Equity, Participation, and Power:
Achieving Health Justice Through Deep Democracy

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Abstract

This article explores how health governance has evolved into an enormously complicated—and inequitable and exclusionary—system of privatized, fragmented bureaucracy, and argues for addressing these deficiencies and promoting health justice by radically deepening democratic participation to rebalance decision-making power. It presents a framework for promoting four primary outcomes from health governance: universality, equity, democratic control, and accountability, which together define health justice through deep democracy. It highlights five mechanisms that hold potential to bring this empowered participatory mode of governance into health policy: participatory needs assessments, participatory human rights budgeting, participatory monitoring, public health care advocates, and citizen juries.

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Introduction

We are living in tumultuous times. The Affordable Care Act—and continued Republican opposition to the law—has reshaped the institutional and political terrain of health policy and politics. So too have even larger forces. Since the 2008 recession, the neoliberal consensus and political alignments prevailing since the 1970s have been fracturing and shifting. Spontaneous popular movements including the Tea Party, Occupy Wall Street, and Black Lives Matter have erupted and upended the status quo. Racist inequities in education, employment, housing, wealth, and health care are by many measures worse than in the 1960s, tens of millions of Americans are trapped in poverty, and ever more of the middle-class is sliding into precarity. Politics have become as geographically, generationally, racially, and educationally polarized as any point in recent memory, and global politics are in turmoil. On top of all this came the COVID-19 pandemic and the resurgent Black Lives Matter uprisings, which are transforming our lives, economy, and politics in rapidly emergent and unpredictable ways.

In the face of such uncertainty, there will be an impulse to double down on professional expertise, shifting health policy decision-making away from contentious and often ineffectual legislatures and partisan executives to supposedly apolitical markets and appointed managers. There are certainly times, such as in executing emergency responses to the novel coronavirus, that top-down, centralized, professional decisions are needed. But this essay argues that what is really needed in health policy in the coming years is not less democracy, but much, much more. Regardless of how the pandemic develops, who wins November's elections, or which signature health policies they pursue, in the coming years we need to radically rebalance decision-making power by deepening democratic participation throughout the fractured, public-and-private administration of American health.

Drawing from several complementary scholarly frameworks and my direct experience working with social movement organizations in struggles for justice in health governance, I present a new framework for deep democracy and health justice designed to achieve *universality*, *equity*, *democratic control*, and *accountability*. The purpose of health systems and of health governance should be to *universally* guarantee health care, food, water, housing, education, work with dignity, public health, and other fundamental health needs to all members of society. These fundamental needs should be *equitably resourced* according to people's ability to pay and *equitably delivered* in order to achieve equal health outcomes between all social groups in society, and *equitably repair* racial and other intergroup disparities. Everyone should also be guaranteed meaningful *control* over decisions that affect their lives. This self-determination should operate both on an individual level—everyone should have reasonable sovereignty to make decisions for themselves—and on a collective level—all groups of people with common needs should be able to shape the health and economic systems that affect them. On both levels, democratic control requires that people be able to hold both public and private actors with decision-making power in health systems *accountable*, meaning that policymaking is responsive to public needs and priorities and that power-holders are both answerable and subject to meaningful and enforceable legal, political, or economic sanctions.[1] All four of these goals—universality, equity, democratic control, and accountability—should be measured not simply according to process or intentions. Human outcomes of health and wellbeing and democratic responsiveness are the ultimate measure of health systems and of democracy.[2] In this paper I refer to health justice through deep democracy as shorthand for these four goals.

This paper proceeds in three parts. Part I surveys literature from multiple disciplines to offer structural explanations for why health justice and democracy are not being realized and pointing the way toward solutions. Part II presents a framework for advancing health justice through deep democratization of public-private health governance, sets forth six criteria participatory mechanisms should satisfy, and briefly surveys historic and contemporary models of democratization that hold lessons for health law and policy. Part III suggests five mechanisms for achieving health justice through deep democracy: participatory needs assessments, participatory budgeting, participatory monitoring, public advocates, and citizens' juries.

I. The Structural Causes of Health Injustices and Deficits of Democracy

Unfortunately, the United States is a neither a paragon of health equity nor of an engaged, effective democracy. Despite per capita health expenditures twice those of similarly wealthy countries, our life expectancy and other health outcomes are worse. This is largely a result of deep racial and economic inequities that produce life expectancy gaps of up to 15 years across lines of race, income, and geography.[3] Tens of millions of people are uninsured or underinsured and forced to forgo essential medical treatment.[4] Structural unemployment, homelessness, educational and economic inequities, occupational hazards, addiction, gun violence, pollution, diabetes, and poor preparedness for infectious disease emergencies all harm public health.

In theory, in a representative republic like the United States, pervasive health inequities should be solved by through electoral government. Elections are supposed to translate the public will into public policy and, along with courts, hold politicians, regulatory agencies, and the industries they regulate accountable.[5] Yet mounting empirical evidence shows that "policy outcomes strongly reflect the preferences of the most affluent but bear virtually no relationship to the preferences of poor or middle-income Americans"[6] and that "economic elites and organized groups representing business interests have substantial independent impacts on U.S. government policy, while average citizens and mass-based interest groups have little or no independent influence."[7] Political scientists also find that policy outcomes stray farther from public preferences in states with less direct forms of democracy.[8]

In order to properly understand why health injustices have proven so intractable and why government has been so unresponsive, we must seek structural explanations. Insights from legal scholarship, political science, development studies, and other disciplines help explain deficits of democracy and inequities in American health and point the way to solutions.

A. Regulatory Capitalism, Market Bureaucracy, and Private Governance

There is broad recognition that since about the 1970s, a dominant ideological paradigm has shaped political and economic governance in the United States and around the world. Many observers label this a *neoliberal* era marked by deregulation, privatization, and the withdrawal of the state from providing social goods.[9] While this is true, the emphasis on deregulation has sometimes obscured an even larger increase in *new* forms of regulation, many of which are carried out by non-governmental private actors. David Levi-Faur, Jacint Jordana, and John Braithwaite call this mode of governance *regulatory capitalism*. It is marked by a "regulatory explosion" in which the privatization and fragmentation of health care and other systems have produced tremendous growth in regulatory agencies, rulemaking, auditing and other regulatory institutions and practices.[10] Privatization has expanded private regulation as companies, professional associations, third-party auditors, and other extra-governmental parties create, monitor, and enforce their own rules and regulations. It has likewise expanded public regulations as professional associations, consumer groups, unions, social movements, and especially corporations have lobbied for laws and policies that protect their interests.

Allison K. Hoffman applies this vein of analysis to the health care system, describing a *market bureaucracy* in which idealized, empirically unfounded theories of market competition lead policymakers to spend immense policy and regulatory effort attempting to construct and maintain market competition within and between health care industries. These "competition-based policies," Hoffman explains, "have required armies of health regulators, reams of regulation, and seemingly endless evaluation and adjustment by technocratic experts—to no avail. The result is a market-lubricating regulatory scaffold—a governmental bureaucracy that may be as large or larger than what would have grown out of more direct regulatory approaches and also vulnerable to capture."[11] To set up and run the Affordable Care Act's market exchanges, for example, the federal government and states spent tens of billions of dollars, the Department of Health and Human Services issued 24 new rules and 64 guidance documents, and scholars, policymakers, and the media (not to mention patients and their families) spent incalculable hours and dollars picking apart the complexities of the system, all to bolster a market structure that provides insurance for a mere 3 percent of the population.[12]

Nancy Fraser, Martha T. McCluskey, Suzanne Mettler, and other feminist scholars provide a complimentary perspective by challenging the conventional delineation between *public* and *private*. The popularly conceived boundary between these spheres breaks down under inspection, they show, revealing sprawling public-private social and economic systems that defy simple categorization. They further demonstrate that the harsh delineation of the family and the market as 'private' spheres supposedly unsuited to public regulation hurts women, poor people, people of color, and other marginalized communities, who are dismissed as "special interests" whose needs and demands are in conflict with supposed natural laws of the economy and with a presumed common good that is somehow distinct from their own.[13]

Applying these lenses to the governance of American health care and public health reveals that the problems driving health inequities are structural in nature, that they span the public and private sectors, and that public-private bureaucracies are critical sites of decision-making in health care and other systems that deliver essential public goods.

B. The Toll of Privatized, Fragmented, and Exclusionary Bureaucracy[14]

Delegating decisions to private actors is not always bad. In fact, I argue, we should decentralize and distribute far more health-governance decisions. But regulatory capitalism and market bureaucracies do not deregulate decision-making; instead they produce highly regulated, publicly supported modes of private governance that grant sweeping authority to private health care companies while denying health care, social and economic needs, and political power to those at the bottom of hierarchies stratified by race, gender, economic status, and other lines of difference. Market bureaucracy exacts critical harms that must be redressed in order to advance health justice and democracy.

Market bureaucracy subsumes fundamental political decisions about who and what we value as a society and how we want to allocate our shared resources. Health care companies, not democratic deliberation, decide how we price, finance, and ration care, which doctors people can see, what treatments and medicines they can get, and whether or not they have a hospital in their county. Market bureaucracy removes these decisions from the public sphere by turning them over to health care companies and professional associations; delegating them to professional analysts and managers who are deemed to operate above politics in the realm of expertise, professionalism, science, rationality, and objectivity; shifting responsibility onto families and individuals through legal structures and ideological constructions of consumerism and moral worth; and leaving decisions to obscure, unaccountable "market forces" that supposedly exist outside of the laws and institutions that create markets.[15] Overreliance on markets for researching, financing, and delivering health care and the social determinants of health also fails to uphold the guaranteed fulfillment of fundamental needs as human rights and bestows the power to allocate and withhold essential care and services to private entities with financial incentives to ration access. This commodification materializes in people's lives as domination and vulnerability, especially for poor and working-class people of color.[16]

Health law and health care's market bureaucracy sort people into administrative categories according to employment status, income, age, disability status, immigration status, family status, and a host of other factors, granting different groups of people unequal coverage and unequal care. Because these categories map onto differences in education, income, jobs, housing, and criminal justice, they also replicate and amplify broader racial, class, gender, and other disparities. Thus, for example, regardless of people's medical needs, citizens are deemed worthy of publicly subsidized care while undocumented immigrants are not; people with full-time professional jobs get top-line care while part-time, temporary, gig economy, and informal-economy workers, small-business employees, and unpaid caregivers do not; and people in wealthy white neighborhoods enjoy ready access to highly resourced hospitals and nursing homes but people in working-class Black neighborhoods do not.

These systematic, racialized patterns of exclusion and inequity are not accidental, but an essential strategy for justifying privately controlled, for-profit health care.[17] Sorting people into a hierarchy of deservingness capitalizes on racist anti-Black and anti-immigrant ideologies to generate the idea that some people do not deserve care because they are either irresponsible or have chosen that fate. This is profitable because it undercuts political demands for universal, publicly financed health care and also legitimizes the separate-and-unequal tiers of coverage that enable insurance companies to cherry pick healthier and wealthier patients, ration coverage and care to varying degrees to nearly everyone, and shift the least profitable patients—poor people and people who need more care—onto public programs. It also allows insurers, providers, legislators, and public administrators to selectively target punitive, disciplinary cost-cutting measures.[18] They grant wealthier, whiter patients (who are more profitable and more politically powerful) largely unfettered access to care and dignified treatment while implementing measure after measure to control poor people's behavior and ration their care. They continually scrutinize and cut Medicaid's federal and state budgets, for example, while leaving tax subsidies for employer-sponsored insurance untouched, and require patients on Medicaid and workers' compensation to continually re-enroll in insurance programs, re-verify their eligibility, apply for pre-authorization of coverage, endure invasive monitoring of social media and their private lives, and prove the medical necessity and work-relatedness of their treatments and medical conditions. Wealthier patients rarely have to endure such bureaucratic burdens, barriers, and indignities (though health care workers increasingly experience a similar cost-cutting regime of monitoring and control).[19]

In addition, fragmentation produces enormous complexity that makes it hard for everyday people to navigate health bureaucracies as they try to meet their basic needs, produces unnecessary administrative costs that shift resources away from more important uses, makes it difficult for individuals and groups without paid staff and technical expertise to engage in regulatory governance, and makes it difficult for legislators to monitor and hold regulatory agencies and industries accountable.[20] All this insulates power-holding decision-makers, both public and private, from accountability to patients, workers, and citizen-residents, allowing them to act with virtual impunity.[21]

Market bureaucracy also erodes our very notions of citizenship and democracy by framing members of society as consumers, clients, or holders of individualistic legal rights rather than as active participants in co-governance who hold collective rights and mutual responsibilities.[22] The shrinking of citizenship to voting and input—and the concomitant absence of democratic spaces for contestation over real levers of power—dissuades people from more active engagement. Legislators and regulators lose too as they are deprived of more meaningful information on constituents' needs and aspirations, a more robust and responsive regulatory state, and truly effective health care and public health systems. As K. Sabeel Rahman writes, we should view democratic self-rule "not as the mere registering of voter preferences, but rather as the realization of equal voice and political empowerment."[23]

A common vein running through these harms is the unequal distribution of power. To eliminate health inequities, health governance must assess political, economic, and cultural power differentials among stakeholders, implement strong corrective measures to balance participation and representation, and hold all actors accountable for due process and just outcomes.

C. Technocratic Managerialism Is an Inadequate Corrective to Market Bureaucracy

Some scholars and advocates recognize the failures of market bureaucracy, but contend that democratic approaches to managing markets introduce more problems than they solve. The best-functioning institutions in government, they argue, are institutions like the Federal Reserve that derive their legitimacy from professional expertise rather than elections, insulating them from messy interest-group fights and partisanship. These technocrats' favored approach to managing health care markets' failures and advancing health equity is therefore to shift more decisions away from contentious political spaces toward regulatory agencies, special commissions, third-party monitors, judiciaries, and other bodies that are said to operate above politics in the realm of rational expertise and data-driven decision-making. They also emphasize strategies that distill big problems into discrete, manageable pieces, which can be ameliorated through legal and technical solutions that incrementally improve outcomes.

The goal of de-politicizing and technologizing health governance is, however, an illusory one. Structuring and managing our health systems requires making inherently political judgments about who and what we value, where we want to put our resources, and how we sort out our priorities.[24] Technocratic managerialism subsumes political decisions just as markets do. It cloaks them in the language of data, rationality, and professional expertise, and controls them through formalistic processes. Ultimately all decisions in governance are political: who is invested with investigatory and decision-making power, what questions they ask, who they consult, what data and perspectives they consider legitimate, and what goals they pursue are all political judgments.[25]

Technocracy places too much faith in purportedly objective professional judgment and indirect public accountability through accountability to executives, legislatures, and judicial review.[26] By emphasizing voice (the option to provide input) rather than power (actual ability to shape decisions and outcomes plus the ability to hold other actors accountable), it centralizes decision-making power among unaccountable political and economic elites, fails to correct power differentials between interest groups, reproduces racial and other inequities, creates few spaces for meaningful public engagement, provides virtually no direct lines of accountability from public and private power-holders to the public, and impoverishes our conceptions of democracy. Ultimately, by sidestepping contentious political fights and failing to contend with disparities of power, technocratic approaches are unable to address the underlying structural dynamics that harm people's health and produce stark inequities.

II. Realizing Deep Democracy

Deep, participatory, accountable democracy is necessary to achieving health justice. In this Part, I present a framework featuring six criteria articulating what deep democracy means in practice, and discuss the mixed track records of efforts in prior decades to democratize health care governance.

A. A Framework for Health Justice and Deep Democracy

I propose six criteria that governance mechanisms should satisfy to further health justice and deep democracy.

First, all mechanisms for democratizing health governance should center *equity* by ensuring that disadvantaged communities are equitably included in governance, power is equitably distributed among interest groups, and normative goals with measurable indicators guide all governance processes toward achieving equitable health outcomes. They should center the needs and leadership of specific groups of people who face health injustices and barriers to participation and control in different contexts, including Black, Indigenous and other people of color, immigrants, poor and working-class communities, rural and post-industrial communities, people with disabilities, people with chronic conditions and illnesses, people who are incarcerated, women, LGBT people, people with addiction or other mental health needs, people who are unhoused, older and younger people, home health aides, nursing home workers, and other low-wage non-union health workers.

Second, in recognition of the fact that power is wielded in governance not by individual actors, but by organized interest groups, and that there are gross imbalances of power between groups, governance mechanisms should take a social-movement *mobilization* approach. This approach creates countervailing power by actively cultivating community organization in marginalized communities and labor sectors that lack organizational infrastructure, facilitating unionization, and delegating specific powers to community and worker organizations.[27]

Third, governance mechanisms should pursue *maximum feasible participation* by democratizing control and knowledge. Mechanisms should foster active, meaningful participation by making information and opportunities to engage in governance widely accessible to non-professionals and by distributing deliberative decision-making as close to the ground as possible while maintaining centralized national and state-level financing and accountability to universal goals and standards.

Fourth, participatory governance must *empower* communities and individuals by transferring decision-making power to people who are directly affected by governance decisions. This means involving patients, workers, and citizen-residents as central stakeholders with meaningful control and influence in co-governance, wholly devolving decisions to local communities and health care workers where possible, and removing inequitable cost and procedural barriers that deny people the foundations of a healthy life and prevent them from substantially engaging in governance.

Fifth, models of participatory governance should be *institutionalized* to integrate them with other mechanisms of governance so as to give participatory processes real power to shape broader decisions, operations, and outcomes and to provide institutional support such as legal mandates, financing, training, technical assistance, and enforcement mechanisms.

Sixth, *accountability* with real powers of legal and political enforcement must be built into governance mechanisms to enable both individuals whose rights are violated and organized classes of people to hold powerful public and private entities to account.

These six principles articulate essential values and goals that should guide health governance toward achieving health justice and deep democracy, constituting what we might call a "democracy in all policies" approach. They should also serve as standards to which all mechanisms of democratic governance should be held, including the five models I present in the following section.

I derive these criteria from several complementary scholarly frameworks that I have assessed against my direct experience working with social movement organizations in struggles for justice in health governance. I draw in particular from Andrea Cornwall's and Vera Schattan Coelho's model of democratization,[28] Archon Fung's and Erik Olin Wrights' empowered participatory governance,[29] K. Sabeel Rahman's and Hollie Russon Gilman's civic power,[30] Rahman's policymaking as power-building,[31] Jodie Thorpe and John Gaventa's democratization of economic power,[32] Jody Freeman's collaborative governance,[33] Jennifer Prah Ruger's shared health governance,[34] Irma Sandoval-Ballesteros' democratic-expansive transparency,[35] the 1964 Economic Opportunity Act's and Tara J. Melish's maximum feasible participation,[36] Kali Akuno's Jackson-Kush Plan,[37] Praxis Project's "Centering Community in Public Health,"[38] the Healthcare Is a Human Right framework created by the Vermont Workers' Center's and Partners for Dignity & Rights and further developed by other organizations including Put People First! Pennsylvania,[39] and the New Social Contract framework I co-developed with Cathy Albisa for Partners for Dignity & Rights as an attempt to capture common demands for democratization and community and worker control emerging from a broad set of social movement organizations in the U.S.[40]

Although I draw elements from scholarship on deliberative democracy, I depart from proponents' faith in consensus without contestation. I contend instead that deliberative processes should be thought of as tools, not as strategies, and should be embedded within larger strategies and structures that intentionally correct imbalances in power and unequitable outcomes by establishing clear normative goals and creating space for contestation.[41]

B. Lessons from Historic and Contemporary Models of Participatory Democracy

Despite the turn to market bureaucracy and technocracy in recent decades, there have been a range of efforts, large and small, to democratize governance of American health. In Part III, I propose mechanisms for achieving health justice through deep democracy. Here I briefly survey a handful of past and current initiatives to promote participation in health governance.

Following from the Civil Rights Movement and other social movements of the 1960s and 1970s, there was a wave of regulatory reform across American government with many parallels to what I propose today. The Economic Opportunity Act of 1964 mandated the "maximum feasible participation" of poor communities in developing and implementing anti-poverty. It created the federal Office of Economic Opportunity and two new local institutions for participatory governance—community action agencies (CAAs) and community action programs (CAPs)—and tasked them with assessing community needs and developing plans to meet them.[42] The Comprehensive Health Planning and Public Health Services Amendments of 1966 created a new model of state and local health planning in which local advisory councils representing communities (called '314(b) agencies' or just 'b agencies') were tasked with building consensus around community needs and measures for meeting them.[43] The National Health Planning and Resources Development Act of 1974 established a national network of some 200 local Health Systems Agencies (HSAs) to coordinate the use of public and private health resources through participatory community engagement strategies.[44]

Each of these models quickly drew criticism from across the ideological spectrum. Scholars contend they suffered from vague goals and priorities, a lack of experience and training among practitioners, a lack of methodological rigor, limited powers and funding, too technocratic an approach, lack of support from government, capture by medical providers, and problems defining authentic community representation, among other challenges.[45] Each model, in turn, lost favor and was defunded by Congress. Yet each model had its successes too. They surfaced political decisions about how to allocate health care and social-welfare resources, created new spaces for participation, and delivered some real benefits to communities. The chief lesson here is that the success or failure of programs hinges on the details of policy design, the institutional structure within which programs are embedded, and the level of political support they enjoy. More study of these and other historic models is needed.

In recent years new models have emerged that are ripe for study as well. Community organizations, workers' organizations, and urban planners have pioneered community benefits agreements (CBAs) and project labor agreements (PLAs) as participatory models for promoting equitable land use planning by bringing community and labor organizations into tripartite agreements with cities and developers. Meanwhile Boston and New York City have introduced mayors' offices that have drawn praise for increasing public engagement across city government by creating visible targets for mobilization, advocacy, and participation, and by building in real levers of influence and accountability.[46] CBAs, PLAs, and mayors' offices also have mixed records of success—records that hold key lessons for health care governance and likewise deserve further study.

III. Mechanisms for Democratizing Health Governance

This section presents five mechanisms that hold promise to advance health justice and democratize health governance: participatory needs assessments, participatory human rights budgeting, participatory monitoring, public advocates, and citizen juries. These models should be seen as complements to one another and to institutions of representative and regulatory government. For them to succeed, institutional linkages into other institutions of governance are essential.

Each of the mechanisms is based on proven models of success in the U.S. and around the world, but none yet exist at anywhere close to the scale I suggest is needed. Therefore I propose a flexible, experimental, and evolutionary process beginning in suitable city, county, state, and federal agencies, and adapting and scaling the mechanisms over time.

A. Participatory Needs Assessments

Participatory needs assessments are collaborative processes in which professional researchers work collaboratively with community members to directly involve them in identifying and prioritizing medical, social, economic, and other needs in their communities through interviews, focus groups, surveys, data collection, and other research and documentation activities. Participatory assessments improve the quality of research informing policymaking—thus improving policy outcomes—by drawing on community members' experiential knowledge. They also uphold democratic values by capturing community members' values and priorities, giving people more voice and real influence in policy decisions that affect their lives, and engaging people as active citizens with an important role to play as members of a democratic society.

All this is especially true for poor people, people of color, and other marginalized communities who are systematically disenfranchised and denied fundamental needs by non-participatory research, legislative, and regulatory processes. Because participatory needs assessments are guided by principles of universality and equity, they create an inclusive space that welcomes a diversity of community members and captures a broad set of needs while also intentionally centering the participation and needs of poor people of color and other sub-communities who face especially high obstacles to meeting their fundamental needs.

Although many community-based organizations in the United States conduct participatory research to gather and document information and facilitate political education and community organizing, true mandates to conduct participatory needs assessments—in which community-defined and community-generated documentation of human needs is legally required as an enforceable basis for budgetary and regulatory governance—are exceedingly rare. If any such provisions currently exist in the United States, I am unaware of them.

1. Community-Led Participatory Research

Many community groups use participatory research methods to collect both quantitative and qualitative data on health needs in their communities.[47] In 2011, for example, Voices of Community Activists & Leaders (VOCAL-NY), a grassroots membership organization of low-income people affected by HIV/AIDS, the drug war, mass incarceration, and homelessness, teamed up with the Community Development Project of the Urban Justice Center (now called TakeRoot Justice) to documental medical and social service needs among New York City residents living with opioid and heroin addiction. Together they conducted surveys and focus groups of methadone users in New York City and compiled secondary research from public health journals. Methadone patients worked with staff to design, conduct and review the research, which was published in a joint report.[48]

VOCAL-NY's research documented inadequate testing and care for Hepatitis C among methadone patients, ongoing drug usage among a significant number of current and former patients, 75% support for needle exchanges among respondents, and frequent administrative barriers to treatment including limited clinic hours, Medicaid case closures, and delays with transportation assistance. The report recommended on-site hepatitis C testing and care coordination, naloxone distribution, public education, on-site syringe exchange, and administrative reforms to prevent treatment interruptions.

Such participatory research actively involving people who are directly affected by health policies helps surface essential information and priorities—such as the need to remove administrative barriers—that may well escape notice in technocratic decision-making processes that do not actively and substantially involve directly affected communities. Nor is this research purely instrumental: participatory processes help build a more robust network of civil-society organizations representing marginalized communities by creating opportunities for these organizations' members to learn, build skills and collectivity, organize fellow community members, and directly influence policymaking and governance.

Successful participatory research relies on established relationships, trust, organizational infrastructure, knowledge, and experience within communities, and is therefore best carried out through organizations like VOCAL-NY whose members and staff are deeply rooted in a given community. But community-based organizations almost invariably have limited money and staffing, and thus rarely have the in-house capacity to conduct extensive research on their own. External funding and technical assistance, such as VOCAL-NY's grantmakers and TakeRoot Justice provided, is essential.

To scale up participatory research to wider use, public funding is needed to underwrite both community-based research projects and technical assistance organizations. Funding should be targeted equitably to ensure that all health care workers and patients are adequately represented in needs assessments, especially groups with the greatest needs. To provide institutional backing and enable successful implementation, funding should also be dedicated to providing training for administrative-agency staff on what participatory needs assessments are, why they are important, and how they fit into the rest of agencies' work.

In addition to funding, a legal framework is needed to mandate, standardize, and provide technical and institutional support for a broad expansion of participatory needs assessments. Health impact assessments and community health needs assessments could serve as the basis for such an expansion.

2. Health Impact Assessments and Community Health Needs Assessments

The participatory research model developed by groups like VOCAL-NY and TakeRoot Justice provides part of the foundation for broader adoption of participatory needs assessments, but new legal mechanisms are needed to institutionalize participatory research in policymaking and governance and bring it to scale. Health impact assessments pioneered by city and county health departments and the Affordable Care Act's community health needs assessments could be adapted to provide such a framework.

Over the last twenty years health impact assessments (HIAs) have emerged as a tool with promise to bring consideration of human health needs into decision-making processes, especially in land-use, housing, transportation, and environmental planning. HIAs entail a six-step process: screening, scoping, assessing, developing recommendations, reporting, and monitoring and evaluation.[49] Agencies are encouraged to involve community members in all six steps. HIAs have been primarily implemented by city and county agencies, though several states have passed supporting legislation and the Environmental Protection Agency has integrated HIAs on a limited basis.

The Affordable Care Act (ACA) requires nonprofit hospitals to conduct triennial community health needs assessments (CHNAs)[50] to document their patient population's health needs and generate plans for meeting those needs, improving health outcomes, and reducing inequities. Although the Act itself provided very little detail on what CHNAs would entail, the Internal Revenue Service issued subsequent guidance fleshing out the requirements. One particularly important aspect of this guidance has been requiring hospitals to pay special consideration in their CHNAs to "medically underserved populations, low-income persons, minority groups, or those with chronic disease needs" including "populations experiencing health disparities or at risk of not receiving adequate medical care as a result of being uninsured or underinsured or due to geographic, language, financial, or other barriers."[51]

Both the HIA and CHNA frameworks place important focus on community health needs in public and private governance, a critical intervention that challenges the neoliberal norm of prioritizing fiscal efficiency over other health concerns. They also emphasize important principles compatible with human rights values: HIAs stress community *participation* in defining health needs, CHNAs require attention to *equity*, and both require *transparency* by requiring assessments and plans to be made publicly available.

Yet in their current form, neither HIAs nor CHNAs qualify as the sort of participatory needs assessments I propose. They are both fundamentally technocratic mechanisms that fall short of deep democracy. They elevate professionals' knowledge over community members' experiential knowledge by limiting people who are directly affected by policies to providing input while delegating all powers of interpretation and decision-making to professionals. HIAs and CHNAs define community representation and participation very loosely, with little consistency as to who authentically represents communities, how representatives are held accountable to community members, and whether participation carries meaningful influence or is mostly symbolic.[52] HIAs and CHNAs also largely ignore the larger structural imbalances of power that produce health inequities. A CHNA focused on a single hospital cannot properly address community health needs that extend beyond a hospital's wall, and an HIA focused on a single development cannot fix health inequities produced by larger systems of education, employment, finance, housing, transportation, and wealth. In addition, HIAs and CHNAs obscure trade-offs among values, such as how local communities might weigh the accessibility benefits of having multiple health clinics against the comprehensiveness and efficiency benefits of more centralized delivery of care. Finally, the impact of HIAs and CHNAs on policy and on people's lives is unclear. A 2008 assessment of 27 early HIAs in the U.S. found very limited evidence of whether they influenced subsequent policy decisions or benefited affected communities.[53]

To achieve health equity and democratic governance, participatory needs assessments must proactively promote democratic inclusion and shared power among stakeholders by actively developing community-based civic infrastructure among structurally marginalized community stakeholders, equitably redistributing power among stakeholders in decision-making processes, and making measurable and enforceable progress toward equitable health outcomes. They must also open up space for transparent, participatory public deliberation and judgment on questions of values, priorities, tradeoffs, and distribution of resources. Though achieving these outcomes at scale will require a radical transformation of health governance, participatory research, HIAs, and CHNAs nevertheless show how local needs assessments can be institutionalized and brought to scale. If properly designed and employed, this institutionalization of community-led participatory research would shift health governance along the spectrum from stakeholder input into exclusionary, inequitable systems toward co-governance and community control.[54]

3. Implementing Participatory Needs Assessments

Forward-thinking local governments, administrative agencies and hospitals can voluntarily turn existing information-gathering processes (HIAs, CHNAs, notice-and-comment, public hearings, etc.) into more robust participatory needs assessments, but to universally protect human health and democracy, legal mandates, not volunteerism, are ultimately needed. Congress; state legislatures; federal, state, county, and city health agencies; and county and city supervisors all hold power to create requirements and provide institutional backing. As of 2017, for example, Maryland, Massachusetts, New Jersey, Vermont, and Washington had all passed legislation requiring HIAs in some processes,[55] and many cities have adopted HIAs in some capacity too.

To effectively promote health justice and a robust democracy, statutes should require participatory needs assessments in public budgeting processes at all levels of government and across all spheres of rulemaking and regulatory enforcement including financing, insurance, hospitals, clinics, correctional facility medical contractors, nursing homes, drug and device manufacturers, pharmacies, biotechnology, research and development, medical education, professional licensing, staffing, and public health programs.

Introducing needs assessments on this scale would be a major and somewhat unpredictable undertaking, so the process of institutionalizing assessments should be flexible across different contexts and adaptive over time as best practices emerge. Such piloting requires some degree of agnosticism about the ultimate form that needs assessments take, leaving room both for best practice to emerge and to allow variation across contexts as communities can shape their own documentation processes. At the same time, however, participatory needs assessments should be held to clear universal standards to make sure they fulfill their purposes. They should be explicitly designed to further normative goals of health justice, democracy, and equity, and should have both institutional backing and accountability.

To promote health justice and democracy, needs assessments should define health broadly, including the social determinants of health in needs assessments. They should articulate clear values and policy goals through principles drawn from human rights law, health law, public health, and communities' self-identified values and priorities. These should likely include universality, equity, accountability, participation, transparency, quality, comprehensiveness, and effectiveness, but the best way to determine the right set of principles in different regulatory contexts would be to conduct a participatory process to enable stakeholders to collectively shape the global principles to which needs assessment processes will be held.[56]

To promote equitable and authentic community representation, needs assessments should require and facilitate proactive outreach to community groups to meaningfully engage and empower them in all stages of needs assessments from screening through conceptualization, scoping, defining terms and research questions, and determining research method and design. Community needs assessments should document the needs of multiple communities including patients, health care workers, and local/regional residents. They should especially focus attention on sub-communities who face structural health and labor inequities or whose needs and rights are typically underrepresented in regulatory policymaking. Depending on the context, this may include people of color, immigrants, poor and working-class communities, rural and post-industrial communities, people with disabilities, people with chronic conditions and illnesses, people who are incarcerated, women, LGBT people, people with addiction or other mental health needs, people who are unhoused, older and younger people, home health aides, nursing home workers, and other low-wage non-union health workers.

Legal frameworks should provide grants and fund technical assistance providers to enable community organizations to meaningfully participate in needs assessments. In communities and labor sectors in which strong community infrastructure does not already exist, participatory needs assessments can help catalyze the formation of new community organizations and unionization drives, but this process must develop organically. Seed funding and technical assistance can help new groups get off the ground, but should not force the formation of organizations.

Needs assessments also need ample institutional backing to proliferate and succeed. Legal frameworks should provide training for staff of administrative agencies on what participatory needs assessments are, why they are important, and how they can support and complement agencies' other work. They can coordinate data standardization, require and facilitate empirical rigor, and pilot methodologies for aggregating local community needs assessments to feed into regional, state, and national needs assessments in ways that involve and are accountable to representatives of local communities.[57]

One past pilot that holds lessons and merits further study is Oregon's effort in the early 1990s to establish a transparent and participatory public process for determining what treatment the state's Medicaid program would and would not cover.[58] Though the initiative maintained a technocratic professional bias by primarily drawing input from physicians rather than from Medicaid enrollees and nurses and other health care workers, it did use surveys, community meetings, and public hearings to draw on broader public opinion. The effort did not reduce Oregon's Medicaid expenditures, as many proponents had hoped, but achieved what I would argue is a more important outcome. By making rationing decisions explicit, it helped halt and reverse the series of benefit cuts that had singled out Oregon's Medicaid enrollees and left them with fewer and fewer covered services.

Because needs assessments focus on providing information and do not replace legislative or regulatory decision-making, they carry relatively few risks and limitations. The primary risk is that they can vary in inclusivity, rigor, and effectiveness, so institutional support and accountability is essential.

Finally, participatory needs assessments should be connected with other deep democracy mechanisms, such as by building needs assessments into participatory budgeting and participatory monitoring processes, utilizing public advocates to advocate for patient, worker, and public needs in government, and exploring deliberative citizens' juries as a possible methodology for assessing needs.

B. Participatory Human Rights Budgeting

Participatory budgeting gives residents a direct role in shaping public budgets by empowering them to assess community needs and determine spending priorities. Participatory budgeting processes emphasize inclusive, transparent, deliberative processes designed to draw on a diversity of perspectives and build shared understanding and consensus around mutually beneficial spending priorities. The model originated in Porto Alegre, Brazil, in 1989, and has since spread around the world. In the United States, hundreds of municipalities, districts, schools, and organizations have incorporated varying degrees of public participation into their budgeting decisions.[59]

Participatory budgeting in the United States has so far been relatively narrow in scope, operating within four significant limitations. It has generally been limited to the municipal or sub-municipal level, to a small segment of public budgets (usually a portion of capital expenditures), to spending (not revenue), and to the procedural goals of participation, deliberation, and consensus-seeking (but not outcome goals like equity and justice). In Porto Alegre, in contrast, participatory budgeting emerged and was operationalized within a larger social movement ecosystem in which participatory democracy was designed for the expressed purpose of fighting corruption and shifting power back to communities, and participants were given control over a larger portion of public budgets.[60] Brazil has, for example, over 5,000 municipal health councils in which designated representatives from civil society, government, and service providers make decisions such as approving annual plans and health budgets, act as consultative bodies, and exercise oversight.[61]

I propose a variant of the Porto Alegre model that I call *participatory human rights budgeting* in which budgeting processes are designed not only to open up space for participatory deliberation, but to do so with the expressed purpose of advancing health justice and shifting the balance of power that different interests hold over public budgets. This model was developed by the Vermont Workers' Center and Partners for Dignity & Rights as a proposal for shifting how the State of Vermont conducts its annual statewide budget process.[62]

Participatory human rights budgeting begins with active recruitment and social-movement mobilization to get a diverse, equitable, and representative set of participants in the room. Facilitators help establish a clear scope and goals for the process, underlining guiding principles of universality, equity, and democracy. They lead participants through assessing community needs by listening to presenters, studying empirical data, sharing their own experiences, and deliberating with one another.

Comprehensive participatory needs assessments can be conducted as part of the budgeting process or in advance of it. Over a period of days, participants prioritize and hone a set of spending proposals that are brought to a vote among participants or among the broader public. In narrower budgeting processes, these proposals can be specific expenditures. For a statewide budget like Vermont's, the proposals are much broader principles, not specific line items. Participants conclude the budgeting process by producing a report capturing the needs, priorities, and recommendations they identified, and submit this to the public officials in charge of producing the budget. The officials are required to craft a budget that meets the community-defined needs and priorities, including equitably raising sufficient revenue.

This is a major departure from conventional budgeting processes in which legislators and executives first make a political decision about how much tax revenue they want to collect and then decide how to distribute that fixed pool of money, an approach that creates scarcity and zero-sum competition between health, housing, education, and other priorities. Participatory human rights budgeting flips this on its head. The process begins with a comprehensive, participatory human needs assessment to determine the needs of residents. Legislators and executives are statutorily required to raise and allocate sufficient revenue to meet community needs, and to raise revenue equitably. They are still entitled to make political judgments as they develop and pass a budget, but are held accountable by the democratically developed needs assessments, by participatory monitoring of the prior year's budget as part of the annual participatory budgeting process, and by elections.

As the Workers' Center and Partners for Dignity & Rights explain, raising revenue to meet human needs would mark "a paradigm shift in budget and revenue policies more generally, moving from competitive allocation, based on assumptions of scarcity, to collaborative proposals for funding shared goals."[63] Yet needs-based budgeting already exists in discrete settings. The Connecticut Office of the Healthcare Advocate is financed, for example, through an assessment on insurance companies that is scaled up or down each year according to the budgetary needs of the Office.[64]

The biggest challenge to implementing participatory human rights budgeting at scale is the sheer political opposition that introducing so much public accountability would arouse. Wealthy and powerful industries and economic elites draw huge profits from current budgetary frameworks, which allow them to lobby for favorable tax treatment, subsidies, government contracts, and other fiscal benefits. Although the political, economic, public health, police brutality, and climate crises we are experiencing could open space in the coming years for social movements to organize to win large-scale participatory human rights budgeting, a more likely scenario in the near future is that participatory human rights budgeting could be implemented at smaller scales.

Over the last ten years, participatory budgeting has exploded in the U.S. from a single pilot project in Chicago's 49th Ward to hundreds of participatory budgeting processes around the country. One clear way to shift budgeting processes toward participatory human rights budgeting would be to strengthen existing participatory budgeting processes by adding clear outcome goals to advance equity, growing the amount of expenditures communities have control over, and using community needs assessments to determine revenue requirements.

Participatory human rights budgeting could also follow the recent lead of the Tacoma-Pierce County Health Department by introducing community and worker participation into budgeting processes for cities, counties, states, public health departments, and even private health care systems.[65] Participants could conduct human needs assessments to set priorities for public budgets and monitor the prior year's budget. They could also be given the power to allocate a portion of the public budget, especially to guide spending on non-medical supportive services in the community such as community health workers, mobile health services, medical transportation, disease testing and immunization, addiction treatment services, mental health services, occupational health centers, housing, nutrition programs, fitness programs, culturally and linguistically appropriate care services, and rural health services. Both publicly and privately owned hospitals and community clinics could similarly be required to open up their budget processes for community services to enable patients, workers, and local residents to establish needs, allocate spending, and monitor progress.

There are good reasons for opening up budgeting of community health services to public participation. First, not all communities have the same needs. People South Texas and South Los Angeles have different needs and priorities. Local community members and health care workers are best able to identify neighborhood, municipal, and regional priorities. Second, these services are perennially underfunded because they cost money but lack an organized constituency to fight for them. Opening up budgeting processes for community health services would make these programs for more visible and salient to the public, creating what political scientists call a new "public" that comes together to advocate for programs meeting community health needs.

To be effective, participatory human rights budgeting processes should receive institutional support such as funding, technical assistance, and training for participants, facilitators, and agency staff; accountability, such as through universal guiding principles and standardized methodologies for ranking priorities and reporting; and direct formal linkages into the rest of their jurisdiction's budgeting process, such as mandates that public budgets address community-identified needs and spending priorities. At the same time, participatory processes should avoid placing onerous participation requirements on marginalized communities in order to get the same basic needs like hospitals and safe streets that more wealthy and white communities get automatically; processes must be designed to ensure that participation is of benefit to communities, not a burden. Lastly, participatory human rights budgeting should always include proper participatory monitoring, as discussed in the following section.

C. Participatory Monitoring

Rahman and Gilman define citizen audits as "the organized, strategic use of participatory monitoring techniques to hold government actors accountable." I add private power-holders—health care companies, employers, and other parties with decision-making power in health systems—to the mix, defining participatory monitoring as the organized, strategic use of participatory monitoring techniques to hold both government and private power-holders accountable.[66] Although some participatory monitoring techniques like public hearings are relatively common, true participatory monitoring—the organized, strategic use of multiple monitoring techniques over time—is quite rare.

A good example of participatory audits and monitoring is the Fair Food Program. The Program is operated by the Fair Foods Standard Council (FFSC), a nonprofit organization established by the grassroots Coalition of Immokalee Workers to monitor working conditions in Florida's tomato industry, which has a history of severely abusing migrant farmworkers.[67] The FFSC is granted monitoring powers through contractual agreements signed by the tomato growers who employ the farmworkers. Although the FFSC is professionally staffed, workers played a central role in developing the standards of conduct to which employers are held, and play an ongoing role in the monitoring, enforcement, and upkeep of the standards. Every time the FFSC audits a workplace, it interviews at least fifty percent of workers, an unusually large number by conventional auditing standards, and workers are the front line of defense for monitoring and reporting employer abuses.[68]

Participatory monitoring can and should be implemented broadly in health governance, especially in regulation of sectors that lack accountability because they are highly decentralized (such as both home-based and institutional long-term services and supports), have consolidated market power (hospital and pharmacy companies, for example), or lack public visibility and scrutiny (like workers' compensation insurance companies and pharmacy benefit managers).

Participatory monitoring should also be deployed much more broadly to hold both elected and appointed public officials to account, especially in budgetary decisions and to advance equity for disadvantaged groups.

Medicaid, for example, would benefit from participatory monitoring. As a means-tested program, Medicaid is routinely targeted for budget cuts whenever inadequate federal financing and recessions combine to stretch states' budgets, and sometimes even when they don't. In 2011-2012, for instance, after the Great Recession, fourteen states cut Medicaid dental benefits.[69] Such cuts are often enacted through little-noticed legislative or administrative maneuvers and receive little pushback from Medicaid enrollees, who are not politically well organized. Yet these cuts have devastating effects on people's lives. Cutting dental benefits, for example, forces people them to endure chronic pain and infections, have teeth pulled, and suffer mental and occupational fallout.

The current economic crisis is already beginning to bring a new wave of Medicaid cuts, with many more surely on the horizon. Cuts to Medicaid benefits have enormously harmful effects on some of the most vulnerable people in our society, and hurt the broader body public by eroding public health and everyone's ability to trust they will always have care. They are also enacted through incredibly undemocratic procedures that subject Medicaid—but not private-insurance plans—to benefit cuts, and that exclude the people who are impacted by cuts from having any real say in budgetary decisions.

Although participatory monitoring would not prevent cuts to essential benefits, it would bring significantly higher transparency and scrutiny that would make cuts much more difficult. Indeed, as Jonathan Oberlander as his co-authors write about the Oregon Health Plan (described in the needs assessment section above), "the more public the decisions about priority setting and rationing, the harder it is to ration services to control costs."[70] Although a society can legitimately elect to ration certain health benefits to allocate resources to other needs, cuts that are thrust onto poor and marginalized communities are neither equitable nor democratic. Participatory monitoring can help level the playing field by bringing these decisions out into the light.

Participatory monitoring is most effective when it engages organizations and individuals from communities who are directly impacted by a public or private power-holder's actions and inactions. Those closest to problems have unique knowledge, are best positioned to conduct monitoring, and have a direct interest in successful monitoring and enforcement. Participants should be engaged in all stages of monitoring from establishing the metrics against which power-holders are to be measured through data collection, analysis, and reporting. Participants should be able to measure and evaluate both process and outcome indicators to ensure that people are treated fairly in health systems and that health inequities are narrowed and eliminated over time. To give participatory monitoring real power, the problems it uncovers should trigger formal enforcement proceedings. All findings should be made public to facilitate transparency, enable civil-society groups to make use of evaluations, and provide an extra incentive for power-holders to behave appropriately.[71] Finally, as with other mechanisms, institutional support is essential. Successful participatory monitoring requires clear goals and standards, strong and committed facilitation, training and technical assistance for participants, financial support, and direct feedback loops into other institutional processes including public budgeting and enforcement mechanisms.

As with other mechanisms of participatory governance, participatory monitoring could be piloted and phased into different levels of health governance over time. Monitoring should be distributed but centrally coordinated.

D. Public Advocates

Public advocates, as I define them, are public, professionally staffed offices headed by an appointed Advocate, and that serve as proxy advocates representing patients, workers, and the public in legislative and regulatory processes; help individuals administratively appeal adverse health care decisions; conduct public education on people's health care rights; and receive complaints on, conduct investigations into, and report on systematic health care or public health problems involving both private companies and public agencies. Public advocates promote accountability by serving as a politically independent third-party monitor of regulatory agencies and by strengthening lines of accountability from health care companies and public programs to individuals and groups of people who rely on them. They help legislators by assisting constituents and by consolidating and reporting information on sprawling health systems that cut across multiple regulatory regimes and jurisdictions. Advocates do not typically hold powers of enforcement, but provide critical information to lawmakers to facilitate legislative and executive action. They hold broader jurisdiction, responsibilities, and powers than classical ombudsmen, inspectors and auditors general, and special commissions, which focus solely on monitoring administrative agencies or otherwise have narrower powers to conduct investigations, advocacy, and direct assistance.

Both Connecticut and Nevada have public advocate offices that provide direct assistance to residents struggling with denied insurance claims, erroneous medical bills, and other problems. For residents facing imbalances of information vis-à-vis health care companies and a confusing array of appeals processes, these advocates are a tremendous resource. Since 2005, for example, Connecticut's Office of the Healthcare Advocate (OHA) has returned over $112 million to residents by helping them successfully appeal more than 63,000 adverse decisions by insurance companies.[72] Nevada's Office of the Consumer Health Advocate (OCHA) helps residents appeal some 2,000 to 3,000 cases a year, and has wide jurisdiction and designated staff to help residents appeal denied coverage, erroneous bills, discrimination and other decisions in Medicaid, private insurance, workers' compensation, and hospitals.[73] Both offices also work with legislators to help draft new legislation to improve their states' health care systems.

Not all public advocates are equally successful. Scholars have identified a number of factors that can help ensure advocates' independence and efficacy, including creation by statute, designating adequate and earmarked funding, establishing a public office but insulating it from other agencies, appointing the Advocate and instituting professional and independence requirements for both the Advocate and staff, and giving the Advocate sufficient powers including the power to initiate own-motion investigations, collect information, report to the legislature and executive on pervasive health care problems, advocate on behalf of patients in public hearings and processes, and make legislative recommendations.[74]

Lawmakers and legal scholars have put forth a number of proposals for creating a public advocate to monitor the federal bureaucracy and represent public interests in rulemaking. The Congressional Research Service has documented many proposals for ombudsman and advocacy offices over the years.[75] Nicholas Bagley suggests Congress should establish an executive agency to investigate, document, and report on instances of capture, coordinate inspectors general, and automatically spur legislative action.[76] Tara J. Melish proposes a National Office on Poverty Alleviation to orchestrate anti-poverty efforts and a United States Human Rights Commission to monitor agencies, serve as a clearinghouse for civil-society reports, and synthesize and report findings.[77] Mariano-Florentino Cuéllar propounds creating an independent federal agency to document public needs and preferences and represent people's views in rulemaking processes.[78] These are strong mechanisms, but more mechanisms are needed that include oversight of private actors rather than just public agencies.

Although public advocates' offices are staffed by professionals, they provide significant institutional representation of underrepresented needs and voices. They can also open up meaningful opportunities for community participation and encourage social-movement mobilization by utilizing such participatory mechanisms as public hearings, community advisory boards, and collaborative efforts with community-based organizations to help design and execute public education, outreach, and engagement.

One major risk to implementation is that public advocates can be too limited in scope, powers, and budget to be effective. Though the long-term care ombudsmen program established by the Older Americans Act provides important assistance to hundreds of thousands of people per year, for example, ombudsmen are only authorized to assist with individual complaints, not to investigate systematic problems arising from privatized ownership, fragmented regulation, and inadequate funding and staffing. Another risk is that advocates can be weakened or captured, which is why the criteria for independence and effectiveness I propose are important.

Nevertheless, public advocates are a well-proven mechanism. Connecticut's and Nevada's offices are both well respected and enjoy broad bipartisan support from legislators. Public utilities ombudsmen in the U.S. are recognized as have successfully restrained utility rates, and there are thousands of ombudsmen in operation around the world. A wave of ombudsmen was created to advocate for people in long-term care, utility-rate setting, and other matters in the 1970s and 1980s. It is time for a new wave of advocates, this time including jurisdiction to monitor the private sector.

E. Citizen Juries

A citizen jury is a deliberative body designed to stand in for the larger body public. Members are chosen by stratified random sampling in which they are selected by lottery, but balanced according to demographic characteristics to ensure that they are proportionally representative of the larger population. Citizen juries can be very inclusive, including immigrants without citizenship, youth who have yet to reach voting age, and people who are denied voting rights because of a criminal conviction.

As a form of civic republicanism, citizen juries can be a valuable complement to elections, public-opinion polls, lobbying, ballot initiatives, and other mechanisms intended to define the public will and translate it into policy.[79] They complement institutions of representative government by submitting their analysis and recommendations to legislatures to inform policy decisions, and also make their reports available to the public.

Citizen juries are especially suited to wicked problems in which seemingly intractable disagreements arise because different values that people hold are in tension, such as liberty and equality, professional expertise and popular opinion, or present and future value. They hold the potential to inform contentious health policy decisions such as how to ration scarce hospital beds and ventilators if COVID-19 exceeds hospitals' capacity; how to weigh the public health, economic, and privacy trade-offs of managing the spread of the pandemic; whether, when, and how to ration health coverage, as in designing drug formularies or deciding when to cover experimental treatments; how to properly uphold the rights of minorities, such as people with rare diseases; how to weigh data collection to improve treatments and public health against patient privacy; and how to approach policies on health care issues that are largely interpreted through a moral lens, such as abortion, organ transplants, assisted suicide, and end-of-life care.

Citizens juries have been conducted in the United States since 1974. Recent redistricting efforts in California and Oregon used citizen juries to redraw their states' gerrymandered Congressional districts, drawing widespread praise for both their processes and results. Over the years the Jefferson Center, a leading proponent and facilitator of citizen juries, has convened juries on several health care issues: transplants, President Clinton's health plan, assisted suicide, data collection from autism patients, and ways of engaging patients in reporting diagnostic errors.[80]

Ireland convened a citizens jury in 2016 called the Citizens' Assembly to seek common ground on abortion as well as climate policy and procedures for referenda. The Assembly met twelve times over two years before delivering its recommendations. Because its members were a fair representation of the body politic and because its deliberative process gave ample voice and consideration to all sides, its recommendations were widely respected by the public. In 2018, the Citizens' Assembly's recommendations convinced the Irish public to vote for a constitutional amendment that legalized abortion. The amendment passed by a margin of two-to-one, an outcome that would have been unthinkable in the heavily Catholic country just a few years earlier.[81]

Despite their proven capability to break logjams created by competing values, citizen juries are not well suited to most situations. They have several major drawbacks. Citizen juries are not well suited to resolving political conflicts in which conflict largely exists between distinct interest groups competing in zero-sum competition over resources or representation. They are best reserved for situations in which the primary barrier to policy progress is that many members of the public are struggling to resolve tensions in their own minds between different values they hold. Citizen juries are also expensive. They require significant staffing to provide facilitation, training, and operational support and require stipends to enable working-class participants to commit time. They also typically require participants to commit multiple days of their time over a period of weeks or even months. Although building a robust, healthy democracy is worth spending resources on, citizen juries should be reserved for situations where other means of priority-setting do not work.

In addition, the reality of citizen participation is more complicated than the deliberative ideal. Participants are expected to act as citizens, but everyone lives with multiple roles and identities: citizens, patients, taxpayers, beneficiaries, workers, parents, women, Puerto Ricans, and so on. By rejecting interest-group politics and striving for consensus without contestation, citizen juries can flatten identities and leave certain perspectives and priorities underrepresented.[82] Perhaps most importantly, citizen juries, like all forms of deliberative democracy, risk reproducing societal inequities and biasing their results. In society riven by hierarchies of race, class, and gender, it is simply not possible for participants, facilitators, and presenters to leave all pre-conceived notions at the door of a citizen jury.[83]

Despite these limitations, citizen juries hold potential to help provide clarity on a small set of thorny issues in which broadly held values have come into tension with one another, preventing policy progress toward health justice. They should not be to seek an impossibly distilled unitary voice, but to draw out and communicate the various values that people hold and are weighing against one another.

IV. Conclusion

In this article I have argued that to advance health justice and fulfill democratic values, we must radically democratize the governance of American health care and public health. The governance mechanisms I have presented here should be introduced widely as part of a larger transformation of the financing, delivery, and governance of health care and public health, but any such effort must be undertaken iteratively with plenty of room for piloting, experimentation, adaption, and flexibility. Health systems are incredibly complex, and there is no single solution that will deliver health justice and deep democracy. Rather, I contend, we should view democracy and governance as endlessly contingent and contested processes, and seek an array of models that can be adapted to different institutional, social, and cultural contexts, different geographic locations, and different times. As such, the five mechanisms I present here are but a handful of examples. More work is needed to theorize and pilot these and other models.

There will no doubt be significant political, institutional, and operational challenges to implementing these mechanisms, particularly at scale, in a way that ensures they are inclusive and effective in delivering better health and democratic outcomes. But if we believe in health justice and democracy, we cannot fall back on markets and technocratic managerialism to remedy the enormous health, economic, and political challenges we face. Achieving more just and democratic health governance will require tremendous organizing and political leadership as well as a new civic ethos about what it means to be part of a democratic society. Legal mechanisms cannot deliver health justice and democracy on their own, but are an essential part of the solution.

Endnotes

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8 G. Simonovits, A.M. Guess and J. Nagler, ‘Responsiveness without Representation: Evidence from Minimum Wage Laws in U.S. States,’ American Journal of Political Science, 63, no. 2 (April 2019): 401–10.

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18 On broader regimes of disciplinary control, see, for example, Rahman (2018), supra note 14, and the work of Virginia Eubanks, David W. Garland, Pamela Herd and Donald P. Moynihan, Michael B. Katz, Tayyab Mahmud, Mae M. Ngai, Marianna Pavlovskaya, Frances Fox Piven and Richard Cloward, Sanford F. Schram, Joe Soss, Dean Spade, and Loïc Wacquant.

19 See, for example, A. Banerjee and P. Armstrong, ‘Centring Care: Explaining Regulatory Tensions in Residential Care for Older Persons,’ Studies in Political Economy, 95, no. 1

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24 See M-F. Cuéllar, ‘Rethinking Regulatory Democracy,’ Administrative Law Review, 57, no. 2 (2005): 411–499, at 497-498. (“The vast majority of regulatory questions simply cannot be resolved without making value choices and policy trade-offs. Any narrative of regulatory activity eliding those components of regulatory decisionmaking is misleading.”)

25 See, for example, N. Bagley and R.L. Revesz, ‘Centralized Oversight of the Regulatory State,’ Columbia Law Review, 106 (2006): 1260–1329.

26 See Rahman (2019), supra note 16, at 24-25.; M.W. Dowdle, ‘Public Accountability: Conceptual, Historical and Epistemic Mappings,’ in P. Dragos, ed., Regulatory Theory, 1st Edition, (Acton, Australia: ANU Press, 2017): 197–215.

27 See Rahman (2011), supra note 23, at 586 (“Democracy inheres, then, not in the sovereignty of the atomized voter as a bearer of preferences and values, but in the organization of individuals into groups of shared values, interests, and aspirations.”); Rahman (2017), supra

note 16.; K.S. Rahman and H.R. Gilman, Civic Power: Rebuilding American Democracy in an Era of Crisis, 1st ed. (Cambridge: Cambridge University Press, 2019).; Cornwall and Coelho, supra note 15; L.F. Wiley, ‘Health Law as Social Justice,’ Cornell Journal of Law and Public Policy, 24, no. 1 (2014): 47–105.

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