an awareness both that racism is driving this terrible public health policy [Medicaid non-expansion] and bad public policy period. And the people most hurt by it are working-class white and Black and Hispanic folks. It is like the impacts are felt, you know, across communities regardless of race and zip code, and there have been explicit conversations, sometimes with [Black-led organizations] and partners who have said, you all gotta go get your folks. You gotta go get the white folks who are not showing up, who are not seeing themselves, are not willing to see themselves as people who would benefit and are being harmed. . . . It's like, how do we show the broad spectrum of impact of this and build cross-racial solidarity? And that is a challenge that we have on every campaign we work on.

Such explicit acknowledgement of racism creates tension between elite white "insider" spaces in advocacy and lobbying spaces (coalition meetings, statehouses) and the grassroots "outsider" side of Medicaid policy work. Organizations that tried to engage both sets of actors felt these tensions acutely. Rita's group faced this dilemma and was "really feeling the pinch right now between like an insider strategy and an outsider strategy." Part of that "pinch" was the result of starkly different sentiments around racism. Rita details this difference:

We do place-based organizing. Like, we convened meetings in local community to highlight the cross-section of people who are stakeholders who are impacted, who have an interest in this. . . . I will say that, speaking about that insider versus outsider strategy, our grassroots funders are 100 percent like "we don't want to see you put out a message that doesn't mention race inequity, here's our messaging guidance on race equity and racism." And then we have these insider partners who are like, "no way no how. I'm not using that." . . . We literally have state leaders who are trying to ban critical race theory and firing state officials who talk about equity.

This pushback did not cause Rita's group to entirely pull back from addressing racism. For example, she notes that her group produces "reports, blog posts, [and] press releases [where] we explicitly have a race equity lens." I easily confirmed this by searching their website. Nevertheless, tensions around centering racism determine where and how Rita's institution deploys language related to racial inequality. Specifically, she says they

are more hesitant to do so in the context of larger coalitions that involve grassroots actors: “As a coalition, our coalition messaging has less of a race equity lens on it, and that is because our partners, some partners in particular, have said ‘I don’t want to put my name on this. It’s like it’s not aligned with our messaging.’”

For many of the organizations included in this study, conflict over whether and how to address racism made connecting to, working with, and building the power of racially and economically marginalized communities more difficult. At the same time, the troubling realities of racism sometimes inspired funders to take grassroots power building more seriously. So racism and funding can interact in ways that can generate possibilities. Alana explained how that happens:

[Advocates] have had some really intensive race conversations, and that has really allowed them to lean into the power building and the grassroots work in that regard because people are fired up, and they’re upset and angry and want to get involved. So a lot of that work [involves] taking the time to build those relationships and to hear people because people are traumatized . . . particularly Black Americans and folks that have been historically denied because of systemic [racism]. . . . People are traumatized, and they’re distrustful of government. . . . So the recognition that people power is truly necessary is, I think, growing, and I think that, therefore, has led to more investment, which is what ultimately I think needs to happen. Without additional dollars from funders and others who see the importance in that, it’s not gonna grow the way it needs to, but it’s also ridiculously labor intensive, right? Like, you can’t just fly into a community and then fly out and have it transactional. There’s so much groundwork that needs to happen. So again, just resources, resources in many different ways.

Political Institutions: Partisan Politics

Partisan dynamics were mentioned in many interviews as a barrier to the inclusion of grassroots actors in Medicaid politics. Partisan constraints made passing any policy with potentially partisan contours more difficult, especially in states where there was little party competition (and thus little reason to compromise). As Rita notes, “There’s always that fight within our statehouse, since we don’t really have a minority party that is, in a meaningful way, able to exert power right now.” But partisan polarization was also a challenge specifically to grassroots power. Walking the fine line of partisan divisions made lobbyists and

other elites especially protective of their elite relationships and fervently defensive against any forces that might alienate elected officials or upset the balance of power across partisan divides. Joan explains how this unfolded in her state:

When we couldn't overturn the [governor's] veto, a smaller portion of that table of coalition partners was like, we gotta try something new [a more grassroots approach]. We can't keep doing the same thing over and over again [a mostly grassroots approach]. Because it was always like, well, maybe the legislature will become slightly more blue the next election. . . . But the numbers never worked out in our favor. So we finally took it to ballot. And, you know, not everyone [in the coalition] came with us. The medical association didn't come with us. AARP didn't come with us. The American Cancer Society didn't come with us. I think they are just more traditionalists in their method of advocacy and work very much inside the dome, and so working outside the dome was like a little bit of a threat to their power. Because they didn't have power outside the dome. They didn't know how to leverage their power outside the dome. Their currency was . . . relationships with legislators, and legislators hated the [Medicaid ballot initiative] campaign. So it was a smaller group of us, mostly more local organizations . . . that took it to ballot.

It was a partisan barrier—the veto of a Republican governor—that made the traditional approach of taking the legislative avenue ineffective. At the same time, traditional advocacy organizations' protectiveness of their relationships with legislators in a difficult political environment made them cautious about taking a more grassroots route. Small, local organizations that were not beholden to those relationships and did not have to worry as much about the partisan balance of power were the primary actors willing to move forward.

Partisan constraints also interacted with the funding environment structuring Medicaid politics. Organizers like Sam—that is, those located in southern nonexpansion states—reported that they struggled to get funding for Medicaid expansion campaigns until recently, because funders strategically selected states where expansion seemed most likely to be successful. In places with staunch partisan opposition to expansion, funders were less willing to risk investment in expansion campaigns. Thus, the geographic variation in partisan contexts within a decentralized federated polity meant that funders could shop for the venues that were most likely to offer success. This meant that the more politically challenging states received the fewest resources. Only recently—with the lowest-hanging

Medicaid expansion fruit gone, and only the toughest political terrain remaining—have funders begun to turn to states like Sam’s.

The Promise of Grassroots Power

Notwithstanding the barriers elaborated above, it’s important to underscore the promise and possibility of grassroots power. Interviewees emphasized how grassroots actors played a role in Medicaid policy in a wide spectrum of ways, ranging from supporting Medicaid expansion efforts to pushing back against policies such as work requirements and benefit cuts. Tina gives this example: “I was our Medicaid organizer in the fight to stop work requirements from being implemented in [our state]. And we won that, and what we’ve been doing [since] is kind of a continuation of that fight and that base and this process of trying to protect and improve the program.” While this referenced a specific policy campaign with a central role for organizing Medicaid beneficiaries, Tina’s institution also made an effort to consistently position Medicaid beneficiaries to engage elected officials and influence discussions in decision-making spaces. For example, Tina talked about the impact of bringing beneficiaries who were part of her organization’s base (“Medicaid members”) into legislative committee meetings:

They’re doing this summer study committee, and the framing is that Medicaid’s the fastest area of growth in our budget, and we need to be looking at the services and membership of the program [we can cut]. So we . . . have been doing a bunch of [legislative] meetings about it with Medicaid members, which has been . . . exceptionally cool. . . . We had a member tell his story of [chronic illness] and Medicaid, and then one legislator was like, “we’re not gonna kick you off. . . .” And then [the member] goes, “yeah, but what about my friend [Alice, a member who was also present at the meeting], who is the Medicaid member who just lost coverage for going \$47 over?” In this particular situation, it was a white guy from [a very rural, very conservative area] and a Black woman from [a diverse urban area]. And it was really like, no, no, no, you don’t get to choose. So [our members] got to do that, and then I’m pushing the policy side of it, which is like, if you want to save money, kicking people off will not get you there. What you need to do is . . . reduce administrative burdens. So it’s been this really cool marriage of what can you do if you actually have [membership] base in the room who can move people emotionally, ideally are in legislators’ districts, are puncturing the stereotypes about the program, and are . . . putting [elected officials] in that uncomfortable position.

Like many of the people interviewed for this study, Tina highlights the important role for bottom-up actors whose power is intentionally built through cultivating relationships with a membership base that can take concerted, strategic political action. Despite ample difficulties and uneven commitments in practice, Medicaid advocates and organizers converged around the core belief in the promise and possibility of bottom-up political actors being transformative agents of change.

Discussion and Conclusion

Grassroots political actors who are most directly affected by health policy hold the promise of fundamentally (re)structuring Medicaid politics. However, social scientists have paid insufficient attention to whether and how grassroots actors operate within Medicaid politics. The evidence presented above suggests that grassroots organizing does not yet play a consistent, substantial role in setting policy agendas or advancing change in health policy. Leaders within the civil society organizations that work to expand, protect, and sustain Medicaid broadly agree on the need to center the people most affected by health inequity in the processes of changing it. Nevertheless, in practice, these organizations take contrasting approaches to political change. Many such organizations are primarily focused on advocacy meant to influence elites and/or shift public narratives. Such organizations genuinely care about working on behalf of racially and economically marginalized communities, and they sometimes mobilize or educate such communities. Yet they are not directly accountable to grassroots actors and not explicitly working to build power within the populations most affected by Medicaid policies. To be clear, advocacy is important. Advocates have access, influence, and resources that allow them to do crucial work. Nonetheless, advocacy is not an adequate substitute for well-organized grassroots actors with the power to shape policy processes and outcomes.

Organizing is less common in the larger landscape of health policy. Organizers and advocates both insist on the imperative that people who are most affected by policy should directly exercise power over it. Nevertheless, organizing is systematically thwarted by barriers such as philanthropic biases, partisan polarization, and racism. Although these hindrances do not entirely prevent organizers from doing the vital work of building power in support of Medicaid, they do put a ceiling on the transformational possibilities in the US health policy landscape.

The complex insights gleaned from organizers' responses point to many questions that cannot be answered in the scope of this article. Organizers and advocates grapple with their coexistence within a larger political system that positions them quite differently. They share core goals, and there is overlap in their practices and activities (as conveyed in table 1), but advocates themselves admit the limits of what they can do in the absence of much stronger grassroots pressure and demand for change. This configuration of political realities compels those seeking to expand, defend, and protect Medicaid to thoughtfully consider the best strategies for doing so. Should approaches be universal (Medicare for All) or targeted (focusing on racial equity)? How should organizing and mobilizing occur across the broad range of constituencies that Medicaid encapsulates, from disabled people, to elderly dual eligibles, to the low-income expansion population, and so on? How can such efforts span class, racial, and other dimensions of social difference to reflect the heterogeneity of Medicaid beneficiaries, especially in a political environment that foments divisions along these lines?

This article does not contain dispositive answers to these inquiries, but it does frame them through an important lens. Namely, the study's findings help us to understand the role grassroots actors play in forging a path for Medicaid in the years to come. As it stands, organizing approaches that build grassroots power are promising but require deeper investment and a clearer commitment, especially given the formidable obstacles generated by an unequal, polarized political economy. Looking ahead, researchers, funders, and political elites should take organizing more seriously. Advancing knowledge of organizing in the research community and generating support for it among actors with political and financial wherewithal can be a critical determinant of health equity in the years to come.

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