

THE Nonprofit QUARTERLY

On Life Support: America's Healthcare Crisis

The Structural Causes
of Healthcare Injustice

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Welcome

DEAR READERS,
The winter 2020 edition of the *Nonprofit Quarterly* is not cheery and bright—but we are optimistic that a deeper understanding of the brokenness of the U.S. healthcare system will come in the wake of COVID-19. The pandemic is laying bare some of the systemic problems in this area, and there are a plethora of them—so many that it is obvious that a piecemeal approach to reform is likely to fail. The system is deeply and chronically infected by corporate incentives and motivations that feed the system’s dysfunction, and nothing less than an ethics-based redesign is likely to have much effect.

We need a whole new set of organizing principles.

The feature articles within were written as one presidential administration dug its heels in and refused to give way to another, and as the pandemic raged on, disproportionately infecting and killing people of color and the elderly. They were written while the wealth gap in this country exploded to form a vacuum of the assets that remain in the hands of people with less money. The way the healthcare system functions is a reflection of those problems of extractive capitalism, creating its own narratives and definitional boundaries—ones that prevent a real reorganization of healthcare that is both sustainable and designed around the best interests of those being served and their health providers. Here is how the *Guardian* recently summed up the situation:

Despite millions of Americans delaying medical treatment due to the costs, the US still spends the most on healthcare of any developed nation in the world, while covering fewer people and achieving worse overall health outcomes. A 2017 analysis found the United States ranks 24th globally in achieving health goals set by the United Nations. In 2018, \$3.65tn was spent on healthcare in the United States, and these costs are projected to grow at an annual rate of 5.5% over the next decade.

The articles—written even as a federal measure to prevent surprise hospital billings is making its way through Congress under the general cover of a COVID-19 relief bill, and as the GOP continues to make a bid for a corporate liability shield that would provide cover for nursing homes—really only scratch the surface of the need and required direction for a healthcare revolution. But one thing is clear: the principles around which healthcare is currently organized are not based on equitable access and affordability, health promotion, or even medical and health results. What they are, to a great extent, is primarily based on the production of profit—with that system being well supported by industrial lobbyists. Ironically, the cost to U.S. taxpayers continues to creep up even as the argument for keeping things as they are is that we would otherwise be going socialist.

This is a policy area that is likely to see movement over the next four years. Let’s resist the deadly incrementality of a centrist approach, and insist on a wholesale transformation.



The Struggle for Healthcare Justice: It's Movement Time

by Ben Palmquist

“New public policies and new models of participatory governance, as well as robust, enforceable accountability, will be critical to putting decision-making power into the hands of patients, healthcare workers, and the public overall,” writes Ben Palmquist. “Building a more just healthcare system will require all of us—in government, foundations, nonprofits, and other institutions—to open up meaningful spaces for democratic participation, and in so doing relinquish some control over the agendas, priorities, and decisions that emerge from those spaces.”

LAST YEAR, KIM ALTLAND OF YORK, PENNSYLVANIA, who was born with a congenital condition requiring more than fifty surgeries over his lifetime, was told by Gateway Health, the managed care organization that the State of Pennsylvania authorized to manage his Medicaid coverage, that they would not cover the custom orthopedic shoes he needed to walk.¹ After

Heather Waldron of Blacksburg, Virginia, received emergency intestinal surgery at a hospital owned by University of Virginia Health (UVA Health), she and her husband lost their house when the health system sued them and put a lien on their home.² Alec Raeshawn Smith of Richfield, Minnesota, died of diabetic shock after Eli Lilly, Novo Nordisk, and Sanofi raised the price of insulin, and just a month after his twenty-sixth birthday, the day federal law made him ineligible for his mother's insurance plan. Alec's meager \$35,000 salary forced him to enroll in an insurance plan with lower premiums but a higher deductible, meaning he had to pay the entire cost of his prescription out of pocket. He died with his insulin pen empty, just three days short of his next payday.³

BEN PALMQUIST is the program director of Health Care and Economic Democracy at Partners for Dignity & Rights (formerly NESRI), where he supports grassroots campaigns for universal, publicly financed healthcare, democratization of the economy, and the organization's New Social Contract project. He previously worked with the Urban Justice Center, Center for Urban Pedagogy, Hester Street Collaborative, Food Chain Workers Alliance, Restaurant Opportunities Center-United, DataCenter, Interpretive Media Laboratory, and Local Initiatives Support Corporation, among others. He tweets at @benpalmquist.

Any one of these stories is unjust. The sum total is staggering, as millions of people like Kim, Heather, and Alec struggle to get healthcare every year across the United States.



S. REMICK
2020

Make no mistake: the United States has the resources and knowledge to guarantee healthcare to every single person in the country, from cradle to grave.

Now COVID-19 is forever transforming human life in ways we are only beginning to understand. As this article goes to print, a staggering 273,581 people in the United States and 1.4 million worldwide have died in the pandemic.⁴ Transmission is burning faster than ever, schools and businesses are shuttered, jobs and incomes have been cut, food pantries are facing record demand, and untold evictions are looming. The emotional, social, and economic pain of the virus is unfathomable. Most enraging of all is how unnecessary this all is.

Though the pandemic was sparked by a virus, its damage is being wrought by the failure of our government and institutions to decisively implement public health measures and provide people with the economic and institutional supports they need. From Taiwan to New Zealand and Uruguay to Norway, dozens of countries have shown that the virus and its economic impacts can be controlled. By and large, the countries that have done best are those with the most economic and political equality. They provide health and economic security as a basic right of residence, not as a selective privilege, and in so doing have built people's trust in government, in their healthcare and public health system, and between fellow citizens—trust that has been essential in managing the pandemic to the degree it has been managed.

Make no mistake: the United States has the resources and knowledge to guarantee healthcare to every single person in the country, from cradle to grave; but by granting profit-driven insurance, hospital, drug, nursing home, and hospice companies the power to ration care, policy-makers have made it so that millions of people every year forgo needed medical treatment, millions more are pushed into debt and financial turmoil by healthcare expenses, and we lack adequate trust in government, in medicine, and in one another to stage an effective response to the current crisis.

There is much blame to spread around. Craven politicians stoke racial resentment to win

elections, profit-driven media and social media companies highlight conflict to drive ratings, corporate lobbyists and public relations teams warp representative government, and the entire Republican Party leadership has proven itself to be more concerned about scoring political points through repealing the Affordable Care Act and blocking Medicaid expansion than it is about getting people healthcare. But to properly understand the mess we're in, we can't just listen to what leaders say; we have to look at what they've done—at the ways in which they have chosen to structure the healthcare system.

Human Sickness and Well-Being as Market Commodities

Since around the Second World War, a series of policy decisions has turned healthcare from a fundamental human right into a profitable commodity, and sequentially concentrated enormous power in the hands of corporate boards and executives in the insurance, hospital, drug, nursing home and hospice, and other healthcare industries. There have been great steps forward—the creation of Medicare and Medicaid in 1965 was monumental—but the overall trend has been toward greater profiteering and greater concentrations of corporate power. Over the last forty years, things have gotten worse. Our troubles are rooted in three interrelated trends—privatization, inequity, and fragmentation.⁵ These trends have been produced by policy choices pushed by a profit-driven agenda.

Everyone recognizes that American healthcare is ailing. Yes, we have top medical professionals and the latest drugs and treatment for some; but we pay twice as much for healthcare as people in almost any other country on the planet—nearly one in five dollars in our entire economy—yet have worse public health systems, lower life expectancies, and far more health insecurity than people in any other wealthy nation. Healthcare companies are raking in monumental profits as

patients and families collapse under crushing medical bills, and home health aides and other healthcare workers struggle to buy food. More than 30 million people are entirely uninsured year round,⁶ another 19 million are uninsured at some point each year,⁷ and tens of millions more are underinsured—because, despite having insurance, they are priced out of care or forced to go into medical debt, or experience other financial hardship.⁸ Hundreds of hospitals and clinics in rural areas and communities of color nationwide are threatened with closure;⁹ women’s and transgender people’s reproductive health is under assault;¹⁰ whole generations face precarious retirement without guaranteed long-term care;¹¹ too many people with addiction or mental health problems are met with blame, criminalization, and neglect in place of effective treatment;¹² and Black and Indigenous people in many parts of the country face so many health injustices that years are stolen from their lives: they die an average of ten to fifteen years earlier than white people.¹³ This is an inhumane denial of people’s fundamental right to health, and an antidemocratic denial of people’s power and agency over their own bodies and lives.

Since the late 1970s, profit-seeking private industries and billionaires have reshaped our social and economic lives by shifting ever more decisions away from people and the public, and pushing us all into greater and greater precarity. Many observers label this a neoliberal era, marked by deregulation, privatization, and the withdrawal of the state from providing social goods.¹⁴ While this is true, it risks obscuring an even larger increase in new forms of control, many of which are carried out by nongovernmental private actors.

Political scientists David Levi-Faur and Jacint Jordana, and sociologist John Braithwaite, call this mode of governance *regulatory capitalism*. It is marked by a “regulatory explosion” in which the privatization and fragmentation of healthcare and other systems produce tremendous growth in regulatory agencies, rulemaking, auditing, and other regulatory institutions and practices.¹⁵ Privatization has expanded private regulation as companies, professional associations, third-party

auditors, and other extragovernmental 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.

Law professor Allison K. Hoffman similarly describes modern American healthcare as a market bureaucracy, in which idealized, empirically unfounded theories of market competition lead policy-makers to put immense policy and regulatory effort toward constructing and maintaining market competition within and between healthcare 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 bureaucracy as vulnerable to capture and at least as large as what more direct regulatory approaches would likely produce.”¹⁶ 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 twenty-four new rules and sixty-four guidance documents, and scholars, policy-makers, 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.¹⁷

Nancy Fraser, Martha T. McCluskey, Suzanne Mettler, and other feminist scholars provide a complementary 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” and working-class communities, people of color, and others, who are dismissed as “special

Since the late 1970s, profit-seeking private industries and billionaires have reshaped our social and economic lives by shifting ever more decisions away from people and the public, and pushing us all into greater and greater precarity.

Applying these lenses to the governance of American healthcare and public health reveals that the problems driving health inequities are structural in nature.

interest groups” whose needs and demands are in conflict with the supposed natural laws of the economy and with a presumed common good that is somehow distinct from their own.¹⁸

Applying these lenses to the governance of American healthcare 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 healthcare and other systems that deliver essential public goods.

The Toll of a Privatized, Inequitable, and Fragmented Bureaucracy

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

Healthcare’s market bureaucracy subsumes fundamental political decisions about who and what we value as a society and how we want to allocate our shared resources. Healthcare 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 healthcare 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.¹⁹

Overreliance on markets for researching, financing, and delivering healthcare (and housing, education, and income) also leads to failure in upholding the government’s obligation to meet our fundamental needs, and bestows the power to allocate and withhold essential care and services to private insurance, hospital, drug, and nursing home and hospice companies with financial incentives to ration access. This harms our public health and puts everyone but the wealthiest few at risk of having to forgo needed medical care or take on unpayable debt, and especially hurts “poor” and working-class people, women, LGBTQ communities, immigrants, Black, Indigenous, and other people of color, people with chronic illnesses or disabilities, and above all, people who fall at the intersection of these and other hierarchies.²⁰

Nearly Everyone’s Hurting— But Not Everyone’s Hurting Equally

Health law and healthcare’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 separate-and-unequal coverage and separate-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, while 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 healthcare.

Though often administered by healthcare companies, these bureaucratic categories are created by public policy and enforced by state power. Since the late 1970s, federal, state, territorial, and local governments have dramatically expanded militarized and bureaucratic forms of population control. They target Black, immigrant, Muslim, and other communities with policing, immigration enforcement, the War on Drugs, the War on Terror, harsh sentencing, and mass incarceration—all forms of criminalization and punishment that directly harm people's physical and mental health. And by administratively categorizing people with labels like "felon" and "undocumented," they deny people jobs, public and private housing, SNAP food stamps and TANF income subsidies, grants and loans for higher education, and health insurance. Meanwhile, they continually scrutinize and cut federal and state budgets for Medicaid, SNAP, TANF, and other means-tested programs that serve a broad section of people with low incomes—and especially women of color—and have instituted onerous workfare, eligibility, and reporting requirements, invasive drug testing, and digital surveillance, all of which are designed to stigmatize and disqualify people by the tens of thousands from eligibility for public supports. Wealthier and whiter people who receive tax subsidies for employer-sponsored insurance or itemized tax deductions do not have to endure such bureaucratic burdens, barriers, and indignities.

These systematic, racialized patterns of exclusion and inequity are not accidental but an essential strategy for justifying privately controlled, for-profit healthcare.²¹ 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 their fate. This is profitable, because it undercuts political demands for universal, publicly financed healthcare, 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—people with low incomes and people who need more care—onto public programs.

In addition, fragmentation produces enormous complexity that makes it nearly impossible for everyday people to navigate health bureaucracies, 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 onerous for legislators to monitor and hold regulatory agencies and industries accountable.²² All of this insulates power-holding decision makers, both public and private, from accountability to everyday people, allowing them to act with virtual impunity.

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 cogovernance who hold collective rights and mutual responsibilities.²³ Shrinking the permissible space for citizenship to the voting booth deprives people of democratic spaces in which they can contest over real levers of power, and dissuades people from more actively engaging.

Taken together, the privatization, inequities, and fragmentation of market bureaucracy reveal a healthcare system in which power and control are largely situated in an unaccountable private bureaucracy dominated by enormous insurance, hospital, drug, and nursing home and hospice companies. Patients, doctors, nurses, caregivers, families, and the public have largely been stripped of real freedom, autonomy, and power.

These are not natural phenomena but the result of policy choices. The United States stands alone in the wealthy world for *choosing* to leave its people uninsured and insecure, *choosing* to

The federal government has a crucial role to play in guaranteeing healthcare as a human right and a public good. But centralized administration could never on its own achieve a healthcare system that is responsive to the unique needs of such a large and diverse nation.

privatize and commodify such large swaths of the health insurance and healthcare delivery systems, *choosing* to maintain such unequal and exclusionary access to healthcare, and *choosing* to treat illness, injury, disability, addiction, mental health, reproductive care, dental care, and other health needs as individual burdens rather than mutual needs and collective responsibilities. So far we have allowed politicians to make these choices—but but we can do better.

Toward Universal, Just Healthcare: The Role of Nonprofits and Philanthropy

To realize a just healthcare system, we must drive toward two goals. First, for healthcare to truly be universally and equitably guaranteed, we must finance and deliver it as a public good, freely available to all solely on the basis of medical need. Human health needs should guide medical research, medical education, and how we pay for and deliver healthcare—not profits, poverty, immigration status, or any other factor. Second, to advance health equity and uphold democratic values, we must shift treatment decisions from healthcare companies to patients and their doctors, and shift broader governance decisions about how we meet our collective health needs from market bureaucracies to the public—and especially to communities facing the sharpest health injustices.

The Medicare for All Act (H.R. 1384) exemplifies the kinds of policy changes that are needed to transform healthcare from a private commodity into a public good. Medicare for All would eliminate profit motives from health insurance by directly paying for all medically necessary care instead of through insurance companies; requiring hospitals, clinics, drug companies, medical device companies, and other providers and manufacturers providing services through Medicare to operate as nonprofits; establishing

hospital and drug prices in the interest of the public, not profit maximization; and financing construction costs for hospitals and clinics, steering capital investments to where they're most needed.²⁴

The federal government has a crucial role to play in guaranteeing healthcare as a human right and a public good by equitably raising the revenue needed to finance the healthcare system, directing those resources to where they're needed, and taking a more direct public role in delivering care through public hospitals and clinics, drug research, drug manufacturing, and other activities. But centralized administration could never on its own achieve a healthcare system that is responsive to the unique needs of such a large and diverse nation. Along with state, territorial, and local governments, nonprofits and philanthropy have a key role to play in administering and delivering healthcare in local communities.

But it is not enough for the government to simply delegate responsibilities to nonprofits. Delegating responsibilities without clear purpose and accountability risks further entrenching the privatization, inequity, and fragmentation already plaguing the healthcare system.

In fact, many of the worst actors in today's healthcare system are tax-exempt nonprofits. The nonprofit University of Virginia Medical Center didn't just put a lien on Heather Waldron's house: it sued patients more than 36,000 times for a total of over \$106 million.²⁵ The nonprofit University of Pittsburgh Medical Center (UPMC) has been called out by the U.S. Office of Civil Rights for relocating a hospital from a Black neighborhood to a white one,²⁶ and by Pennsylvania's attorney general, who sued UPMC for denying patients care and for acting "in callous disregard of the treatment disruptions and increased costs suffered by its patients" despite receiving \$1.3 billion in public subsidies.²⁷ And all over the country, dozens of nonprofit insurance companies (which pay their CEOs an average of \$3.5 million per year)²⁸ routinely deny patients coverage and care, and fraudulently overbill the federal government billions of dollars.²⁹ All of these companies are, legally speaking, tax-exempt nonprofits, but they are

nevertheless caught up in a chase to maximize revenue, minimize costs, and claim ever greater market power—a chase that levies heavy costs on patients, their employees, and the public. Nor are these companies bad apples. Such behavior has become standard practice in the hospital and insurance industries.

Hospital and insurance companies aside, nonprofits did not produce the failures and abuses of the U.S. healthcare system; but in order to win health justice once and for all, both nonprofits and philanthropy will have to fight for and build solutions:

- They can support advocacy and organizing to win policies like Medicare for All that decommodify healthcare and treat it as an inviolable human right and a universal, equitable public good.
- They can help build equitable, democratic, accountable systems of participatory governance that redistribute power to communities facing health injustices and build greater democratic control into every part of the healthcare system.

New public policies and new models of participatory governance, as well as robust, enforceable accountability, will be critical to putting decision-making power into the hands of patients, healthcare workers, and the public overall. Far too many nonprofits are led exclusively by professional staff and boards, and far too many are more accountable to funders than to people struggling on the front lines of the healthcare system. Building a more just healthcare system will require all of us—in government, foundations, nonprofits, and other institutions—to open up meaningful spaces for democratic participation, and in so doing relinquish some control over the agendas, priorities, and decisions that emerge from those spaces.



As we enter into what will no doubt be a contentious political environment in 2021, there will be an impulse in government, nonprofits, and philanthropy to double down on professional expertise by shifting health policy decision making away from factious and often ineffectual

legislatures and partisan executives to supposedly apolitical markets and appointed managers. There will also be a temptation to sidestep the deeper, thornier problems in the healthcare system and focus instead on tackling discrete, manageable pieces and legal and technical solutions that incrementally improve outcomes. But the goal of depoliticizing health governance is 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. All the important decisions in healthcare governance are political. If we care about health justice, we must be clear about the purpose of the healthcare system, the dangers of profiteering, and what's needed to effect real changes.

Yet though we must be clear on our values and goals and what we're up against, there is no clearly defined path forward. Change always comes unpredictably and unevenly; attempts to chart the way forward raise as many questions as answers. How is it possible to transform a healthcare system in which there are so many vested interests, especially such powerful healthcare industries? What would it take to build enough power to overcome this opposition? How can nonprofits work with government to help build structures and processes to democratize decision making and enhance accountability, and how can they do so in a way that authentically shifts power to the communities that are most impacted by health injustices? Only by pushing forward together and working to answer such questions as we go can we move toward a healthcare system that holds health, and not profit, as its core principle.

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All the important decisions in healthcare governance are political. If we care about health justice, we must be clear about the purpose of the healthcare system, the dangers of profiteering, and what's needed to effect real changes.

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Crisis within a Crisis:

Health Workers on the Front Line of COVID-19

by Karen Kahn

“COVID-19 is revealing the deep cracks in the U.S. healthcare system, particularly for those who labor day in and day out to save lives and give comfort,” writes Karen Kahn. “The deregulated, decentralized market-driven system, when combined with a government that simply doesn’t care, has left workers vulnerable to illness and death themselves.” What are we going to do about it?

AS COVID-19 HOSPITALIZATIONS SPIRALED out of control last spring, thousands of people stood at windows and on front porches or balconies each evening, clapping for doctors and nurses and emergency workers who were risking their lives to care for the sick and dying. That praise was well deserved, but it left out millions of nursing aides, housekeepers, medical assistants, food service workers, and many more healthcare

workers largely invisible to the general public. Ten months into the crisis, as COVID-19 surges across the country, millions of low-wage workers who have been crucial to our COVID response are demanding to be prioritized, so that they can stay safe (and sane) and protect their families from a sometimes-fatal disease.

The Healthcare “Underclass”

Over 18.5 million people work in healthcare in the United States.¹ Of these, only about 600,000 are doctors. By contrast, nurses account for nearly four million healthcare workers. These nurses are spread along a hierarchy based on education, licensing requirements, and workplace settings. Advanced practice nurses are more akin to primary care doctors, and relatively small in number. Registered nurses (RNs) number about three million, with about two-thirds working in hospital settings. A third category of nurses, licensed practical nurses (LPNs)—sometimes called licensed vocational nurses (LVNs)—number about 607,000, with nearly half working in long-term-care settings.²

KAREN KAHN is a writer, editor, and communications strategist who spent nearly two decades as communications director for the nonprofit Paraprofessional Healthcare Institute. The coauthor of *Courting Equality: A Documentary History of America’s First Legal Same-Sex Marriages* (Beacon Press, 2007), Kahn has published frequently on the economic, social, and cultural issues affecting the LGBT community, women, and low-wage workers. Early in her career, she was the editor in chief of *Sojourner: The Women’s Forum*, a monthly national feminist news journal published in the Boston area. You can find her on LinkedIn at www.linkedin.com/in/karenakahn/ or on Twitter at @Karenakahn.



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Well-paid clinicians tend to be white and male, while nursing and low-wage healthcare jobs are filled by women, with people of color overrepresented among the lowest-paid occupations.

Doctors, with their years of education, receive the most respect and privileges of all healthcare providers, earning in excess of \$100 per hour.³ RNs, who manage much of the day-to-day care on hospital floors and in long-term-care settings, earn a median wage of \$35 per hour.⁴ LPNs work under the direction of RNs in acute care and long-term-care settings, administering medications, tracking patient status, and keeping patients comfortable; they have considerably less prestige, and earn a median wage of \$22.83 per hour.⁵ Since COVID-19 arrived, nurses up and down the hierarchy have carried much of the burden. Long concerned about understaffing, they find themselves left struggling to care for far too many patients with critical needs as the virus surges.

Nurses, however, are not the only health workers on the front lines. Another seven million workers occupy “low-wage” roles that also involve direct contact with patients. The Brookings Institution parses these workers into three types of occupations:⁶

- **Healthcare support workers:** Those who assist providers such as doctors and nurses—for example, orderlies, medical assistants, phlebotomists, and pharmacy aides.
- **Direct care workers:** Home health workers, nursing assistants, and personal care aides who support people with physical, cognitive, and social needs in nursing homes, congregate facilities, and private homes.

- **Healthcare service workers:** Housekeepers, janitors, and kitchen and dining workers in hospitals, nursing homes, and other residential care settings.

These workers earn a median wage of \$13.48 per hour. Among the lowest paid are home health and personal care workers, who earn a median hourly wage of \$11.57.⁷

Well-paid clinicians tend to be white and male, while nursing and low-wage healthcare jobs are filled by women, with people of color overrepresented among the lowest-paid occupations (see Figure 1). Across low-wage healthcare support, direct care, and healthcare service occupations, 81 percent of workers are female, 25 percent African American, and 21 percent Latinx.⁸ LPNs, next on the hierarchy, are also mostly female (91 percent), and here, too, women of color are overrepresented: 27 percent of LPNs are African American, and 14 percent are Latinx.⁹ RNs, too, are 89 percent female, but this higher-wage occupation is dominated by white women. Of RNs, 12 percent are African American, and 7 percent are Latinx. Women of color represent the majority of the lowest-paid healthcare workers: long-term-care nursing assistants and home care workers.¹⁰

Low-wage healthcare workers, including LPNs, face an array of challenges, from general lack of respect to inconsistent hours and shifts to less access to paid leave and employer-sponsored

Figure 1: Demographic profile of workers in the health care and social assistance industry, 2019

Occupation	Number of workers	Median hourly wage	% Women	% African American	% Latino or Hispanic
All health care support, direct care, and service workers	6,964,410	\$13.48	81%	25%	21%
Registered nurses	2,604,000	\$35.17	89%	12%	7%
Licensed practical nurses*	607,410	\$22.78	91%	27%	14%
Physicians and surgeons	562,440	>\$100	41%	8%	8%

Source: Brookings analysis of U.S. Bureau of Labor Statistics' Occupational Employment Statistics and the U.S. Census Bureau's Current Population Survey, www.bls.gov/cps/cpsaat11.htm.

*LPN data added from U.S. Bureau of Labor Statistics, bls.gov/oes/current/naics2_62.htm#29-0000.

About half of LPNs work in long-term care settings, alongside nearly 3.5 million nursing aides, home health aides, and personal care aides, the lowest paid and least respected among our healthcare workers.

health coverage. These are critical protections that workers need to stay home and get well if they become infected. Despite the large numbers of healthcare workers without robust benefits (e.g., 16 percent of home care aides have no health insurance, twice the rate of the general population, and 52 percent work part time¹¹), healthcare employers were exempted from the Families First Coronavirus Response Act, the relief bill passed in April that extended emergency paid leave to workers who became ill with COVID. According to the Kaiser Family Foundation, almost all healthcare workers (17.7 million) were excluded. Though the data were not broken down by occupation, the Kaiser analysis points out that among the excluded workers, 75 percent were women, 39 percent people of color, 24 percent work part time, and 18 percent were low-wage employees. While doctors and RNs are likely to have health insurance and sufficient paid leave to remain out of work for two weeks or more, that is not the case for part-time and low-wage workers.¹²

Undervalued Workers Put at Higher Risk from COVID-19

Healthcare workers with direct patient contact, including nurses (both RNs and LPNs) and low-wage direct care workers, are most at risk for COVID-19. The latest research suggests that the risk is highest for those who work in inpatient hospital settings and residential and long-term-care settings, particularly those without access to adequate personal protective equipment (PPE).¹³ As difficult as it has been for hospitals to maintain sufficient supplies of PPE, workers in nursing facilities and in home care have never been prioritized, despite their vulnerability to COVID-19. About half of LPNs work in long-term-care settings, alongside nearly 3.5 million nursing aides, home health aides, and personal care aides, the lowest paid and least respected among our healthcare workers.¹⁴

Underreporting of data has made it difficult to assess the level of infection and death among healthcare workers. The CDC reports, as of December 17, 2020, 3:05 p.m., 278,370 COVID-19 cases and 928 deaths among healthcare workers, including doctors, nurses, and those in multiple other roles in healthcare settings.¹⁵ Of those who have become ill, more than half (53 percent) have been workers of color (26 percent Black, 12 percent Latinx, and 9 percent “Asian”). Workers of color were also more likely to be hospitalized: 52 percent of hospitalized healthcare workers have been Black and 9 percent have been Latinx.¹⁶

Kaiser Health News and the *Guardian* have identified over 1,400 deaths among healthcare workers, and they also found that the majority of healthcare workers dying from COVID-19 are Black, Latinx, and “Asian American.”¹⁷ As of September 2020, National Nurses United identified 1,718 deaths among healthcare workers, 213 of them registered nurses. Of these, more than half were nurses of color, despite representing only 24 percent of all registered nurses. Among those who have died, 32 percent were Filipino and 18 percent were Black.¹⁸ Filipino nurses make up about 4 percent of the U.S. nursing workforce, and, at least early in the pandemic, they were more likely to be in intensive care units (ICUs) and doing risky procedures without sufficient PPE.¹⁹

Most striking is a recent analysis of deaths among nursing home workers, data analyzed by Harold Pollack, a professor at the School of Social Service Administration at the University of Chicago. Among the 91,000 deaths in nursing homes, Pollack has identified at least 1,000 among workers—a number, he says, that is likely an undercount.²⁰ To put that in perspective, the CDC reports 928 deaths among all healthcare workers (as noted earlier), while Pollack has identified at least 1,000 long-term-care workers—many of whom earned less than \$15 per hour—as having lost their lives due to the pandemic.

“We had one patient that we thought had the virus,” said Andrea, a hospital housekeeper. “We asked the charge nurse to send us to get fit-tested for the N95 mask that everyone was wearing. Her response was, ‘No, these are for special people.’”

Healthcare Workers Still Short on PPE

Though the data are not robust, it is clear that PPE shortages are one of the key factors that put healthcare workers at risk—and as cases surge again, the supply problem continues to be unresolved. 3M, the largest domestic producer of N95 masks in the United States, told CBS *MoneyWatch* in early November, “U.S. and global demand for PPE continues to far exceed supply for the entire industry.”²¹

In a September survey of twenty-one thousand registered nurses nationwide, the American Nurses Association found that 42 percent of respondents were coping with PPE shortages they characterized as “widespread or intermittent.”²²

While registered nurses are asked to reuse N95 masks for one or more shifts,²³ LPNs and others further down the hierarchy—who clean rooms or serve food to patients or care for elders in long-term-care settings—have even less access to equipment they need to stay safe. In a series of interviews by Molly Kinder of the Brookings Institution, health support and service workers noted how often they were overlooked in the distribution of PPE.²⁴

“We had one patient that we thought had the virus,” said Andrea, a hospital housekeeper. “We asked the charge nurse to send us to get fit-tested for the N95 mask that everyone was wearing. Her response was, ‘No, these are for special people.’ And we were just like, ‘We are here to clean the room and make sure no one else gets the virus, and you are telling us that these are for special people?’”²⁵

Nursing home workers have faced some of the greatest challenges. Nearly 40 percent of COVID-19 deaths have been among nursing home residents; yet PPE shortages have never been resolved, putting both residents and poorly paid LPNs and direct care staff at risk. A study by the U.S. Public Interest Research Group (PIRG)

found that in late August, 2,981 nursing homes nationwide “had dangerously low supplies of one or more types of PPE.” That’s about 20 percent of nursing homes nationwide reporting that they didn’t have a one-week supply of at least one type of PPE—N95 masks, gowns, eye protection, or hand sanitizer—at the end of the summer.²⁶

Vulnerable nursing assistants are already on edge, coping with post-traumatic stress from the first wave of COVID infections. Edwina Gobewoe, a certified nursing assistant at a skilled nursing facility in Rhode Island, told Judith Graham of *Kaiser Health News*, “It’s been overwhelming for me personally.”²⁷ Not only was there the trauma of losing patients, but colleagues as well. As Graham writes:

At least 15 residents died of COVID-19 at Charlesgate [where Gobewoe works] from April to June, many of them suddenly. “One day, we hear our resident has breathing problems, needs oxygen, and then a few days later they pass,” she said. “Families couldn’t come in. We were the only people with them, holding their hands. It made me very, very sad.”

Every morning, Gobewoe would pray with a close friend at work. “We asked the Lord to give us strength so we could take care of these people who needed us so much.” When that colleague was struck by COVID-19 in the spring, Gobewoe prayed for her recovery and was glad when she returned to work several weeks later.

But sorrow followed in early September: Gobewoe’s friend collapsed and died at home while complaining of unusual chest pain. Gobewoe was told that her death was caused by blood clots, which can be a dangerous complication of COVID-19.²⁸

Nurses and Nursing Assistants Demand Greater Safety and Respect

For exhausted and traumatized healthcare workers, the situation on the ground is continuing to worsen. The only winners appear to be staffing-agency nurses, particularly those who are willing to travel. Temporary critical care nurses are earning \$5,000 to \$6,000 per week,²⁹ while unionized staff nurses (about 20 percent of the workforce) are striking to bring attention to deteriorating working conditions and the failure of multiple hospital systems to negotiate contracts.

In Bucks County, Pennsylvania, eight hundred nurses went on strike the last week in November, citing dangerously low staffing levels. Represented by the Pennsylvania Association of Staff Nurses and Allied Professionals, nurses at St. Mary Medical Center, which is owned by the Catholic health system Trinity Health Mid-Atlantic, have been attempting to negotiate their first contract for more than a year.³⁰ They tried to get the hospital to come to the table during the summer months, when the number of COVID-19 patients had subsided, but the hospital did not make an offer.³¹ Now the nurses are walking out at a moment when they may have more leverage.³²

Headquartered in Livonia, Michigan, Trinity Health owns over ninety hospitals across twenty-two states, five in the Philadelphia area. Nurses at St. Mary Medical Center have been unimpressed with Trinity's management. Robert Bozek, a St. Mary critical care nurse for twelve years, says Trinity management decisions have been slowly undermining the hospital's quality of care. "Trinity is not bought into Bucks County," he told the *Philadelphia Inquirer*. "They're bought into Livonia. We need someone to keep them in check."³³

With an increasing number of hospitals owned by large state or national systems, or, in the case of for-profit hospitals, private equity,³⁴ Bozek points to a growing problem: executives, who are not rooted in the community, care more about squeezing out profits than those tasked with delivering care. For Trinity, St. Mary was a major profit center prior to the pandemic, earning \$58 million annually for the last three years and supporting outsized multimillion-dollar executive salaries.³⁵

Years of cost cutting had already strained relationships between healthcare organizations and hospital staff before the pandemic, write Dr. Wendy Dean and Dr. Simon G. Talbot, cofounders of Moral Injury of Healthcare, an organization concerned with systems that compromise providers' moral compass.³⁶ In response to changes in reimbursements and corporate ownership, the authors argue, hospital executives squeezed all the slack out of the system, increasing pressure on providers while also making it difficult to respond to even minor surges, much less a pandemic. Now, they note, the systems are facing two simultaneous cataclysms:

The abject failure of preparedness driven by the dogma that market forces can best shape health care, and the catastrophic failure at the highest levels of leadership in the U.S. to adequately address and control the pandemic. Health care workers are left to manage in the ensuing chaos feeling disposable, devalued, and demoralized.³⁷

"Nurses are totally burned out," says Deborah Burger, a registered nurse and copresident of National Nurses United, the nation's largest union of RNs. "We've normalized this crisis. We're staffing [hospitals] as if [these] were normal times and [they're] not. Nurses who used to have, say, one [patient] code per shift are now seeing that exploding to where there are multiple codes going on. And it takes a toll."³⁸

As the crisis explodes, nursing shortages are growing all over the country. Olivia Goldhill, reporting in *STAT*, notes that in one Texas hospital, 30 percent of the staff are out due to COVID-19, either isolating because of exposure, being sick, or caring for someone who is sick. The Mayo Clinic reported one thousand staff out with COVID-19 earlier in the fall.³⁹ The nurses left on the floor are under even more stress, working twelve-hour and sometimes longer shifts.

Kencee Graves, associate chief medical officer at University of Utah Health, said, "Our numbers keep increasing. . . . Our nurses feel like there's no end in sight. They get here, work 12-hour shifts in PPE, it's just this churn of seeing critically ill

Bozek points to a growing problem: executives, who are not rooted in the community, care more about squeezing out profits than those tasked with delivering care.

“We didn’t sign up to be sacrificial lambs. We didn’t sign up to fight a deadly disease without adequate resources.”

patients. And then you go to your community and see peak numbers, and having people continue to go to bars and restaurants.”⁴⁰

That’s a setup for the type of moral injury that Drs. Dean and Talbot are talking about. It is driving a wave of strikes in multiple states⁴¹ and decisions to leave nursing altogether.⁴² Though data on how many nurses have left the profession are scarce, hospital decisions to ration PPE, to extend shifts, and to ask nurses who have tested positive to return to work if asymptomatic, as happened recently in North Dakota,⁴³ have made nurses feel they are being sacrificed rather than supported. Rebecca, a nurse interviewed by NBC, explained: “We didn’t sign up to be sacrificial lambs. We didn’t sign up to fight a deadly disease without adequate resources,” she said. “We’re told we’re soldiers. Well, you don’t send soldiers to war without a gun and expect them to do their job, but you are doing that to us.”⁴⁴

The challenges faced by hospital-based RNs are multiplied for those further down the hierarchy: LPNs and low-wage nursing home and home care workers. In June, Service Employees International Union (SEIU), which has organized about seventy-five thousand nursing home workers (about 10 percent), launched a nationwide campaign to protect workers and residents in long-term-care facilities.⁴⁵ The union released survey results that showed nearly 80 percent of nursing home workers felt that doing their jobs put their lives at risk. Half the workers surveyed also said that nursing homes were putting residents at risk.⁴⁶ Most of these workers, earning on average less than \$25,000 per year, cannot afford to give up their jobs.⁴⁷

SEIU presented a list of demands in June that nursing home workers in Chicago recently put to the test. Striking workers demanded a \$15 minimum wage, double-time hazard pay, better COVID-19 testing protocols, and sufficient, medically certified PPE. After eleven days, Infinity Healthcare reached a tentative agreement with the union, which includes a \$15.50 starting wage for certified nursing assistants and at least \$1 per hour raise for workers such as cooks and housekeepers, hazard pay in facilities with COVID-19 cases, and five additional sick days

for COVID-19-related illness.⁴⁸ The union is also pressing to organize more workers to ensure they have a seat at the table in deciding their fate.⁴⁹

In addition to demanding paid sick days and sufficient staffing to protect residents and workers, SEIU wants an “end [to] legal protections for nursing home corporations and employers who have failed to protect all nursing home workers and residents.”⁵⁰ Rather than hold nursing homes accountable for their failures, at least eighteen states have passed measures to ensure corporate owners cannot be sued.⁵¹ In addition, the federal government doled out nearly \$5 billion to nursing homes to help pay for testing, PPE, and better infection control,⁵² but without accountability, it’s not clear how that money has been used. It certainly hasn’t gone to boost pay and protections for frontline workers.

Though critics have pummeled unionized workers for walking off their jobs during a health crisis, evidence demonstrates that unionized nursing homes have outperformed nonunionized homes during the pandemic. A study in New York State found that nursing homes with unions were associated with a 42 percent relative decrease in COVID-19 infection rate among residents and a 30 percent decrease in mortality. The researchers attributed the better outcomes to the effort by unions to ensure their members got access to PPE. Unions were associated with a 13.8 percent relative increase in access to N95 masks and a 7.3 percent relative increase in access to eye shields.⁵³ Better pay and benefits will also have made a difference, decreasing the need for workers to have multiple jobs or return to work when ill.

A Workforce Agenda for the Future

As the new administration takes office in January, it will be confronting the worst health crisis in a century, along with a devastated economy. There are, however, some immediate steps that can be taken to increase safety for our most vulnerable healthcare workers while also reducing the spread of COVID-19.⁵⁴ These include the following:

- **Keep workers safe:** Use the Defense Production Act to direct the production of masks and other PPE and ensure that every hospital, long-term-care facility, and home care

agency has a sufficient supply. Also, ensure regular testing of *all* healthcare workers and that *all* healthcare workers are prioritized for the first vaccines.

- **Increase wages for frontline health workers:** Bring the federal minimum wage to \$15, and require hazard pay, as well. Any additional funding for nursing homes and home care agencies should be directed to increasing wages for the lowest-paid workers, improving testing, and increasing PPE supplies.
- **Expand paid leave:** Make sure that essential healthcare workers are included in any extension of paid leave benefits in the upcoming new relief bill.
- **Remove barriers to forming unions:** Unions represent only a small minority of nurses, nursing aides, and other frontline care, support, and service workers. Unions have proved that by keeping their members safe, they also improve outcomes for the patients. The Biden administration needs to make it easier for unions to organize, and prevent corporate leaders from interfering with that process.



COVID-19 is revealing the deep cracks in the U.S. healthcare system, particularly for those who labor day in and day out to save lives and give comfort. The deregulated, decentralized market-driven system, when combined with a government that simply doesn't care, has left workers vulnerable to illness and death themselves. Whether healthcare workers become sick at work or because COVID-19 has spread so widely in their communities, we now face a crisis within a crisis, as health and long-term-care providers reckon with insufficient staffing that will put further pressure on those who remain.

As with so many challenges facing the United States today, this could be a transformational moment in which we reassess the value of our essential workers and invest in a caring future. Or, we could return to a system in which health systems gobble up more and more resources while giving back as little as possible to their employees and communities. The choice is ours.

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Profit as Primary Driver: The Daily Disaster of U.S. Healthcare

by Ruth McCambridge

“For millions of people who are older or who have a disability that requires support, this country has entirely failed to make the choices necessary to ensure that they are not exploited through the use of taxpayer dollars. Addressing the problem through monitoring and regulations has not worked on these increasingly byzantine corporations. Now, unembarrassed, they reapproach the public coffers for more money and protection, even after they have presented the public with a fail that can be measured in unnecessary deaths—not only among residents but also staff—and, on a more constant basis, enforced misery,” writes Ruth McCambridge. So, what is to be done? As this deep dive into the long-standing faults in this country’s healthcare infrastructure shows, what’s needed is a “dedicated effort based on a clear set of design principles that puts the health of the public over profit-making.”

THE *NONPROFIT QUARTERLY* HAS LONG suggested that some fields of endeavor should be removed from the for-profit marketplace—because when profit takes a front seat in those particular endeavors, they actively violate the public good and rob public pocketbooks all at the same time.

Nursing homes are one of those endeavors that should be restricted to nonprofits and/or be far more tightly regulated to prevent profiteering that is against public interest. Other such enterprises in the realm of healthcare might include

hospice, home healthcare, and the pharmaceutical industry. In each of these fields, there is clear evidence based in research of the profit motive profoundly harming the quality/cost proposition. But there are also powerful lobbying groups at work. Changing away from a system that places profits above mission and patient rights would require a dedicated effort based on a clear set of design principles that put the health of the public over profit-making.

Many long-standing faults in this country’s infrastructure have been laid bare by the COVID-19 pandemic. It is not that what we have found in its wake is new; but, at least in terms of healthcare realities, the problems caused by

RUTH MCCAMBRIDGE is the *Nonprofit Quarterly*’s editor in chief.



S. RENICK
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profit-making in at least some kinds of healthcare systems have been horrifying in their immediate human implications.

This article looks at the differences between for-profit and nonprofit health-related systems. In some cases, we have been able to do a straight across-the-board comparison—for nursing homes, for example—but in other instances we will look at emerging alternatives to profit-centered systems such as Big Pharma that have dominated important fields.

Nursing Homes as Publicly Funded Death Traps

Nursing homes used to be entirely nonprofit and government run, but now 70 percent of them are owned by profit-making corporations. And multiple research studies have indicated that there is currently a clear difference both in quality and cost between nonprofits and for-profits: for-profits charge more for a lower quality of service.¹ That lower quality of service can, at least to some extent, be attributed to lower direct care staffing levels, which translates to the most basic of services: turning people who are bedbound so they do not get sores; feeding people, and helping them with their toileting; spending time with them; and making sure that they are as active as possible.

Additionally, the level of private equity buyouts of nursing homes has increased significantly over the past few years, and new research from the University of Pennsylvania's Wharton School, New York University's Leonard N. Stern School of Business, and the University of Chicago Booth School of Business links that phenomenon with "higher patient-to-nurse ratios, lower-quality care, declines in patient health outcomes, and weaker performance on inspections."² This is not at all surprising.

Private-equity funds have a single, clear objective that distinguishes them from other types of owners, namely "making the maximum of money as fast as possible," says Ludovic Phalippou, a professor of financial economics at the University of Oxford's Saïd Business School. And if a business falls into financial distress, he says, "they will be more willing than others to cut corners in order to keep control of the business to have a

chance to make money." Cutting corners in health care, he adds, "can be tricky."³

This differential between nonprofit and for-profit homes has become much more stark during the pandemic, in part perhaps because 40 percent of all COVID-related deaths in the United States have occurred in nursing homes.⁴ Some of those deaths might be attributed to the vulnerability brought on by age, but some must be seen as the result of congregate sites that are, in some cases, inadequately staffed and prepared—sometimes even by design, because for-profit nursing homes optimize revenue over quality of care as a general rule.

In Mississippi, for instance, the *Clarion-Ledger* reports that for-profit nursing homes have had twice the number of infections and three times the number of deaths from COVID-19 as nonprofits have.⁵ A study in Connecticut puts the deaths in for-profit nursing homes at 60 percent more than in nonprofits. In that state, deaths in nursing homes and assisted-living facilities by mid-August comprised a shocking 74 percent of all of the state's COVID-related deaths—three thousand souls in all.⁶ Researchers in that case call out large chains in particular, saying that they had 40 percent more deaths than independently run facilities.⁷ Another study, in Ontario, Canada, similarly references for-profit chain ownership as a key factor in increased infections and deaths; there, 85 percent of commercial nursing homes are run by chains, and a terrifying 81 percent of all COVID-related deaths have been in nursing homes.⁸

Again, that difference in care is nothing new—nor is it negligible;⁹ so, perhaps we have no right to be horrified by COVID's uneven impact on the elderly served by for-profit versus nonprofit institutions. It is greed as a preexisting condition. The formulas are pretty straightforward—you either play primarily to what you need to fully optimize net profits, or you play to what is needed to provide quality of care and life for residents. Organizations that place profit first will err on the side of frugality of service, even, apparently, when the results are deadly, because there are few financial rewards for doing otherwise. The bald cynicism of the for-profit nursing home field is emphasized in its responses to coming under

scrutiny, which have been less about investing more as necessary and more about lobbying for less regulation and public accountability—even though it is the public footing the biggest part of the bill, through Medicare and Medicaid.

Dozens of state laws have been passed in the past year to protect nursing homes from lawsuits,¹⁰ and the industry has fought hard to avoid consequences of low care standards. As one example of the political machinery deployed, *Politico* reports that relatively early in the pandemic, Life Care Centers of America—a megachain of long-term-care facilities that included the Seattle facility that became ground zero for nursing homes as epicenters—hired no fewer than four of ex-senator Robert Phillips Corker’s (R-Tenn.) aides to lobby on COVID-19 issues among Senate leaders.¹¹ Another multistate chain, Greystone Health, is reported to have donated \$820,000 in 2019 to Trump’s failed election campaign on the same day that bids were due in a federal government auction of another chain.¹² Greystone’s nursing homes later became epicenters of death in the coronavirus crisis even as Greystone facilities made generous use of federal dollars meant for the protection of the public.¹³

In fact, as the *Washington Post* reported in August, many nursing homes that had been the subject of Department of Justice investigations for Medicare fraud received millions in Care Act money.¹⁴ It noted that the largely unconditional money was aimed at supporting the institutions rather than the residents: “Agreements between the providers and HHS include language prohibiting nursing homes from using the federal money for abortions, gun-control lobbying and the purchase of chimpanzees, but do not require homes to spend on such things as personal protective equipment or hazard pay for nurses and aides caring for covid-19 patients.”¹⁵

In May, Karen Kahn wrote for *NPQ* that “under the Trump administration, the Center for Medicare and Medicaid Services (CMS) has reduced staffing requirements and proposed eliminating

an Obama regulation that would have required every facility to hire an on-site infection control specialist. These decisions were bad to begin with, but as tens of thousands of older Americans die as a result of inadequate infection control, they appear utterly negligent.”¹⁶

Writing for the *American Prospect*, Maureen Tkacik calls American nursing homes a long-standing “hellscape,” where predators are set loose on elderly residents.¹⁷ Tkacik points out that the networks of organizations now controlling that industry are next to impossible to trace even if one were to want to regulate them:

Many profitable industries are incestuous and dominated by the sons and grandsons of tycoons. It’s just harder to track in nursing homes, whose trade publications fill my in-box each morning with incessant announcements of the buying and selling, recapitalizing and reorganizing of assets. The New Jersey consultancy commissioned to review the state’s devastating nursing home death toll found that some changed hands “multiple times in a single week.” When a registered nurse named Angela Ruckh decided to sue her old nursing home for defrauding the government, she ended up suing seven different companies. A defense attorney who tried to sue the same chain for wrongful death discovered it was spread out over 15 different entities. But all those entities originated with Formation Capital, a private equity giant founded by Arnold Whitman and his shadowy partner, Steve E. Fishman. “You could spend forever trying to untangle this stuff,” said Ernie Tosh, an Austin-based attorney who runs a side business analyzing nursing home data. “The nursing home industry as a whole should not be looked at through the lens of normal corporate America. If you think of it as organized crime it will make a lot more sense.”¹⁸

Place on top of this the racial disparities that have also acted as a determinant of infection and fatality, and the picture gets even worse.

Even looking at a single nursing home, you might find that owners act also as vendors to the business, thus creating myriad conflicts of interest. Additionally, there appears to be a culture of prioritizing the highest-margin services. This sometimes means placing residents into ancillary services they do not need but for which incentive funding exists, and stinting on the regular quality of care that distinguishes a generally good nursing home from a disastrous one. It can also lead to residents being placed in programs that are worse than useless, such as occupational therapy in hospice. A recent article in the *Washington Post* indicates that this remains the current state of play.¹⁹ Place on top of this the racial disparities that have also acted as a determinant of infection and fatality, and the picture gets even worse; as an analysis by the *Washington Post* found,

the death rate was more than 20 percent higher in majority-Black facilities compared with majority-White facilities. The analysis, which used demographic data compiled by Brown University and included about 11,000 nursing homes—nearly three-quarters of all facilities in the United States—also found that death rates increased as the proportion of Black residents increased.

Homes where at least 7 in 10 residents were Black saw a death rate that was about 40 percent higher than homes with majority-White populations.²⁰

According to *CMAJ* (*Canadian Medical Association Journal*), “If requirements to fund adequate levels of staffing affect the bottom lines of for-profit facilities, then it might be time for this care to be turned over to public and nonprofit entities.”²¹

To be fair, in Europe approximately 50 percent of deaths have been in long-term care,²² as compared to our 40 percent—but that 40 percent was unnecessary if we were paying attention to the multiple cost-benefit analyses that have been done on this country’s mix of for-profit and nonprofit nursing homes. The United States may actually have a chance to lead in this field, but not without recognizing the steps that need to be taken to center the right priorities in the programs

we support to serve the needs of people who require daily care.

Without going into a lot of detail, then, research suggests that hospice and home healthcare are in the same category, exhibiting some of the same problems associated with profit-making. It is interesting to note that before 1980, Medicare required that home healthcare agencies contracting with it be nonprofit.²³ Now for-profits form the majority of the field, but studies indicate that their quality is lower on a number of key indicators, and their costs are far higher on average.²⁴

For millions of people who are older or who have a disability that requires support, this country has entirely failed to make the choices necessary to ensure that they are not exploited through the use of taxpayer dollars. Addressing the problem through monitoring and regulations has not worked on these increasingly byzantine corporations. Now, unembarrassed, they reapproach the public coffers for more money and protection, even after they have presented the public with a fail that can be measured in unnecessary deaths—not only among residents but also staff—and, on a more constant basis, enforced misery. It appears that these problems can be effectively addressed through a choice away from the for-profit sector—in other words, through government’s simple refusal to contract with entities for whom profit is the primary driver.

Big Pharma’s Innovation Edge Gone Awry

As with nursing homes, the machinations of Big Pharma to wrest every last penny out of a dependent public while not meeting its basic obligations to them have been obscene. Here, however, there was no preexisting field of nonprofits to move out of the space, though there were plenty to seduce into positions of support. Over the years, drug prices have skyrocketed even while common and necessary drugs have gotten scarce, because there is an insufficient profit margin. Add a layer of outrageously cynical and exploitative marketing through doctors and patient advocacy organizations, and you have another government-countenanced corporate assault on people who are sick.

The drug companies have traditionally

“Drug companies should be converted to non-profit public service corporations that serve the public interest rather than being used by the 1 percent and oligarchs for unlimited profit.”

defended their pricing by insisting that the proceeds are used to invest in advanced pharmaceutical research—the stuff of which medical miracles are made—but at the same time, the prices of already available and commonly used drugs are driven well past affordability. This, then, approximates the scenario in nursing homes, where for-profit companies are chasing the windows where high profit margins open up, while neglecting to cover their most basic service responsibilities to the public.

As with the nursing homes, pharmaceutical companies have been hard at work lobbying government to optimize their position during the pandemic; but for the U.S. pharmaceutical companies, which lack the basic price controls of other countries, the coronavirus is nothing less than the opportunity of a lifetime.

Writing for the *Intercept*, Sharon Lerner describes the scrum that occurred in the nation’s capital in February and March 2020, as Big Pharma positioned itself:

When the coronavirus funding was being negotiated, Schakowsky (Rep. Jan Schakowsky, D-Ill.) tried again, writing to Health and Human Services Secretary Alex Azar on March 2 that it would be “unacceptable if the rights to produce and market that vaccine were subsequently handed over to a pharmaceutical manufacturer through an exclusive license with no conditions on pricing or access, allowing the company to charge whatever it would like and essentially selling the vaccine back to the public who paid for its development.”

But many Republicans opposed adding language to the bill that would restrict the industry’s ability to profit, arguing that it would stifle research and innovation. And although Azar, who served as the top lobbyist and head of U.S. operations for the

pharmaceutical giant Eli Lilly before joining the Trump administration, assured Schakowsky that he shared her concerns, the bill went on to enshrine drug companies’ ability to set potentially exorbitant prices for vaccines and drugs they develop with taxpayer dollars.²⁵

“The final aid package,” writes Lerner, “not only omitted language that would have limited drug makers’ intellectual property rights, it also left out language that had been in an earlier draft that would have allowed the federal government to take any action if it has concerns that the treatments or vaccines developed with public funds are priced too high.”²⁶

This unseemly positioning for more maximum profit is, of course, nothing new for that industry, which is nothing if not politically embedded with representatives from both parties acting as shills along with the president, whose approach and narrative is that, unfettered by regulation and constraint, everything works better. All of this may not be for naught, however, with some who oppose the Wild West atmosphere of Big Pharma making suggestions that, maybe, this country has a responsibility to its residents to act in their best interests where necessary medications are concerned. F. Douglas Stephenson writes:

The antidote is nationalization of the pharmaceutical industry, large increases in production of non-patent medications and ending monopolization by the Big Pharma industry. Drug companies should be converted to non-profit public service corporations that serve the public interest rather than being used by the 1 percent and oligarchs for unlimited profit. Additionally, we need comprehensive reform in the way we produce new drugs including a public program for producing needed drugs and clinical trials that would produce new

Despite all the machinations and money spent by Big Pharma in support of its monopolies over the last decade or so, nonprofit attempts to break the stranglehold of Big Pharma and its fully owned supply chain have been evolving.

non-patent medications that stay in the public domain.

Drugs would function as real social service items, not huge profit-producing goods for a tiny group of oligarchs. With this new, fundamental reorientation of drug manufacture, drugs become more affordable for patients and society, promote innovation, strengthen efforts to assure safety and effectiveness, and upgrade the evidence available to prescribers and the public. Because drugs developed and manufactured through new public pathways remain in the public domain, they could be economically produced generically throughout the world, benefiting many nations.²⁷

Despite all the machinations and money spent by Big Pharma in support of its monopolies over the last decade or so, nonprofit attempts to break the stranglehold of Big Pharma and its fully owned supply chain have been evolving. A recent white paper for Waxman Strategies brings up a number of what it perceives to be barriers to these kinds of companies, but we are not convinced that the worries they evince are entirely on the mark;²⁸ they remind us in some ways of the concerns advanced regarding news organizations going nonprofit.

And meanwhile, as also happened in the news business, individual efforts are forging ahead without worrying overmuch about impediments. Over the last few years, we have seen a number of enterprises in nonprofit pharma emerge.

One of the oldest (at two years) and largest nonprofit pharmaceutical endeavors is Civica Rx, which is the invention of a group of hospitals that found themselves consistently addressing shortages of drugs that were among the most commonly used in-hospital. The scarcity of the drugs was understood to be tied to pricing schemes by pharma companies, but it was creating havoc in the delivery of direct care, as well as extra costs, in that increasing numbers of hospitals were having to develop drug shortage response teams.²⁹ The hospital group, which has now grown to more than fifty health systems that represent twelve hundred hospitals, established

a design that would ensure that those commonly used but scarce drugs were identified and that alternative manufacturing and delivery systems were put in place to fill the pipelines of need. To provide an indication of the speed with which the effort has been able to mobilize, according to Civica's website, "Eleven Civica medications are being used to help treat COVID-19 patients, including neuromuscular blocking agents, sedatives, pain relievers, and blood thinners. Civica and its supply partners met surge hospital demand of up to 350 percent for some medications and also provided 2.1 million vials to the U.S. Strategic National Stockpile."³⁰

To help others understand the kind of development the effort required, Civica Rx has published a time line that walks people through their development.³¹ This should be an invaluable aid to others entering the field. Civica's mission is to ensure that essential generic medications are accessible and affordable for everyone.

Other nonprofit start-ups, meanwhile, are piloting efforts in drug development. Some of these efforts were recently written up in an article in the *New England Journal of Medicine*, "Sustainable Discovery and Development of Antibiotics—Is a Nonprofit Approach the Future?," in which the authors note:

Because they lack shareholders, nonprofits also face less pressure to increase drug prices and are better positioned to control postapproval antibiotic use (e.g., through the existing limited-population antibiotic drug regulatory pathway). A drug with annual sales in the tens of millions of dollars is a catastrophic failure for many for-profit companies but would be a lifeline for nonprofits, which could reinvest revenue from the drug to sustain research and development efforts. Organizations that highlight the potential of nonprofits in this area include the TB Alliance, which developed the tuberculosis drug bedaquiline and has others in late-stage clinical trials, and the Medicines for Malaria Venture, which developed artesunate and is actively developing other antimalarials.³²

As a direct illustration, the nonprofit TB Alliance has been cleared by the FDA to bring a new TB antibiotic—pretomanid—to market, specifically to treat highly drug-resistant tuberculosis, strains of which infect around 500,000 people each year worldwide. It’s one of a number of next-generation antibiotics that are pricey to produce but unlikely to generate much profit. The United Nations projects that drug-resistant infections could cause 10 million deaths each year by 2050 if a pipeline for the development of these kinds of antibiotics is not established.³³ Pretomanid is now only the third FDA-approved anti-TB drug in the past forty years.

In other words, it may be that attempts to reform a market that has proved itself to be primarily organized for profit-making is a worse use of time than attempting to promote an alternative market that is founded on principles of affordability, access, and, yes, continuing innovation—but in a way that also protects the interests of those who do not need the innovative but rather the tried and true.



We must begin to make far wiser choices about what types of organizations should be entrusted with what roles in society. Nonprofits have proven themselves to be a better choice than for-profits for many health-related endeavors, both in terms of quality and cost—but even they should be more tightly regulated for accountability.

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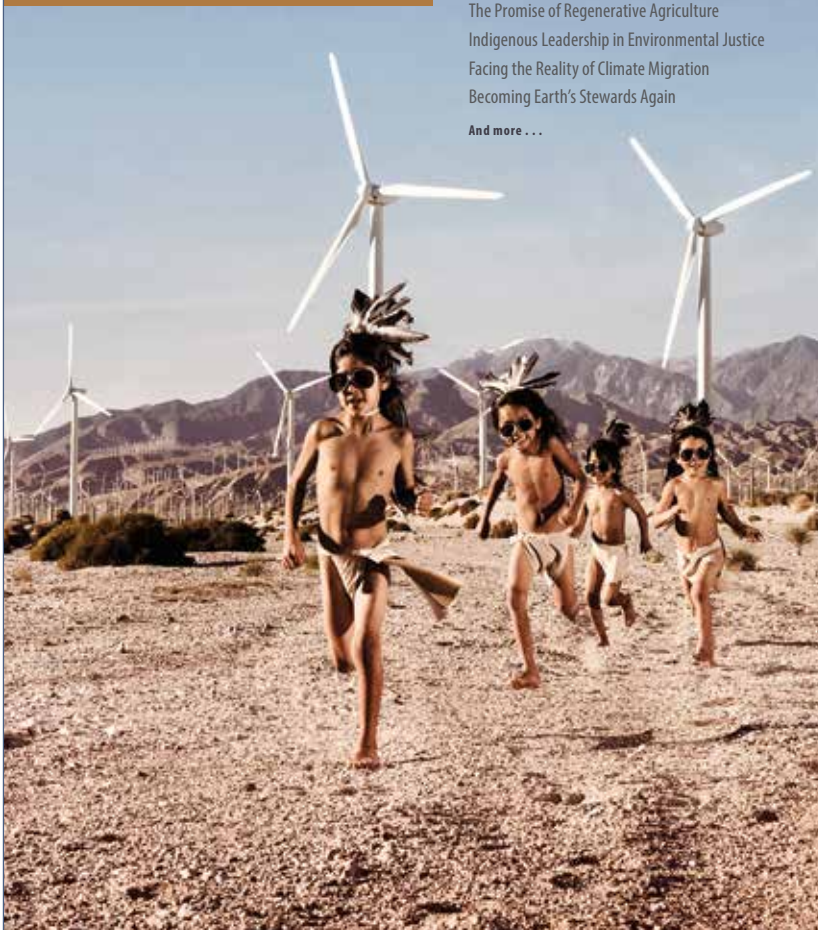
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Recognizing Racism as a Public Health Threat: A Conversation with Dr. Willarda V. Edwards

by the editors

The American Medical Association (AMA) announced this year that it was reorienting the organization around antiracist principles. As Chair of the AMA Task Force on Health Equity Dr. Willarda V. Edwards explains in this interview with the *Nonprofit Quarterly*, “What we’re saying here with this new policy on racism as a public health threat is that it’s going to require us having a shift in our thinking from race as a biological risk factor to a deeper understanding of *racism*—not race—as a social determinant of health.” And this, she says, requires reforming all of the ways in which the current system works and the assumptions that it is built on.

THE *NONPROFIT QUARTERLY* RECENTLY SAT DOWN with Dr. Willarda V. Edwards, who has been helping to spearhead an effort inside the House of Delegates at the American Medical Association (AMA) to reorient the organization around antiracist principles. This has resulted in a policy platform, made public in mid-November 2020, that took on a wide variety of issues seen as needing systemic redress. The new

policy,¹ now approved by the AMA House of Delegates, will do the following:

- “Acknowledge that, although the primary drivers of racial health inequity are systemic and structural racism, racism and unconscious bias within medical research and health care delivery have caused and continue to cause harm to marginalized communities and society as a whole.

DR. WILLARDA V. EDWARDS, MD, MBA, has been committed to organized medicine for over thirty years. She is a past president of the National Medical Association, MedChi (Maryland State Medical Society), the Baltimore City Medical Society, and the Monumental City Medical Society. Most recently, Dr. Edwards was appointed by the Maryland Department of Health to the statewide advisory board for the innovative Centers for Medicare & Medicaid Services six-year agreement on its new primary care program, Comprehensive Primary Care (CPC) Initiative. Putting patients first has been her mission during her ten-year tenure on the board of CRISP (Chesapeake Regional Information System for our Patients), the regional health information center in Maryland. After joining the AMA, in 1994, Dr. Edwards was appointed to the inaugural governing council of the Women Physicians Congress (now the Women Physicians Section), and later served as its chair. Her service to the AMA spans multiple reference committees and task forces, and includes chairing the AMA House of Delegates Committee on Compensation of the Officers and the AMA Council on Constitution and Bylaws. Elected to the AMA Board of Trustees in 2016, Dr. Edwards, as chair of the AMA Task Force on Health Equity, helped lead the way in consensus building and driving action that in 2018 resulted in the AMA House of Delegates establishing the AMA Center on Health Equity.



“The AMA is committed to pushing for a shift in thinking from race as a biological risk factor to a deeper understanding of racism as a determinant of health.”

- “Recognize racism, in its systemic, cultural, interpersonal and other forms, as a serious threat to public health, to the advancement of health equity and a barrier to appropriate medical care.
- “Support the development of policy to combat racism and its effects.
- “Encourage governmental agencies and nongovernmental organizations to increase funding for research into the epidemiology of risks and damages related to racism and how to prevent or repair them.
- “Encourage the development, implementation and evaluation of undergraduate, graduate and continuing medical education programs and curricula that engender greater understanding of the causes, influences, and effects of systemic, cultural, institutional and interpersonal racism, as well as how to prevent and ameliorate the health effects of racism.
- “Identify a set of current best practices for health care institutions, physician practices and academic medical centers to recognize, address and mitigate the effects of racism on patients, providers, international medical graduates, and populations.
- “Work to prevent and combat the influences of racism and bias in innovative health technologies.”²

The platform also addresses related antiracist practices in education and research. One of the more interesting recommendations is the elimination from medicine of the notion of racial essentialism, or “the belief in a genetic or biological essence that defines all members of a racial category.”³ The AMA pledges to, among other things:

- “Recognize that the false conflation of race with inherent biological or genetic traits leads to inadequate examination of true underlying disease risk factors, which exacerbates existing health inequities.
- “Encourage characterizing race as a social construct, rather than an inherent biological trait.
- “Recognize that when race is described as a risk factor, it is more likely to be a proxy for influences including structural racism than a proxy for genetics.”⁴

“The AMA is dedicated to dismantling racist and discriminatory policies and practices across all of health care, and that includes the way we define race in medicine,” says AMA board member Dr. Michael Suk. “We believe it is not sufficient for medicine to be nonracist, which is why the AMA is committed to pushing for a shift in thinking from race as a biological risk factor to a deeper understanding of racism as a determinant of health.”⁵

Dr. Edwards tells us that the new, explicitly antiracist position has a two-decades-long history involving many internal and external stakeholders who have worked for years on issues of health equity.

Externally, she says, the AMA has worked with the National Medical Association—the African-American physicians organization that was established in 1895 because the AMA was a whites-only organization⁶—and with the National Hispanic Medical Association. Internally, she says, groundwork for this recent advance had been laid out by the Commission to End Health Care Disparities, on which it collaborated with both organizations starting in the 1990s. In essence, the work they started then has continued, interrupted in 2016 by sunseting the Commission and continuing its work in the already established Minority Affairs section of the AMA—a move that did not last long. As Dr. Edwards notes:

By the following year, in 2017, our House of Delegates was clear that we needed to bring the commission back—that there was a lot more work that needed to be done. In 2017, we developed recommendations to create a center on health equity within the AMA. The House [of Delegates] approved it in 2018. In 2019, we appointed Dr. Aletha Maybank to be head of our Center for Health Equity. And it wasn’t just another section or another part of AMA—it became embedded in all AMA business units. But then in June of this year, our AMA board of trustees acknowledged the health consequences of the violent police interactions, and denounced racism as an urgent threat to public health. And we proposed then and there to take action to confront systemic

racism, racial injustice, and police brutality. And in November, when we had our usual fall meeting of our House of Delegates—which sets policy for the organization—this policy unanimously passed, and culminated with AMA recognition of racism as a public health threat.

That resolve, of course, was only hardened by the degree to which Black and Brown communities are disproportionately affected by COVID-19. Dr. Edwards points to the fact that the African-American community makes up only 13 percent of the U.S. population, yet represents 25 percent of the COVID-19 deaths; and the Latinx community, if categorized monolithically as 18 percent of our population, represents 33 percent of the new COVID-19 cases. But the racial disparities that cause real differentials in health are so all-inclusive, Dr. Edwards says, that you have to back way up and ask what all the factors are that go into, say, a thirty-year difference in life expectancy between one zip code and another immediately bordering it, as you find in, for example, Chicago.⁷ For that, she says, you cannot just look at issues like better healthcare access, which is certainly a concern in that city, but must also look to the support of business ventures, affordable housing, education, and jobs.

“So what we’re saying here with this new policy on racism as a public health threat is that it’s going to require us having a shift in our thinking from race as a biological risk factor to a deeper understanding of *racism*—not race—as a social determinant of health,” explains Dr. Edwards. This, she says, requires reforming all of the ways in which the current system works and the assumptions that it is built on. Those assumptions show up daily in the way the fact of race is reported on in medical practice, and the ways in which research is framed and done, and a myriad of other learned but biased behaviors. And then those assumptions replicate in sometimes pernicious ways in seemingly “neutral” functions of the system, like technology: “Digital tools that we use in medicine should ideally level the playing field for patients, but we want to make sure that the future technology is not built with the current social and unconscious bias, but is truly,

confidently, based in science and the promotion of health equity.”

In the end, the changes that will be required in the implementation of this new internal policy are not only dizzying in their number and complexity but also appear to be elemental—that is, they would change the whole face of medical care. And, despite the fact that this resolution has been passed unanimously, the proof will, as they say, be in the pudding—up to and including the group’s active positioning on national health policy. Dr. Edwards believes that dismantling racism and all of the ways it works to reinforce itself is the only way forward to truth, healing, and reconciliation, but she agrees that there is a long road to travel from here.

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Nonprofits, Transparency, and Staff Support in 2020: Three Case Studies

by Kori Kanayama

“Our professional and personal lives merged in 2020,” asserts Kori Kanayama, “refusing to maintain the separation imposed by most workplace cultures.” How are nonprofits responding? These case studies are examples of how some organizations have been seeking to make support of their own staff part of their mission.

TRANSPARENCY RULES ARE EMBEDDED in the governance structures of the U.S. social sector, because nonprofits are tax-exempt organizations with missions of public social trust. Compliance with federal financial transparency and public accountability stipulations is a threshold requirement for U.S. nonprofits.¹ Nonprofits operating in good faith strive to meet this legal and financial framework by acting and communicating honestly about the nature of their work and how they do the work.

But how might nonprofits practice transparency toward their primary internal constituency—i.e., the staff who daily carry out their missions? What might be some of their thinking around their obligations to their staff?

These questions have particular poignancy currently, as many nonprofits are facing existential challenges, navigating the pandemic, the heightened racial justice crisis, climate emergency, and the economic free fall all at the same time. Which nonprofits are looking out for the workers on the front lines of social mission work?

Knowing that organizations exist whose practices include centering worker interests, I sought to lift up their internal practices in order to demonstrate what is possible in terms of transparency and staff support at a time of crisis in the nonprofit world. I took a qualitative case studies approach, interviewing a small, representative group of three executive directors who were willing to put their stories “on record.”

The chief executives I interviewed work in human services and community development in the border region of San Diego County, worker advocacy in the Inland Empire region of Southern California, and capacity building in the greater Seattle area. Their stories, which include the personal journeys that led to their current positions and the organizational perspectives of their staff, provide intimate access to the framing for each organization’s programs and internal culture.

The forthrightness with which they shared with me the institutional push to do right by their staff is itself a model of transparency. The descriptions, by no means exhaustive of all that their

organizations do, represent the executives’ viewpoints and provide snapshots of how these organizations are acting to support their staff during these challenging times.

CASE STUDY 1: Lisa Cuestas, Casa Familiar, San Ysidro, California

Personal Journey

“I have worked for twenty years at Casa Familiar,” says CEO Lisa Cuestas. “I came originally as a volunteer. I had just moved to San Ysidro from Tucson, Arizona, with my husband, who took an Enterprise Rose Fellowship, and Casa was the LIHTC [Low-Income Housing Tax Credit] partner, the primary federal funding vehicle for subsidized rental housing. I didn’t know anyone, and Casa became an entry point. I became a youth coordinator for the teen center. I went through seven different roles before becoming the CEO. I was the COO for the previous CEO for seven years.”

Living Rooms at the Border: Representing Casa’s Mission

“It was challenging when I became the CEO, because we were cash poor after

acquiring properties, and we were stabilizing through LIHTC projects. Living Rooms at the Border, a mixed-use [residential and commercial] project, was in planning for eighteen years and our first NMTC [New Market Tax Credit, another federal funding vehicle] project. We rescued a historic church, [and] incorporated a classroom space with UCSD [University of California, San Diego], to house some service spaces and ten housing units. It's also a social enterprise training site. We secured financing because we identified a steady stream of revenue for the services.

“Casa was building projects again after not doing development for a while. We had board support and a good consultant. We wanted the Living Rooms project to be a reflection of Casa’s history for the past forty to fifty years. Everything we use to guide us in our mission and vision needed to be in this project: organizing and engaging residents, using arts and culture, environmental justice. The pieces helped define the role of that project in the community, doubling down on Casa Familiar’s mission.

“As the leading social service provider in a park-poor area, we got the support of donors and the PARC Foundation. The conversation can’t be just about affordable housing; it’s also about quality of life. The church is now a black box theater. Seniors, families, and couples live there. Baristas get training on site, and access to financial education and coaching.

“We heard that the rents were still too high as we were doing that project. This was frustrating, because we didn’t want to displace folks. The idea of using AMI [area median income, the midpoint of a region’s income distribution used to assess housing affordability] ruins everything when it comes to ‘real’ affordable housing. AMI for the City of San Diego is \$60,000 to \$70,000 for a family of four. San Ysidro’s AMI



CASE STUDY 1: Lisa Cuestas, Casa Familiar, San Ysidro, CA

is \$30,000-plus. No one is building [for folks making] 30 or 40 percent of AMI, because it doesn’t pencil out.”

The Journey to Do More

“We are looking at [developing a] community land trust as our next journey. How do you advocate for something better in a broken affordable housing system? The system of building affordable housing and pulling together financing doesn’t work.

“[In low-income communities, there are] new norms of individuals having to pay 40, 60, 70 percent of income toward rent. I question why we have to keep feeding support systems while health disparities widen. As a part of a coalition led by LIISC [Local Initiatives Support Corporation] San Diego, we’re starting to look at how single-family zoning is a product of racial inequities and a clear evidence of redlining. As we were shutting down in the pandemic, we sent a letter to San Diego City Council.”

Casa Operation Post-Black Lives Matter Protests and COVID-19

“We said we have to be advocates and put it all forward, because communities of

color are experiencing painful inequities. We took steps to keep providing services without putting people with underlying conditions on the front lines. We told the board in March that we will use PPP [Paycheck Protection Program] loans to not lay anyone off. There has been no conversation about furloughs. One third of our staff have long-term tenure. This is not the time to lay them off.

“We really operate like a family [with an attitude of] ‘I got your back.’ When we have to shift to meet needs, we do it by individuals stepping up and others supporting. This helps with the generational dynamics. We’re community organizers first, perform in our positions second. Our core is in advocacy and community organizing, the highest priority above anything else.”

Staff Support

“Our staff play multiple roles, sometimes doing too many things. You can get very sick in the pandemic when you are wearing five different hats. We had to quarantine when an exposure happened. Because the pandemic adds different stressors, people’s mental health is suffering. Our group of *promotoras* [community

health workers], who are super organizers, said they want to connect in person more. But we rank third in San Diego County for COVID-19 cases.

“We added a monthly wellness day benefit, because staff were not taking sick or vacation days. We’re all overworked, under additional stress. We told staff to take their wellness days and not check their e-mail. Because of the constant connections to the work, we have to watch for not ever disconnecting, and honor different social norms.

“The leadership team will do a retreat in January to look at how to support ourselves, so we can keep being there for the community. We are the lifeline for some community members. They see us as an extension of their family, though no longer physically ‘there’ in the pandemic. We might bring in wellness experts to work with us.”

Staff Salary Legacy

“We have forty-two staff members, most of whom are direct social service providers, spread over six spaces in San Ysidro. In the past, our norms of annual reviews and capacity building weren’t structured. Casa had been contributing to inequality, because our health benefits package was uncompetitive and inadequate. [Staff] were not earning enough for a long time. There was an internal struggle for the CEO to model our values with the staff. We convinced the board to take bold steps. Nobody wants to look at how people got three raises in twenty years.

“Staff put up with a lot because ‘it’s family.’ We recognized that we haven’t been paying livable wages, given the rents or mortgages our staff have to pay; now, we make sure our wages are not low-income wages. Our mission [now] is to enhance compensation.

“This is the first time we can make an investment in Casa Familiar employees. It’s a big change.”

Next Steps

“A project partner trying to pull cash out of our building became a huge reflection moment for us to stay true to the mission. We fought partners, renegotiated terms, and made it too difficult for them to sell. We said that without a strong first right of refusal and a straight split of the proceeds, we wouldn’t go along with it. Because of the deal we made, we will receive an influx of revenue. The housing is still there, getting additional improvements. This connects to improving quality of life, and allows us to earmark funding for community benefits projects and a land trust, to develop a business plan. We will build permanent affordable housing.

“We will also apply this revenue to enhance staff compensation and benefits across the board, allowing us to lift the salary freeze that we instituted to ride out the pandemic. We are fortunate to be in the position to support our *familia* as a social justice organization.”

Case Study 2: Sheheryar Kaoosji, Warehouse Worker Resource Center (WWRC), Ontario, California

(Disclaimer: The author’s daughter volunteered briefly with the organization in May 2020.)

Personal Journey

“I’m the executive director of WWRC,” says Sheheryar Kaoosji, “a cofounder with Veronica Alvarado, our deputy director. We filed incorporation in 2011, but didn’t scale up until 2014.

“I began working in nonprofit organizations after I was involved as a student organizer at UC Santa Cruz in the mid-1990s, during a time of backlash toward people of color. First, I focused on communities fighting displacement and gentrification in the Mission District in San Francisco, through research and policy work supporting organizing. I also

worked with the UCLA Labor Center, organizing workers and doing research in the disadvantaged parts of California. I learned about farmworkers and food processing, and worked on a campaign in the Inland Empire, organizing warehouse workers, which led to setting up WWRC.”

About Warehouse Worker Resource Center

“Our work is about the nexus between the community and workers, to hold big companies like Amazon to account, [in terms of] the way they impact the broader community. We organize insecure or part-time workers, such as drivers and warehouse workers in the logistics industry, through advocacy and action that improve conditions. We fight [for workers claiming] wage theft, [for worker] health and safety, and we engage the media [in our efforts].

“Amazon is rocketing into the stratosphere, consolidating its power; yet workers are not stable; [all is] at the whim of the company, with no predictability. The state agency that oversees worker safety has been systematically dismantled [over the past] fifty years. Workers need us, because even in the agency’s best moments, they’re not particularly effective. Our biggest impact is to help workers through developing a model appropriate to the Inland Empire and the sector.

“We feel that we’re in the right place, holding the perspective of cross-issue solidarity, building something to last for the long term. Workers all stand together to improve conditions. We are also standing on the shoulders of people who organized here autonomously, and across the world. We learn from them and listen to the workers we organize.”

Transparency

“We’re still figuring it out, think we can do it better. Most of our staff are new—we grew from four to nineteen in a year, so we haven’t had a culture for long,



CASE STUDY 2: Sheheryar Kaosji, Warehouse Worker Resource Center (WWRC), Ontario, CA

creating official and unofficial systems to meet different needs.

“We make sure our staff understand how we make decisions, have clarity on which ones staff control. Staff had a voice in how we set our COVID-19 prevention policy. It’s an ongoing process, where we check in to see if it’s working. We meet every day at nine a.m., offer multiple ways to raise issues, and will create more vehicles for our staff to have a say.

“We operate the Justice HUB, shared with several community organizations.² We coordinate with them and our staff in COVID-19 to make sure they have a safe workplace. We figured out together what we can do at home. We responded to the demand for our services because, in COVID-19, rules were not written, and hundreds of workers called us and asked. We are clear about the need to protect our own workers.”

Staff Support

“Our senior staff are refugees from labor unions and nonprofits with toxic work environments. We consider ourselves part of the labor movement, and must have good working conditions. Though our pay is not as good as the unions with pensions, we protect and support our

staff, and intentionally create evolutionary and supportive space to keep staff.

“Organizers tend to work long hours. We organize low-wage workers and [otherwise economically disadvantaged] people, who work longer hours than anyone. That’s unsustainable for everyone. Because there’s an infinite amount of work, we must balance a strong work ethic with rest. We make sure people are taking breaks and finding space to regenerate.

“We communicate constantly about where we are and what we are doing. We work really hard, because [it is] our privilege to work at a place that pays a decent wage. If things are great, sometimes we work eighty hours a week. There’s an ebb and flow to our work, and we can’t go hard every day, so we rest when we can. The pace forces us to be flexible. That’s the way the movement goes—it’s broader than just a job.”

Addressing the Middle Gap

“Across labor organizations, we have a middle gap. The senior people in leadership tend to be locked in, with a lot of young people coming into the movement. They can do organizing for a while and burn out if they don’t see an opportunity

to move up. And there’s a bit of brain drain of folks leaving the Inland Empire for better opportunities.

“We established a tight wage scale, where the chief executive is not making more than double the entry-level person, to provide enough for entry- and mid-level workers. They might be in their thirties, have a kid. We need more workers, and the middle tier is the greatest problem. We pay well compared to some nonprofits—make up for wages with other things, like decent healthcare with family coverage, and a 403(b) plan. The overtime rule sets the base, so we have to do \$50,000 a year or better.”³

Being a Part of the Labor Movement with Immigrant Roots

“We are organizers and campaigners. A lot of us are children of immigrants, first in the family to go to college. We have had personal experiences comparable to the workers we organize. Our staff want to change conditions that their parents went through—[they] have the heart and drive plus the brain.

“People have ambitions. I was born in 1977, at a cusp of my generation. Younger people are much more radical, still figuring out what they want. They don’t expect to work at one place for very long, but we want to keep people five to ten years, to have a workplace of rigorous program quality. People should get a say in how their work plays out. Our staff talk with people all day. We constantly ask, ‘What did we learn?’—to jointly make meaning of what we’re hearing, so we can take effective action.”

Cultural Awareness in the Movement

“We are building a culture of accomplishment and focus on fighting [powerful corporations]. People get gratification from [this] work. We help people to see that it is very important, and we want to win. It has to be a fit.

“We want to see that they’re staying in the movement or in the region. We care about that. I worked for LAANE [Los Angeles Alliance for a New Economy], a nonprofit [that’s been] around for twenty-five years, where I learned what to do and what not to do. I think they set up a primarily feminist culture, and some of their staff have been there for twenty years. Black Lives Matter, as a movement, is primarily women-led. They seem to process internal tumult differently compared to other movements.

“The majority of our staff are women. Veronica has led on our culture. [We know to pay attention to culture because] some unions self-destructed. We have a traditional hierarchical structure. The leadership sets objectives. We figure out how we get there together, with everyone.”

Case Study 3: Ananda Valenzuela, RVC, Seattle, Washington

Personal Journey

“I’m the interim executive director of RVC [formerly Rainier Valley Corps],” says Ananda Valenzuela. “Having grown up in Puerto Rico, I know what it’s like to live in a modern-day colony, with politics far more corrupt than what we’re used to here. And it was also a very diverse place, with folks from different backgrounds, which inspired me to get involved in work that centers equity—putting power in the hands of those most impacted by inequitable systems.

“I think of nonprofits as a vehicle for change. Good capacity building can have a multiplying effect, fueling leaderful networks, a concept championed by Change Elemental.⁴ The work will take many [acting] from different angles. This thinking brought me to my current role.”

About RVC

“RVC is a capacity-building organization both led by and serving people of



CASE STUDY 3: Ananda Valenzuela, RVC, Seattle, WA

color in the greater Seattle area. We do capacity building for forty partner organizations. Our approach is described in a *Stanford Social Innovation Review* article [by April Nishimura et al.] about transformational capacity building.”⁵

Transparency

“Transparency is core to our work, because integrity and transformation are core values for us. In order to be a learning organization,⁶ we have to be able to know and share information. When information gets stuck and doesn’t flow freely, we can’t make good decisions—like the concept from family systems theory of secrets being like plaque in your arteries.⁷

“Transparency also has a deeper meaning for us, because we have a distributed leadership structure.⁸ For people on the front lines to make good decisions, we need to have transparency.

“There’s always complexity. We hold the value of transparency in balance with trust. Someone from a partner organization might share something with an RVC staff member that they may

not want shared with anyone else. We hold our trust with partners sacred, and support our partners in understanding how we operate, so that they can trust a staff person to hold their information securely.”

Staff Support

“By centering wellness, we aspire to give our staff a sense of safety and a deep acknowledgment that we care about staff as whole beings. We make sure to provide good healthcare that covers therapy costs, and we take extra steps when things are hard—like hiring an art therapist to work with staff individually soon after the [COVID-19] quarantine began. This is our whole-human approach to work⁹—meaning when staff walk into our workspace, they don’t have to hide any aspect of their identity.

“In this moment, our communities are dealing with multiple crises, such as the continued murders of Black people at the hands of police; immigrants and refugees inhumanely imprisoned; and a crumbling economy. There are so many intersecting issues of safety and

wellness for people of color. We are trying to take a holistic approach.

“Another example is our flexible paid time off policy, offering twenty-three days of paid time off a year that staff can use however they wish. We also make sure to pay a living wage, not a minimum wage, and offer extensive benefits with a \$0 deductible healthcare plan. Centering staff wellness results in different decisions. We are also constantly doing internal equity work; for example, we are currently focusing on how we center Blackness. No matter who you are in the world, there’s always more work to be done around equity and inclusion.”



The three EDs’ reflections share the following characteristics:

- A mindset that achieving a worthwhile objective is a continual journey;
- Understanding that awareness of culture is a key element of rigorous program operations;
- Orientation toward being a workplace that addresses compensation, benefits, and everything that affects morale;
- Desire to be in mutuality with their staff, who are whole beings at work; and
- Evolutionary approach to supporting staff during a national health and economic emergency.

The EDs back up the common acknowledgment that staff make mission possible, by asking themselves if how they treat their staff aligns with their values. They want to figure out what a good workplace looks like—not just *for* but *with* their staff. Most remarkably, the lens they use, of “modeling organizational values with staff,” authenticates their approach to achieving social missions.

Lisa Cuestas deserves special mention for her (and Casa Familiar’s) modeling of transparency and vulnerability in voicing regrets about past practices and willingness to make amends by putting their money where their mouth is, so to speak, during the COVID-19 pandemic. Such decisions based in truthfulness build bonds based in trust, and strengthen internal culture.

All three EDs believe that centering staff is not just good for business but also integral to achieving their organizations’ missions. This stance seems especially vital when all of us are individually trying to stay healthy, and when taking care of our families and communities is our highest priority. Our professional and personal lives merged in 2020, refusing to maintain the separation imposed by most workplace cultures. These case studies demonstrate that practicing an organization’s values with transparency and in wholeness vis-à-vis staff is a viable approach for nonprofits—or any institution—to keep evolving amid the existential challenges of our time.

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- KORI KANAYAMA** is the founder of Kanayama Partners, organizational consultants who specialize in intentional process consultation—the creative art of eliciting the outcome the client seeks by accessing their highest intent through inclusive and transparent participation, to facilitate growth, learning, and meaningful change.
- To comment on this article, write to us at feedback@npqmag.org. Order reprints from <http://store.nonprofitquarterly.org>.

6 Steps for Nonprofits to Be Effective Advocates of Community-Supporting Policy

by Jennifer Njuguna and Heather Hiscox

As Njuguna and Hiscox write, “Failure to engage in policy advocacy results not only in missed opportunities toward authentic solutions but also maintains the status quo set forth by others.” It is time for nonprofits to recognize their vital role in providing human services, and recognize their power as a united force.

HISTORY HAS PROVEN THAT, IN THE absence of grassroots advocacy, policy can have significant, long-lasting destructive effects, especially on marginalized, disenfranchised communities. Nonprofits are well positioned to offer solutions and policies that address the spectrum of challenges our society faces—and in the current environment, it is imperative that nonprofits engage in policy advocacy, and that funders support them to do so.

While some may think advocacy simply means politics and protest, it encompasses a far broader variety of actions that nonprofits and funders can incorporate into their work, including the following:

- Developing strategic partnerships and coalitions
- Organizing, mobilizing, and creating spaces for communities to be empowered
- Advancing education campaigns to ensure an informed public
- Influencing through lobbying (yes, nonprofits *can* lobby) and sharing

perspectives regarding laws, legislation, regulations, and government budgets being proposed, particularly at the state and local levels

- Making use of impact litigation
- Leveraging expertise to bring about change

Failure to engage in policy advocacy results not only in missed opportunities toward authentic solutions but also maintains the status quo set forth by others. A nonprofit that provides mental health services to students, but does not engage in the local city budgeting process to advocate against budget cuts to these services, helps to facilitate an environment where underfunding prevails, resulting in a dearth of vital services. An example of the opposite approach is the New York nonprofit Cypress Hills Development Corporation, which has used its platform to advocate against such cuts, and in doing so, enlisted the support of New York City Council member Mark Treyger to help advocate for support in the city budget.¹

Here are six effective advocacy steps nonprofits and their funders can take:

1. Collaborate and Build Partnerships

We don’t like to talk about it, but the nonprofit sector suffers from extreme competition. Resources are limited, and nonprofits—even in (indeed, *especially* in) the same mission area—must compete with one another to stay in business. In this environment, collaborations are often inauthentic and ineffective. We need to break down the competitive silos in the sector and orient our efforts around collective action and shared power, and funders must work to eliminate this toxic dynamic. In other words, nonprofits build power in numbers and strengthen one another in an environment where systemic change takes time and where victories do not come easily.

Even though there is often a narrative about lack of or limited resources, the nonprofit sector wields a significant amount of influence and power, which as of 2017 (the latest data available)

employed nearly 12.5 million people.² Further, according to the Urban Institute, as of 2019 the nonprofit sector had total assets reaching \$3.79 trillion dollars (nonprofits registered with the IRS); in 2018, charitable contributions reached \$427.71 billion; and in 2016, the sector contributed an estimated \$1.047 trillion to the U.S. economy, comprising 5.6 percent of the country's gross domestic product (GDP).³

And let's be honest: the government often relies on human services nonprofits to provide vital services that government is responsible for providing. It's up to nonprofits to recognize this, partner on common issues—through coalitions, strategic partnerships, joint ventures, and other informal and formal designs—and claim power as a united force.⁴

2. Stop the Fear, Be Informed, and Ask the Bigger Questions

In order to address what prevents so many nonprofits and foundations from engaging in policy, it is important to ask, "What/who are we afraid of?" Generally, organizations are most worried about upsetting their funders, donors, and board members, and this *who* connects to the very power dynamics that inhibit the use of policy as a strategy for increased equity and justice.

It can feel like too great a risk to jeopardize funding sources, as these enable nonprofits to do their work. However, now is a time for nonprofits and funders alike to strike while the iron is hot. Philanthropy is having a reckoning of its own, and is rethinking some of its old practices and who and how it funds. This is a perfect opportunity to push past the fear around funding and have honest conversations with funders, donors, and board members about what is needed to have true impact.

Some organizations also fear losing their 501(c)(3) status, or fear facing IRS penalties of excise taxes—but these fears

are unfounded. There is an abundance of websites, experts, and organizations whose job it is to help support organizations with their policy efforts.⁵ Regarding the restrictions placed on the sector for its use of financial resources to effect political change, why this is the case is also worth a deeper conversation. It is interesting to note, for example, that in a five-year period (2007–2012), "200 of America's most politically active corporations spent a combined \$5.8 billion on federal lobbying and campaign contributions. A year-long analysis by the Sunlight Foundation suggests, however, that what they gave pales compared to what those same corporations got: \$4.4 trillion in federal business and support."⁶

Nonetheless, to be clear, as the National Council of Nonprofits states, the "prohibition against political campaign activity (defined as 'supporting or opposing a candidate for public office') is SEPARATE from lobbying or legislative activities, which charitable nonprofits *ARE* permitted to engage in."⁷

At the end of the day, we must break through the mindsets and internalized ways of working that are motivated by scarcity and pandering to power.

3. Intentionally Build Advocacy into Nonprofit Work

What if, when a nonprofit was created, a strategy for policy work was expected along with the budget and bylaws? What if policy advocacy was a necessary component included in strategic and other planning efforts? What if nonprofit board members and staff received regular training in advocacy and were expected to engage their networks in this work? What if nonprofits listened to their communities and aligned policy with equity and justice?

Asking these questions gives nonprofits the opportunity to reimagine their work and openly enlist the support of willing funders, and it results in a

world where advocacy is a given. The possibilities are many. We must stop treating policy work as a "nice to have" or another "I'll get to it when . . .," and instead make it the charge of all nonprofits to *engage*. Building advocacy into nonprofit work through intentional planning normalizes it.

4. Diversify and Build Inclusive Organizations Tasked with Social Change

We'd be remiss if we didn't specify that the nonprofit sector as a whole must do more to ensure it actually reflects the communities in which nonprofits are situated and serve, as these are the organizations that are truly in proximity to the challenges and, ultimately, the solutions. If "79 percent of Congress is white,"⁸ 87 percent of all nonprofit executive directors or presidents are white,⁹ nearly 79 percent of nonprofit board members are white,¹⁰ and "92 percent of foundation presidents and 83 percent of full-time staff members are white,"¹¹ why are these the people in charge of creating change for communities that look nothing like them? This homogeneity in power creates homogeneity in norms, practices, networks, and decision making that have become hegemonic and that reproduce practices of colonization, all from a sector created to "do good." Tené Traylor, who oversees grantmaking at the Kendeda Fund, put it best when she said, "We still trust white folks to tackle black folks' problems."¹²

This chasm of representation is important, because core to the work of policy and advocacy is self-interest: we fight for what impacts us or those we care about. To stop perpetuating inequity, nonprofits and funders must examine their internal makeup and practices and ensure that Black, Brown, and Indigenous communities are a part of the infrastructure as staff, leadership, and board members.

5. Fund Policy Work, Movement Building, and Black-, Brown-, and Indigenous-Led Organizations

While there are myriad power paradoxes in the nonprofit sector, one that is most prevalent is the chasm between those closest to the pain and those closest to the resources. How is it that the least amount of support goes to those leaders, organizations, and communities that are suffering the most? Far too often, the organizations closest to the lived experience of underinvested and undervalued communities, and best positioned to engage in policy and movement building, have been left teetering on the edge of existence.

Lori Villarosa of the Philanthropic Initiative for Racial Equity (PRE) hit the nail on the head when, regarding COVID-19 response, she wrote: “Small grassroots organizations with direct roots, access, and accountability to their communities have been busy taking calls, visiting affected residents, and handing out supplies, while dealing with the challenges of their own families. As a result, they are rarely the first in line in responding to funding opportunities. . . . The likely result: philanthropy ends up too often falling short of desired outcomes, while racial inequity and injustice are all too regularly perpetuated.”¹³

While there has been a substantial increase recently in the amount of funds given to movement organizations and Black-, Brown-, and Indigenous-led organizations, prior to the recent outcries for support, funding that reached people of color has been less than 10 percent and stagnant.¹⁴ And, one must wonder what will happen to those funds in the future as other priorities emerge?

Funding must be directed to reach beyond program and service work and drive systemic change. While as a sector

we struggle to assign capacity to policy work, year after year we continue to lose progress, and entire swaths of our sector suffer.

6. Empower Communities to Engage in Policy Work

Regardless of budget size and staff size, nonprofits have the power to come together and share information, and with such tools at their disposal, can be a part of the critical work of convening, sharing with, and empowering their communities to engage in policy work. Many of our greatest societal changes have come directly from the people, rather than those with the most money or political power, and nonprofits can certainly be a link connecting communities that have traditionally been marginalized from the levers of power.

By ensuring that the community at large is kept abreast of how the environment is shifting, so that they are ready to respond, nonprofits will meet the responsibilities they have to their constituents by centering them in the policy work.



What if the nonprofit sector activated its powerful voice and the voices of the communities we serve, and shaped the policies and the resulting practices to create deeper, more sustainable change? What if funders supported nonprofits to do that work? We say we want to create a more just and equitable world. The time to do this work is now.

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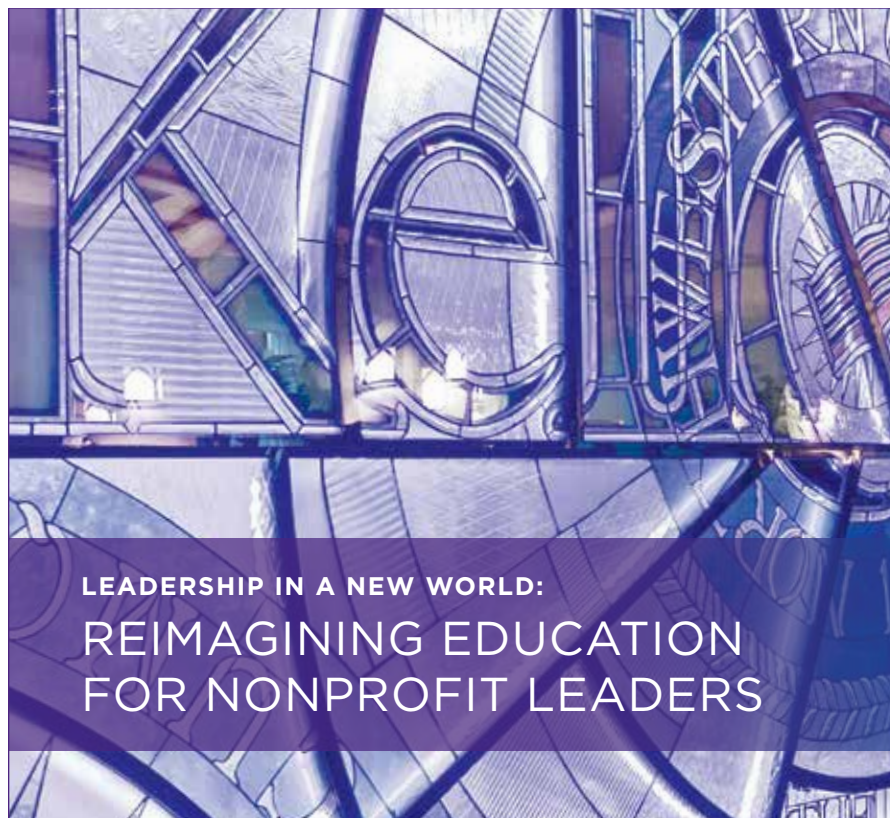
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JENNIFER NJUGUNA, Esq., is an equity- and inclusion-focused attorney who is passionate about empowering communities and supporting mission-driven organizations. Njuguna is COO at Common Future, and consults with nonprofits and small businesses through her practice, JSN Strategies, LLC. Previously, she served as the chief strategy officer at Brooklyn Community Services (BCS). **HEATHER HISCOX** is founder and CEO of Pause for Change, where she seeks to provide simple skills to help nonprofits and foundations navigate uncertainty. Hiscox also cohosts the online "talk show" Possibility Project, and regularly speaks at national and local conferences about social impact disruption and innovation.

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Scaling Up: The Power of Catalyst Partnerships

by Tom Kamber

As social entrepreneur, educator, and activist Tom Kamber explains, catalyst partnerships facilitate “the acceleration of social outcomes through connections with existing high-capacity organizations,” by enabling “smaller organizations to contribute unique knowledge, content, or support to a larger organization that can translate their role to a more extensive footprint with larger impact.”

OVER THE LAST YEAR, THOUSANDS OF nonprofits have had to adapt traditional services to meet changing demands emerging from COVID-19 in an unprecedented socially distanced landscape. For some organizations, the effects of lockdown on capacity and sustainability have been devastating, pointing to the need for new, more resilient systems. For others, the challenge has been quickly scaling to meet increased demand for services.

Older Adults Technology Services (OATS), the nonprofit I founded in 2004 to help seniors learn technology to transform themselves and their communities, is no stranger to either of these issues. Scalability and systems change have been two core goals, as we’ve sought to grow our impact in response to COVID-19. But as Ryan Glasgo and Sandhya Nakhasi note, these ideas can appear to be at odds: “Scale requires a competitive approach to growth, for example, while systems change requires collaboration, transparency, sharing, and collective adaptation.”¹

One tool OATS has employed to reconcile these impact approaches is the catalyst partnership—an arrangement whereby OATS helps another, larger organization create or improve a program or service, so that *their* clients are more connected, empowered, or successful.

Catalyst partnerships are important, because they enable what we call “leveraged impact”—the acceleration of social outcomes through connections with existing high-capacity organizations. Rather than building a client base and distributing services directly, catalyst partnerships enable smaller organizations to contribute unique knowledge, content, or support to a larger organization that can translate their role to a more extensive footprint with larger impact.

A successful catalyst partnership will leverage the strengths of each entity to generate transformative change at scale. We have found that the following three guidelines are particularly helpful when considering a partnership like this:

1. **Establish a shared goal.** Catalyst partnerships are not corporate philanthropy but rather mutually beneficial collaborations between two organizations, in which one may have more expansive resources but both sides bring complementary assets to the table. It is essential that the ultimate goal for the partnership is authentically aligned with both organizations’ core values.
2. **Identify each organization’s unique strengths.** Large organizations take many years to develop wide-ranging networks of operations, properties, and customers, but they may still benefit from the specialized support of smaller, innovative social change organizations. For example, Capital One wanted to encourage older customers to make use of their online banking tools, but learned that many seniors were uncomfortable with online financial management. OATS tapped into its experience and knowledge in developing technology

It is essential that the ultimate goal for the partnership is authentically aligned with both organizations' core values.

programming for seniors, and designed forty-four online instructional videos.

3. **Determine what needs expansion.** Some catalyst partnerships operate by bringing a smaller organization's program directly to a larger organization's audience. Others might achieve a stronger impact by supporting a larger organization's capacity with niche expertise. In 2017, when the Israeli nonprofit JDC Eshel was tasked with finding a way to include more seniors in a national campaign to close the digital divide, OATS worked with them to provide a series of capacity-building trainings, along with a partner guide with resources for trainers and world-class content, to help shape their practice at scale—resourcing them to work more effectively with other organizations, and helping them to better serve approximately fifty thousand older adults in Israel.²



The social impact space provides a great opportunity for organizations like OATS to use these types of leveraged-impact partnerships to achieve strategic objectives, support sustainability, and overcome the challenges of scale. By combining the deep customer knowledge and program expertise of nimble

organizations with the infrastructure, reach, and reputation of more established entities, smaller nonprofits can multiply outcomes without having to devote years of effort to building mass delivery systems in-house. Over the last eight months, catalyst partnerships have played a significant role in putting OATS on track to double the amount of participation in its Senior Planet programming by the end of the year. And as the long-term effects of COVID-19 on the social impact space continue to unfold, OATS is betting the catalyst partnership model will prove to be a game changer for many others, as well.

NOTES

1. Ryan Glasgo and Sandhya Nakhasi, "Asking Questions About Sustainability, Scale, and Systems Change," *Stanford Social Innovation Review*, December 9, 2019, ssir.org/articles/entry/asking_questions_about_sustainability_scale_and_systems_change.
2. In conversation between the author and Didi Ben Shalom, director of the National Initiative for the Promotion of Digital Literacy Among Older Adults, at JDC Eshel.

TOM KAMBER is an award-winning social entrepreneur, educator, and activist who has created new initiatives in aging, technology, affordable housing, and the arts. As founder and executive director of Older Adults Technology Services (OATS), he has helped over thirty thousand seniors get online, and created the country's first technology-themed community center, Senior Planet, for older adults. Kamber has taught social entrepreneurship and philanthropy at Columbia University, and has published widely in academic journals on topics including public policy, business strategy, and technology.

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Asking the Right Person for the Right Amount

by Kim Klein

“In the end,” writes Kim Klein, “you don’t know how much someone can give—and even if you knew everything about their financial situation, you still wouldn’t know how much they might give, because that number will depend on their mood, on how generous they feel, on what other experiences with money they have had that day. Your job is to be as accurate and as respectful as you can. Their job is to say yes, no, or maybe.”

Editors’ note: The Grassroots Fundraising Journal (GFJ), in publication from 1984 through 2020, is now being archived on the Nonprofit Quarterly’s website. The 600+ articles that comprise The Grassroots Fundraising Journal are used widely by fundraising professionals and volunteers, professors in university courses on nonprofit management, seasoned practitioners, and people brand new to the ideas and concepts presented there. This article, first published in print in December 2000, was published online by the Nonprofit Quarterly on May 5, 2020, with some updates. It is republished here with minor edits.

Three True stories Told to Me by Recent Clients

1. Last year, the board member of a large social services agency serving teens decided to ask all her neighbors for a donation. She wrote a letter in which she made an eloquent case for the agency, already well known in the community, and asked each family to give \$10. She hand delivered two hundred of these letters, with a return envelope. The letter raised \$1,200 from eighteen households. Two neighbors gave \$250 each, and two others gave \$100. Only one person gave \$10. The rest gave \$35 or \$50. Five people replied that they were not giving because they gave elsewhere or were unable to give right now. This board member plans to do exactly the same thing this year—hand deliver two hundred letters asking for \$10.
2. A program advocating for the rights

of prisoners held an open house, at which the development director met a woman who said she would like to make a “significant donation” to the work of this group. This woman had not contributed before, and said she had only recently learned of this group and was very impressed with their work. The development director arranged to meet her for coffee the following week. In the meantime, the development director found out that this woman gives thousands of dollars to a variety of social justice groups and is the “biggest donor” to a large public interest law firm. The development director decides to ask her for \$500.

3. A dentist learned that one of his patients had donated \$10,000 to a land conservation effort in his state. Although the patient has been using this dentist for a long time, the two know very little about each other.

The dentist is on the board of a struggling repertory theater, and decides to ask his patient for \$10,000 for the theater. He assumes the patient gives to the land conservancy because he is community minded, and that he would therefore also be interested in the theater.

Good Idea, Wrong Request

All three stories describe good fundraisers. They are thinking about their group and who might give. They are willing to do the work required to get the gift. Many organizations would rightly be thrilled to have any of these people as board members.

However, without seeming unduly harsh, I would say that in each of these cases, the decision made by the solicitor was wrong, wrong, wrong. Their problems are not unusual; determining exactly who is a prospect and how much

to ask them for has waylaid many a solicitation. Fortunately, there are some simple guidelines that can make the process a lot easier. By discussing what approach each solicitor in the stories should have taken, we can illustrate these guidelines.

In the first story, the board member's first effort—hand delivering two hundred letters to her neighbors—is a great idea, and one that almost anyone could do. It is especially a good idea when the organization being solicited for is not very controversial and is fairly well known in the community. The board member's decision to ask for \$10 the first time is fine, although the response shows that if she uses this method again, she can start with a higher amount, such as \$25, without losing anyone. She gets an almost 10 percent response from her letter—which is excellent, compared to direct mail, for example, where we would expect a 1 percent response, and almost as good as a door-to-door canvass, from which we would expect a 12 to 15 percent response. The neighbors who respond demonstrate that they like her, and they seem to like this organization—particularly those who give \$100 and \$250.

The board member tells me that her decision to go back to the same group with the same request is predicated on not wanting to make people feel like they have to give a big gift again, and to see if some of the neighbors who didn't give might change their minds and give this year. I explain to her that the people who gave larger gifts will be surprised to receive such a letter again, and some may even be hurt if she does not acknowledge their previous gift and ask them to repeat it. If she asks for \$10 from a \$250 donor, without meaning to she is telling that person, "I want \$10, try to get that straight this year."

After speaking with me, she decides to write personal letters to her eighteen donors, asking for renewals. She will

follow up with phone calls or visits, depending on her relationships with these people. She will again take a letter around to the rest of the neighborhood, this time requesting \$15 to \$35. She is prepared for a much lower response this time, but wants to keep the organization in her neighbors' minds. All eighteen of her donors renew. One person who had given \$100 gives \$200, and the rest give what they had given previously. Ten neighbors who had not given last year give a total of \$300, including gifts from two who had not been able to give the year before.

In the second story, a donor who gives gifts in the \$1,000 to \$10,000 range says she wishes to make a "significant gift" to an organization. The development director does not want to alienate this person by asking for too much. I explain that having said "significant gift," the prospect cannot really be shocked by being asked for a large amount, even an amount that may be more than she had in mind. The development director knows that this prospect is comfortable with giving large gifts. Of course, we don't know what she means by "significant," but she probably means more than \$500. The development director decides to show her the organization's gift range chart, which calls for a lead gift of \$15,000, three gifts at \$10,000, four gifts at \$5,000, and so on. The purpose of sharing this information will be to establish a giving range for this donor to this group. I suggest asking the prospect if she can give in the "\$2,500 to \$5,000 range." Skeptical but willing, the development director does just that, and receives a pledge of \$5,000.

The third story is about an enthusiastic but not terribly sensible board member. I ask him if he knows anything about this patient besides his dental history and his gift to the land conservancy. He knows he has two children and is a partner in a small business, but he does not know the nature of the

business. To his knowledge, this prospect has never come to his theater. "You can't start by asking him for a gift that is the same size as his biggest gift to his favorite charity," I explain. "You have no evidence that he believes in supporting the arts or has interest in theater."

I suggest starting with a conversation about theater and the dentist's role in the theater. If the patient shows interest, the dentist should offer him two free tickets to a play. If the patient takes them, the dentist should try to find out if he actually goes to the show. Only after a few more indications of interest will it be appropriate to ask for a gift, and even then, starting with a small request by mail may be more appropriate.

When the dentist next sees this patient, he skips having a conversation about the theater and just offers him two free tickets. The prospect seems touched and thanks him, but says, "Don't waste these on me. I am not a theater person. I never even go to the movies or watch TV." The dentist reports to me that he was relieved that he pursued his patient less directly than he had originally planned.

Who Is a Prospect? Three Guidelines

Although each of these stories is different, they raise many of the same issues. To begin with, it is important to be clear on who is and who is not a prospect. This is the first guideline to follow.

A prospect is someone who we know gives money—and have an idea of how much money they give and what kinds of causes they support. We know these things because we know the individual personally. Certainly, we can approach someone without having all this information, but our chances of getting a gift are diminished, and we can sometimes do damage to a relationship by not paying attention to what we don't know.

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neighbors asking for money, you need to know that some of them won't respond, because they don't give away money at all (about 30 percent of adults don't make any charitable contributions). Another group won't give because they already have a set list of organizations they support, and aren't going to add more. Another cross-section won't give because they don't believe in or care about the cause. Finally, some people won't give because they don't respond to mail appeals, no matter how personally they arrive.

In our first story, the board member probably got a 50 percent response from the people in her neighborhood who were *truly* prospects. Out of her two hundred neighbors, sixty (30 percent) are not givers. Upward of 30 percent more either don't give by mail or have already decided which groups they support, and won't add more. Even though the group she represents is popular and well respected, at least 10 percent of her neighbors either don't care about it or think that because it is popular it doesn't need their money. This leaves about sixty households that may be prospects; after two appeals, she has gifts—some of them large—from twenty-eight of them. As readers of the *Journal* will recall, a 50 percent rate of “yes” is what we expect from a personal solicitation.

A second guideline in approaching prospects is one that we don't talk about nearly enough: the solicitor needs to be on a level playing field with the prospect. For example, it is not good to solicit people who work for you. No matter how friendly everybody is, there is an unequal relationship between supervisor and worker, and a good employer will never want an employee to feel coerced into giving. The same is true for using confidential information as a background for soliciting people. This makes it difficult for accountants to solicit clients,

for example. They know which clients give away money, how much, and often to what. But they learned that in a setting that the client has reason to believe is confidential. If a client asks for advice about what kind of charities to support, certainly an accountant could then talk about his or her favorite group. Lawyers, therapists, financial planners, and the like are in similar positions with their clients. Medical professionals are in a more fuzzy area here, but the relationship is often one in which the patient feels vulnerable or exposed in some way, and medical professionals should be careful. Again, unless you are also a friend of your clients, you will want to think carefully before soliciting your client list.

I have, however, seen instances in which people solicited clients very successfully. For example, the owner of a garden store that specializes in native plants, organic fertilizer, alternatives to pesticides, and so on, is on the board of a local environmental organization. In a letter to his mailing list he wrote that he knew his customers shared his values and would want to know about this group if they didn't already. He is on a level playing field with the customers that have signed up to be on his mailing list: he knows little or nothing about them from his professional dealings, except that they shop at his store. His letter was very successful, raising almost \$3,000 from seventy people from a mailing list of five hundred, and many customers thanked him for introducing them to the organization. He is, of course, as in the previous example, writing to some people who are not givers and to some who have already established commitments.

Third, once we know that a person supports certain kinds of causes, we have to ask ourselves how close our organization is to the cause the person supports. Certainly, many people who support conservation also go to the

theater, so our dentist wasn't wrong to think of his patient as a potential donor, but he needed more direct evidence that this person was also interested in the arts. The patient made it clear that he is not interested in theater, at least as a member of the audience. It is true that some people support community organizations without ever using them, such as parks, libraries, museums, and theaters, to say nothing of service projects such as shelters or food banks, but the dentist has no information that his patient falls into that category either. He does not even know why this person supports the land conservancy. Besides the patient's dental history, the dentist doesn't know much more about him than he might find in the newspaper. He does not have a relationship with this person that will allow him to pursue any kind of gift at this time.

How Much to Ask For

Once we have established that the people we want to approach are, in fact, prospects—they have the ability to make a gift, they believe in the cause, and we know them, like them, and they like us—then we have to ask, “What size gift shall we request?”

Here we examine where the prospect is in relation to our group. A long-time donor is asked for a different amount than a first-time donor. If the person has a long history of giving to organizations similar to yours, you will probably start with a different amount than for someone who has only recently become interested in your issue. And, of course, we take a clue from the prospect: if she says, “I want to make a significant gift,” we feel freer to ask for a large amount than if we are the ones initiating the conversation. Finally, we look at our fundraising goals and our gift range chart, so that we can justify the amount we are asking for as being one of the many gifts we need.

Donors should not be asked for a

CHECKLIST FOR DETERMINING WHO IS A PROSPECT AND FOR HOW MUCH

Give one point for each item you know for sure, unless noted otherwise.

THE PERSON IN QUESTION:

gives to the following nonprofits: (one point for each one that you know)

gives the following amounts: (three points for knowing exactly; two points for knowing within a range, such as “He’s a silver donor to that group, so gives between \$500 and \$1,000”; zero points for not knowing anything about size of gift)

\$ _____ \$ _____

knows the following about our nonprofit: (one point each for as many as apply)

it exists

it has a good reputation

and/or: (one point each for as many as apply)

has friends or colleagues who work or volunteer there

has been personally helped by our group

has talked about our group with others

has given money to our group in the past two years: (check as many as apply)

by mail less than \$100

by phone \$100 to \$500

at an event more than \$500

in response to a personal request

is friends with [prospect’s name], who describes their friendship as: (check as many as apply)

long time and very close (five points)

very close (four points)

good (three points)

friend of friends (one point)

sees at social events, house of worship, with other friends (two points)

cordial, neighborly, or keeps in touch (one point)

TOTAL NEEDED FOR A TRUE PROSPECT: 10 or more points

Now, take the information you have about amounts this person gives to groups, and combine it with what they think about groups like yours, then match that with your gift range chart to find an amount to solicit them for.

certain size gift just because that is the same size gift they gave somewhere else or because we heard that they “have money.” Once a person has made a gift of any size, we have a place from which to start negotiating for another gift. “Can you give again?” “Can you double this gift?” “Would you consider giving this much every month?” and so on, depending on our relationship with the donor.

In the end, you don’t know how much someone can give—and even if

you knew everything about their financial situation, you still wouldn’t know how much they might give, because that number will depend on their mood, on how generous they feel, on what other experiences with money they have had that day. Your job is to be as accurate and as respectful as you can. Their job is to say yes, no, or maybe.

KIM KLEIN cofounded the *Grassroots Fundraising Journal* in 1981, and was its

publisher for twenty-five years. She is the author of five books, including *Fundraising for Social Change* (Wiley, 2016), now in its seventh edition. Klein has provided training and consultation in all fifty states and in twenty-one other countries. She lives in Point Reyes, California, with her wife, Stephanie Roth.

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