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of Healing for All*

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Healing Justice?**



**Birthing Black:  
Community Birth Centers as  
Portals to Gentle Futures**

**Disability Justice—in the  
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# WELCOME



Dear Readers,

This year, *NPQ* launched a health justice desk to better understand and advance edge thinking and practice in the field of health. And we are learning a lot! One thing we are noticing is that health justice both intersects with all of our other justice areas—racial, economic, and climate—and is at the forefront of articulating what it looks and feels like to achieve well-being.

This edition of the magazine sets a foundation for how we should be looking at health. It explores what it looks like—and takes—to thrive, from a multilevel, systemic perspective. It takes as its premise that *health equity* is simply not enough; we need *healing justice*, which proposes that an absolutely essential component of healthcare is understanding and taking into account the historical and ongoing violence and harm done by systems of oppression outside of “healthcare,” so as to get to a deeper-level recognition of the connection between surface-level symptoms and generational, historical traumas.

And although there are very few resources offered for healing justice work, many groups are endeavoring to expand consciousness about how health intersects with justice—and change institutional practices. This edition lifts up some of the visionary leaders who are driving joyful, albeit complex and challenging, innovations in the health field and across social justice movements.

At the root of health injustice is the notion that some bodies are to be more cherished than others. All of the articles within, in one form or another, describe what we gain when *all* bodies are cherished. We offer this edition to all bodies, with our love.

Cyndi Suarez  
President and Editor in Chief  
*NPQ*

# What Is Healing Justice?

by *Nineequa Blanding*

*This article was first published online by NPQ on October 10, 2022. It has been further edited for publication here.*

●  
 What would our future look like if we all operated from a place of healing? It would be a world where we value wellness as liberation, appreciate our interdependence, are in tune with our inherent capacity to heal, honor the wisdom of all cultures and bodies, and are guided by a shared understanding that our collective health is inextricable from our relationship with the earth.

In public health, we often talk about *closing the gap in health inequities* in order to create conditions for optimal health for all. These discussions reflect a growing consensus that health is a human right, which sets the stage for a shared vision of health justice. They also mirror ongoing efforts to achieve racial equity by addressing structural racism and its attendant injustices, and, in the process, expanding the health focus from the individual to the collective and society. These conversations and the work they inspire position the field of public health as a major actor in helping to protect, promote, and preserve our wellness.

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”<sup>1</sup> It is “a dynamic state of wellbeing emergent from conducive interactions between individuals’ potentials, life’s demands, and social and environmental determinants.”<sup>2</sup> Although our collective health and well-being depend upon mutuality and our ability to heal, these critical concepts are often missing from public health discussions centered on addressing health inequities.

Focusing on mutualism and healing builds a shared understanding of our interdependence and our inherent capacity to heal. As we strive to create conditions in which everyone can thrive, we must all collectively heal from the trauma caused by structural racism, and understand that our connections with one another are inextricable from our ability to improve our health. These efforts lead to new approaches that draw upon our shared strengths and shift us away from focusing on perceived deficits. As Sara Horowitz, founder and former executive director of the Freelancers Union, notes, “mutualism is not about charity, it’s about human beings’ strengths—our powers, our magic . . . mutualism calls on these to be in reciprocal relationship.”<sup>3</sup>



## *A movement is under way to create spaces that allow for an exploration of practices to transform oppression—within our bodies, our communities, and the systems that perpetuate it.*

What strategies will enable us to understand our interconnectedness, leverage our shared power, and heal from the trauma caused by structural racism?

A movement is under way to create spaces that allow for an exploration of practices to transform oppression—within our bodies, our communities, and the systems that perpetuate it. Longtime freedom activist and scholar Angela Davis—who has more than fifty years of experience leading social justice movements—highlights such healing-based transformation in her work. Davis says, “Self-care and healing and attention to the body and the spiritual dimension—all of this is now a part of radical social justice struggles.”<sup>4</sup>

In part, this shift in the social justice struggles that Davis references is the emergence of healing justice, launched in 2007 by the Kindred Southern Healing Justice Collective.<sup>5</sup> Cara Page, one of the leading architects of healing justice, defines this work as one that “identifies how we can holistically respond to and intervene [in] intergenerational trauma and violence.”<sup>6</sup> This movement, which is quickly gaining momentum, draws upon the historic ways that communities have resisted systemic oppression and thrived.

The Kindred Collective states, “We do not seek to promote single healers as one model, nor models of healing as singular, nor to build individualized care, but to build mechanisms and systems that build collective wellness; transform generational trauma and violence; and build quality care that is accessible to all.”<sup>7</sup>

Thus, healing justice work honors ancestral and Indigenous wisdom in an effort to respond to generational trauma, facilitate collective healing, and transform systemic oppression. It proposes that healing and joy are essential elements of liberation.

While healing justice initially developed in the Southeast region of the United States, healing justice-centered approaches are evolving, led by a growing network of global healers and changemakers who seek to forge an accessible path to our collective well-being—both within communities of color and across cultures.

In that spirit, The Kindred Collective outlines a framework for healing justice that centers on four main values<sup>8</sup>—some of which are absent from both traditional public health frameworks and approaches to advancing equity:

### **1 Our collective wisdom and memory enable well-being**

*We value our collective wisdom and memory towards our collective well being.*

—The Kindred Collective<sup>9</sup>

A major aspect of healing justice involves naming the historic and present-day violence and oppression imposed on communities of color by government and healthcare, the criminal legal system, education systems, and more. According to the Kindred Collective, healing justice work acknowledges that our collective well-being is “integrally connected to . . . abusive experiences as based on a legacy of trauma, control and genocide of communities.”<sup>10</sup> This view uplifts the notion that individual and collective trauma are, in fact, linked.

Current research provides evidence that supports the understanding that healing justice draws upon cultural wisdom that understands that our individual health is dependent upon our collective well-being. Recent developments in epigenetic studies are now confirming that trauma is passed down through generations, which can shape quality of life and, ultimately, life expectancy.<sup>11</sup>

The long-standing history of oppression—in the form of anti-Blackness and structural racism—and its impact on our health are made visible through modalities such as community storytelling, accounts of visceral experiences, and decades of social and biomedical research. In *Medical Apartheid*, for example, author and medical ethicist Harriet Washington documents—in over four hundred pages—stories of the multitude of traumas imposed on Black people in the name of science.<sup>12</sup> One of these harrowing stories is that of Saartjie (pronounced “SART-kay,” which means “little Sara” in Afrikaans) Baartman—famously known as Sarah Baartman.

## *Healing justice sheds light on oppression and simultaneously uplifts the power of community to heal.*

As Washington recounts, at the age of twenty-one, under the guise of promised prosperity, Baartman was forced to “enter an arena where she would become an object of unbridled medical curiosity and physical lust.”<sup>13</sup> She was taken from her home by British surgeon Dr. William Dunlop and subjected to years of anatomical scrutiny. “Men of science made pilgrimages to London’s academic and medical settings to sketch, measure, and endlessly analyze” her body.<sup>14</sup> After years of suffering rape and countless supposed medical examinations—actions justified, in the name of science, by racist ideology that permeates our medical system today<sup>15</sup>—Baartman “died from an infectious illness at the age of twenty-seven.”<sup>16</sup>

After Baartman’s death, her body was held captive by scientists and placed on public display in Paris’s Musée de l’Homme until 1985.<sup>17</sup> Baartman’s story is one of many examples of the “medically exploitative display of black peoples.”<sup>18</sup> Widespread systemic trauma such as this creates intergenerational ripple effects that are further compounded by present-day oppression.

Racial inequities persist across all social systems, not just in healthcare, and they are driven by historic and present-day oppression and violence that rely on their continued justification and normalization of ideologies similar to those that normalized Baartman’s subjugation. In response, healing justice “honor[s] individual agency, and therefore honor[s] people’s right to make decisions about their own bodies.”<sup>19</sup>

Healing justice sheds light on oppression and simultaneously uplifts the power of community to heal. “We see that health and healing can be achieved by returning to ancient & traditional healing and earth & nature based modalities and creating new practices to respond to our political and social context.”<sup>20</sup> In our time, when so many systems are working to remove the autonomy and agency we have over our bodies as individuals, these practices are needed.

## **2 Wellness is liberation**

*We value wellness as a tool of liberation.*

—The Kindred Collective<sup>21</sup>

Healing justice values wellness as a path to liberation. The Kindred Collective notes that these efforts work to “sustain our individual and collective wellness as a response to transform generational violence and trauma.”<sup>22</sup> Healing justice addresses “racism and oppression as a public health issue and social illness that informs our physical, emotional, environmental, spiritual, and psychic well being.”<sup>23</sup> It uplifts the strength and inherent capacity of communities to harness our own power and transform oppression through healing.

In this way, healing justice pushes the existing health justice and health equity frameworks beyond what is currently considered to fall within the rubric of health. It brings attention to the inequities—the systemic injustices—that shape social determinants of health; but it also goes deeper by focusing on the traumas that have resulted from historic, intergenerational oppressive social relationships that impact individual and community health today.

Healing is restorative and essential to our well-being. When we create the conditions for healing to occur—an intrinsic process—and actively engage in our own healing, we harness our individual and collective strength to move beyond trauma. This work creates a path for the healing of both people and systems, fostering new ways of being. Healing justice offers a way for us to reimagine how we show up for each other and how current systems dictate communities’ trajectories.

Artist and healer Londrelle notes, “The thoughts we feel create our reality. If our minds are rooted in fear, our vision becomes clouded, and it becomes difficult to see the abundance that surrounds us.”<sup>24</sup> When we allow ourselves to heal from fear caused by systemic oppression, we operate from a place of power and can shift our thinking from a scarcity mindset toward abundance, creating new possibilities for ourselves and our future generations.

## *Healing justice requires expansive thinking beyond limited notions of good versus bad health, and honors all bodies.*

### **3 Our interdependence is essential**

*We value our interdependence.*

—The Kindred Collective<sup>25</sup>

As noted by the Kindred Collective, healing justice values “dignity for all life” across all races and identities.<sup>26</sup> This framework centers on an understanding “that the ways we live with and treat each other ha[ve] direct impact on our wellness and collective well being towards . . . transforming our conditions.”<sup>27</sup> Our wellness is reliant upon our relationships with individuals, our communities, society, and all life within the earth’s ecosystem.

In a recent article on healing-centered leadership, Shawn Ginwright, professor of education in Africana Studies at San Francisco State University and CEO of Flourish Agenda, speaks to the need for this work:

The only path to reimagining the future is through healing our collective trauma and restoring a sense of possibility in our work. This can only happen when we foster a collective imagination that restores communal wisdom and sets a path toward more humane ways to show up in life.<sup>28</sup>

Ginwright highlights a key aspect of healing justice—that our individual healing enables a shift in how we relate to one another, cocreate community, and transform systems.

The healing justice framework also values and is “conscious of the connection of our health . . . to the environment and the . . . healing of the earth.”<sup>29</sup> As climate change affects every country across the globe, keen attention to and a shared understanding of our interdependence are needed.<sup>30</sup> In *Design as Politics*, Tony Fry notes, “No matter the differences of our circumstances as individuals, cultures or nations, we now share a time that is new. We all share a continual moment of the diminishment of time. The actual finite time of our life on the planet (and the life of much else) is being reduced by our own destructive actions as a species.”<sup>31</sup>

### **4 Our wellness requires honoring all bodies**

*We value all bodies and the conditions that we live in.*

—The Kindred Collective<sup>32</sup>

The healing justice framework provides an opportunity to expand the ways that public health examines inequities. This country’s systems are entrenched in structural racism and white supremacy, and this ideology shows up in how population health data are collected, analyzed, and used to develop interventions. Without an intentional effort, public health data approaches can perpetuate long-standing inequities rather than addressing them.

The Robert Wood Johnson Foundation speaks to this issue by noting,

We use the category of race as a means of identifying and measuring disparities. However, race has no biological meaning; it is a social construct designed intentionally to relegate people and communities of color to second-class status and to privilege white people. It is the racism that accompanies [unfounded] racial hierarchy that has profound health consequences. The gaps and failures in our public health data systems today, in fact, stigmatize entire communities instead of doing what data can and should do: provide the roadmap and path toward systemic change.<sup>33</sup>

At present, there is a tendency to compare outcomes for Black people, Indigenous people, and people of color to their white counterparts. Yet, in the absence of efforts to counter unfounded racial hierarchies, this approach can unintentionally uplift white supremacist ideology. The health outcomes of white people cannot serve as the gold standard that people of color strive to attain. Our ideal should be grounded in a vision of collective liberation, healing, and well-being.

Indeed, healing justice requires expansive thinking beyond limited notions of good versus bad health, and honors all bodies. As noted by Adaku Utah of Harriet’s Apothecary, this framework is “informed and grounded by economic, racial, disability and reproductive justice movements.”<sup>34</sup>

## *Healing justice is critical for catalyzing the type of systems transformation that enables . . . vision to become reality.*

Further, tracking and analyzing data through a demographic lens places the onus of health inequities on individuals and communities rather than addressing the social ills and systemic oppression that create these injustices in the first place.

### **A NEW VISION FOR ADDRESSING STRUCTURAL RACISM**

The United States is residentially segregated by race. Public health studies show that life expectancy rates vary dramatically by neighborhood, and therefore by/in conjunction with race. The Robert Wood Johnson Foundation has mapped life expectancy rates by neighborhood across the United States.<sup>35</sup> In some areas, there is a thirty-year gap in life expectancy between neighborhoods that are positioned just a few short miles apart but have different racial makeups. Structural racism, not race, drives these stark differences.

Racism impacts everyone, inhibiting our ability to attain optimal health as a whole. Although structural racism traumatizes people of color most, studies show racial trauma also affects white people. Structural racism structures opportunity in a way that “saps the strength of the whole society” by wasting human resources.<sup>36</sup> It is also arguably the most significant barrier to racial and health equity.

Recognizing the debilitating impacts of structural racism across systems, local jurisdictions across the country have galvanized to formally acknowledge racism as a public health crisis<sup>37</sup> and create policies and practices that aim to transform the social determinants of health (SDOH), which influence how communities live, grow, work, and play.<sup>38</sup> These determinants include housing,<sup>39</sup> education, economic stability, neighborhood environments, social cohesion, health-care,<sup>40</sup> food security,<sup>41</sup> water access,<sup>42</sup> civic engagement,<sup>43</sup> incarceration,<sup>44</sup> and more.

In an October 2021 report, the American Public Health Association revealed its analysis of 198 declarations and thirty-eight accompanying strategic actions to promote health equity.<sup>45</sup> The report details the growing movement within local government to finally acknowledge that

structural racism is a threat to public health.<sup>46</sup> Since 2018, APHA has tracked 250 declarations issued by high-ranking government officials and adopted by entities such as city/town councils, county boards, governors and mayors, education boards, public health associations, and public health departments. The number of these declarations increased at the height of the pandemic, as COVID shed light on long-standing injustices faced by Black and Indigenous people and people of color.

APHA's analysis revealed that nearly all the declarations include a commitment to some level of data collection, analysis, and reporting, with varied commitments to creating a task force to ensure accountability. More than a third of the declarations outline an obligation of forming and strengthening partnerships with community groups and organizations that are addressing racism—and almost half of those declarations include strategic action to promote an “equity in all policies” approach to future policy development, along with a commitment to reviewing existing policies and programs through a racial equity lens.<sup>47</sup> Leading with a racial equity lens enables examination of how policies impact people's experiences along racial lines—shaping opportunities, outcomes, and power.

While significant efforts are under way in local jurisdictions to address systemic racism as a public health crisis, strategies that foster community healing to address the harms caused by structural racism are not at the forefront of these efforts' strategic plans. This prompts the question: What if healing justice efforts served as a guidepost, as the foundation of a collective vision, for all government strategies to address structural racism?

What would our future look like if we all operated from a place of healing? It would be a world where we value wellness as liberation, appreciate our interdependence, are in tune with our inherent capacity to heal, honor the wisdom of all cultures and bodies, and are guided by a shared understanding that our collective health is inextricable from our relationship with the earth. Healing justice is critical for catalyzing the type of systems transformation that enables such a vision to become reality.

## NOTES

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**NINEQUA BLANDING** is *NPQ*’s senior editor of health justice. Blanding has dedicated the entirety of her career toward working at the intersection of health and social justice. Prior to joining *NPQ*, Blanding was vice president of Health Resources in Action, where she led the direction and growth of the organization’s grantmaking services. Blanding was the former director of health and wellness at the Boston Foundation, where she applied her vision, leadership, and racial equity lens to develop, implement, and evaluate TBF’s strategic priority to improve population health. Prior to her work at TBF, Blanding held senior leadership positions at the Boston Public Health Commission, where she led local and statewide strategies to advance health equity. She also held former roles with Mount Sinai School of Medicine and the New York City Department of Health and Mental Hygiene. She currently cochairs the Harvard T.H. Chan School of Public Health’s Prevention Research Center Community Advisory Board. Blanding has a BA in psychology from Spelman College, and an MPH with honors from Long Island University, and she was previously funded by the National Institutes of Health to conduct postbaccalaureate research in trauma-related risk factors for post-traumatic stress disorder at Emory University and the Center for Cognitive Neuroscience at Duke University.

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# Writing New Narratives for Health

by *Sonia Sarkar*

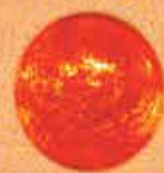
●  
Shifting our health narratives requires centering a different set of voices. For centuries, the perspectives most listened to in shaping our healthcare system have been those of white, male “experts”—often, clinicians with formal academic training. The result is a narrow set of stories through which to understand what health can or should be.

*This is the fifth article of a five-part series, Reclaiming Control: The History and Future of Choice in Our Health, published online by NPQ from July to November 2022, examining how healthcare in the United States has been built on the principle of imposing control over body, mind, and expression. That legacy stands alongside another—that of organizers, healers, and care workers reclaiming control over health at both the individual and systems levels. This article has been further edited for publication here.*

**A**s a longtime science-fiction fan and health justice practitioner, I’m drawn to works that imagine the future of our healthcare system. These worlds bustle with technological marvels: lifesaving science that makes immortality attainable, artificial intelligence–controlled diagnostics and treatments, cloned organs (and sometimes cloned humans). They also echo all-too-familiar realities: concierge care available only to the wealthy, paradigm-shifting pandemics, environmental crises, and continued exploitation of communities that already experience the greatest health inequities.

Such realities can feel dystopian, especially when they’ve been with us for centuries. Systems of oppression have produced and are buttressed by mainstream stories about health, bodily autonomy, and choice. Who deserves good health? How is healthcare designed and delivered? What is our individual and collective right to a healthcare system that enables true healing?

Until recently, people seeking to answer these questions worked off of outdated scripts about race, sex, gender, ability, sexual orientation, class, and more. However, organizers, healers, and other change agents have long lifted up counternarratives of health and healthcare. By building power to hold healthcare institutions accountable, designing alternative healing models, decolonizing



medical education, and much more, they are imagining health systems that center the wisdom of Black, Brown, and Indigenous communities, generate sustainable abundance for people and the planet, and enshrine people's right to choose what they seek for their own minds and bodies.

A 2021 brief published by the American Public Health Association, the de Beaumont Foundation, and the National Collaborative for Health Equity highlights our brain's ability to use stories and images to create meaning and shape what we perceive to be "true, possible, and good. [Narratives] are central to the development of our worldview and the values we hold sacred . . . creat[ing] the scaffolding under which we co-create the systems and structures that govern our lives and influence our access to resources and our collective health and well-being."<sup>1</sup>

Transforming our stories, then, is fundamental to creating liberatory systems that center autonomy. Without such transformation, we default to stories we've been told. This may be why literature depicts plenty of healthcare dystopias but offers few imaginings of a better way—and even fewer acknowledgments of the rich ancestral healing traditions that existed long before the birth of modern medicine.

## **COCREATING STORIES TO CHALLENGE SYSTEMS**

Shifting our health narratives requires centering a different set of voices. For centuries, the perspectives most listened to in shaping our healthcare system have been those of white, male "experts"—often, clinicians with formal academic training. The result is a narrow set of stories through which to understand what health can or should be.

One example of how a singular story can cause unintended consequences is the body mass index (BMI), which in the twentieth century came to be seen as a key indicator of overall health status. Far from a neutral standard, BMI was developed in the 1800s, when racism was deeply embedded in health science. The standard height and weight that serve as the foundation for BMI assessment were based on an unrepresentative sample of white European men.<sup>2</sup> Furthermore, such assessments were never intended to measure individual body fat or health but to serve as a population-level statistic.<sup>3</sup> Nonetheless, a person's BMI can impact the medical advice they receive, their access to treatments, their insurance coverage, and more. This can cause enormous harm, including worsening long-term health

outcomes—particularly those of people already facing discrimination in the healthcare system.<sup>4</sup>

Amplifying the voices of people with diverse lived experiences—including negative experiences with the mainstream healthcare system—is key to shifting our national health narratives. Rio Holaday, a visual practitioner and Robert Wood Johnson Foundation Culture of Health Leader, focuses on such amplification through her graphic recording work with health justice-focused organizations, collectives, and convenings, as well as visual coaching with individuals across the country. Using visuals and words, she draws on her own experiences as a health justice advocate to engage in deep listening and uplift people, themes, and connections that may otherwise go unnoticed. In particular, Holaday explores the necessity of grappling with internal transformation and reflection in order to be an active agent in narrative rather than a passive recipient of it.<sup>5</sup>

"What are the narratives about how we get to change and liberation? That is often systems work, structures work. It is not, a lot of the time, [about] internal work, nor doing both at once. One [concept] that has always stuck with me and been foundational to my approach is from adrienne maree brown, this idea that we can only create a future as whole as we are,"<sup>6</sup> Holaday explains.<sup>7</sup> Participants in the graphic recording process often describe feeling *heard*. Recognizing that those with marginalized identities often face reprisals for stating their opinions, participants have the option to request confidentiality or correct the record. The visual artifacts of these sessions are used to spur further dialogue and are integrated into future justice work.

"Going into graphic recording was a way of asking, 'How can we shift power? What does it mean to actually listen to people? What does it mean to be listened to, and to feel seen and heard? And how do we capture that in a way that is not just the written word?,'" Holaday shares. "What parts of ourselves as humans are telling the narrative? Typically, it's the brain, there's not a lot coming from the body. I'm doing a lot more of: 'What does this actually feel like?,' and drawing that."<sup>8</sup>

To step beyond our existing models of health, we must also grapple with the values that underlie our healthcare system. The Health Equity Narrative Infrastructure Project,<sup>9</sup> an initiative co-led by County Health Rankings & Roadmaps and Human Impact Partners, convened several partners (including health departments and the American Medical Association) from across the country to engage in such exploration.



SisterSong, a national reproductive justice organization, embodies this approach through its Artists United for Reproductive Justice initiative. “Art has the power to break down barriers, uncover plugged ears, raise new questions and conversations, inspire compassion, spark activism, and rally multitudes around a cause,” the AURJ website states.<sup>13</sup> By centering diverse groups of artists working across various mediums, the program supports the development of art that can be easily replicated and shared with movement allies. This culture work serves the dual purpose of bringing together the organization’s members to engage in dialogue and deploying a form of political education and mobilization with people outside the organization.

Last year, I had the opportunity to work on *The Light Ahead*,<sup>14</sup> a speculative fiction podcast produced by Beloved Economies and Avalon: Story, that imagines what 2030 might look like if our US economy centered healing and care. Each episode features a vignette informed by dialogue between movement activists and podcast writers. One of my favorite episodes is “Kayla’s Village,” which features Kayla and Marcus, a Black couple preparing for Kayla’s birthing experience.<sup>15</sup> They are supported by a midwife named Rosie and by Kayla’s mother, Josephine, who adopted Kayla when her biological mother died during childbirth. Born out of a conversation between

Angela Aguilar, a birth worker and codirector of Movement Generation, and writer Jacquelyn Revere, the episode envisions holistic communal support for birthing people rooted in the rituals, knowledge, and care that oppressed communities often already deploy to support one another through life’s challenges.

“Kayla’s Village” demonstrates how new visions for health are in many ways based in the ancestral practices of BIPOC communities. These practices, which have survived despite racial capitalism’s attempts to eliminate them, are rooted in values of respect, dignity, and connectedness to one another and the land, while still honoring individual choice and autonomy.



We need new narratives to push the boundaries of what health can be in this country and to challenge mainstream narratives, whose ongoing power is reflected in the Supreme Court’s recent stripping away of reproductive rights and in ongoing structural racism and economic exploitation. Highlighting the stories of movement organizations, grassroots entities, and healing practitioners of all backgrounds offers us a different set of dreams to reclaim bodily control from the state, the healthcare industry, and other oppressive systems.

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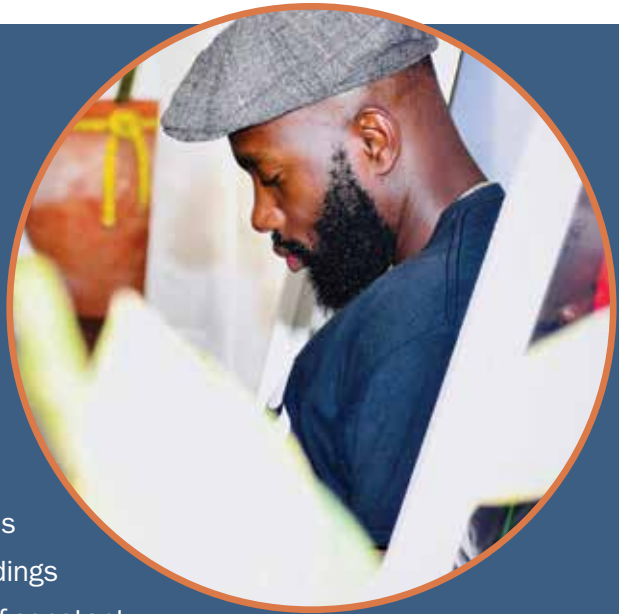
**SONIA SARKAR** is NPQ's health justice editor. Sarkar has a background in health equity, democratizing capital, and social justice. Previously, she served as the director of social homes and health equity at the P3 Lab at Johns Hopkins SNFAgora Institute, where she partnered with social movement organizations across the country to conduct research on power building for health equity. Sarkar was also the chief policy and engagement officer for the Baltimore City Health Department, and the chief of staff/special advisor at Health Leads. In 2017, she was named a Culture of Health Leader by the Robert Wood Johnson Foundation; she is also a Social Entrepreneur in Residence with Common Future. Sarkar holds BAs in public health and international studies from Johns Hopkins University, and an MPH and DrPH from the Johns Hopkins School of Public Health.

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### About the Artist: Ekow Brew

Ekow Brew is a Ghanaian-born, self-taught contemporary visual artist who specializes in new media art forms. Brew considers his surrealistic digital collages, which explore the forces of nature in a figurative manner, to be an extension of his perceptions and expressions of his surroundings and view of life. Life, for Brew, is a journey of constant exploration, and he sees each new artwork as an opportunity to rediscover himself.

Believing in the importance of individual artistic perception and experience, Brew creates with the intention of giving freedom to his audience to explore their own viewpoints and understandings of (and through) his work.



# Birthing Black

## Community Birth Centers as Portals to Gentle Futures

by Leseliey Welch and Nashira Baril

Imagine a world where birth is safe, sacred, loving, and celebrated for everyone. Imagine giving birth with midwives in a community birth center designed in response to the dreams, hopes, and needs of the community it calls home. We believe that when Black birthing people are centered, healthcare is transformed.

*The white fathers told us: I think, therefore I am.  
The Black mother within each of us—the poet—whispers in our dreams:  
I feel, therefore I can be free.*  
—Audre Lorde (“Poetry Is Not a Luxury”)<sup>1</sup>

# Y

ou walk through the door, so happy to be able to receive care at a community birth center right in your neighborhood. You, your partner, and your children are greeted by name, maybe even with warm hugs. You are asked how you are doing and can tell that the person asking genuinely cares. They offer you water, tea, snacks, and you settle into a cozy sofa. Art by Black artists graces the walls. There are shelves of birth, nutrition, breastfeeding, and parenting books for you to borrow, and a toy nook in which your little ones can play.

In the exam room, you feel at home with the warm colors and cozy furniture. Your partner feels they belong here too, with posters celebrating Black and Brown fathers and disabled, queer, and trans bodies. Your midwife greets you, and you remember how relieved you felt the first time you met, knowing that they were from your community. They welcome your whole family to the visit. Your kids listen to the baby and see them on the ultrasound. Your midwife asks you about how you’ve been feeling physically and emotionally, what you’ve been eating, and how much rest you have been getting. They talk with the whole family about ways to connect with the baby and how to support you. It’s unlike any healthcare appointment you have had, and when it’s time to go, you almost don’t want to leave.

When you go into labor, there is no frantic rush to the hospital. Your partner calls the midwife, who reminds you what active labor looks and feels like, and how to know when it is time to come in. Hours later, you are on your way.







*You walk into your birth suite and breathe a sigh of relief. Your midwife is there, and they have prepared for your birth journey. You feel loved, knowing that you can labor where and how you feel called to. Your power playlist comes through the speakers while you move and sway and breathe. You walk some, sit on the toilet for a time, then move to the birthing tub. Your partner whispers reminders of your beauty, your strength, your power. Your mother is softly singing your favorite childhood song. A familiar scent wafts from the kitchen where your aunts are warming food they prepared earlier. They take the kids into the living room to play. Labor is hard work, yet your surroundings are soft and gentle. You feel seen, heard, honored, and supported, assuaging any concerns that you can't do this.*

*You feel your baby's head emerge. The midwife's eyes are reassuring. You change positions at will, responding to the knowing in your body. The surges come with more intensity, and you burrow into your partner's chest. The newest member of your family arrives earthside in this sacred container of love—and everyone and everything is forever changed.*



Imagine a world where birth is safe, sacred, loving, and celebrated for everyone. Imagine giving birth with midwives in a community birth center designed in response to the dreams, hopes, and needs of the community it calls home. We believe that when Black birthing people are centered, healthcare is transformed—and the experience of birth has the power to transform and heal individuals, families, and communities. Mere survival is not the goal; we are creating birthing environments where so much more is possible.

We, the authors of this article, are Black women birthing community birth centers, and we are founders of a national network of Black people, Indigenous people, and people of color who are also leading community birth centers. Birth Center Equity has as its mission to make birth center care an option in every community by growing and sustaining birth centers led by Black people, Indigenous people, and people of color; the mission of Birth Detroit, founded by Welch, Char'ly Snow, Elon Geffard, and Nicole Marie White, is to “midwife safe, quality, loving care through pregnancy, birth, and beyond;”<sup>2</sup> the mission of Neighborhood Birth Center, founded by Baril, is to offer comprehensive midwifery care throughout pregnancy, labor, birth, and the postpartum period by integrating an independent freestanding birth center into Boston's healthcare and community landscape.<sup>3</sup>

Birth Detroit and Neighborhood Birth Center will be the first of their kind in their cities and states. Our work is guided by the belief that the world we want to live in—from a healthy family to a healthy planet—requires the reimagining of healthcare and the equitable distribution of capital.

### **COMING BACK INTO OUR BODIES: VISIONS FOR COMMUNITY BIRTH**

Increasingly, media coverage frames Black maternal health as a “crisis.” While attention to Black maternal health is certainly overdue, the current narrative does not offer a structural analysis of the root of the problem nor affirm Black power. This dominant narrative and the data and assumptions that result create fear in Black birthing people, cast Black birthing bodies as the problem—either explicitly or inadvertently—and suggest that white maternal health outcomes, white birthing bodies, and a white-dominated birthing system are the norms to which we should aspire. The resulting public health response is to “close the gap” and aim to level the rates of Black maternal and infant outcomes to match those of the white population.

The truth, though, is that maternal health outcomes across the United States, including for white populations, are atrocious when compared to similarly economically advantaged countries in which midwives are the leaders in providing maternity care and designing the systems of care.<sup>4</sup>

The narrative of a “Black maternal health crisis” ties the crisis to one racial group and ignores the fact that the system is not working particularly well for anyone—and that because of structural racism, the system bears down inequitably on Black birthing bodies. In fact, we argue that because of structural racism—policies and practices that implicitly or explicitly uphold white supremacy—the entire United States faces a crisis of maternal health.

Leading with the Black maternal health crisis narrative repeats the trauma of those of us who have been impacted by the tragedies of maternal and infant morbidity and mortality. Yet, we ourselves have often taken part in presenting and amplifying this frame—standing with our health department badges in front of a big screen projector and sharing the painful health disparity data, often in rooms full of people whose lived experience makes up the data on the maps and graphs. Being steeped in these data requires some desensitization. For years, our jobs at health departments required us to be in our heads and not in our bodies lest we never stop crying.

We knew we could not build liberated models of care for our communities from this narrative. Setting down our graphs and charts, and fueled by both grief and radical possibility, we chose to practice articulating liberatory visions for community birth—framing our visions not by the trauma and failures of the current system but by tuning in to Black joy and agency, and returning to the wisdom of our bodies. We committed to centering stories of joy and healing in our writing and speaking to remind ourselves and anyone listening that we are powerful and capable of birthing on our own terms, and that we deserve nothing less than transformative, radically loving, high-quality care that affirms our power.

In our practice of coming back into our bodies and feeling our own joy, pain, and power, we do not ignore that we are in a crisis of maternal health that bears down inequitably on Black people. Rather, our analysis requires that we learn and uplift the true history of midwifery and the stories of Black people being experts in their own reproductive health; celebrate firsthand accounts and images of elders catching their grandbabies; and honor Black midwives and the call to uphold reproductive justice—“the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities.”<sup>5</sup> Our practice of visioning and of honoring the past, present, and future helps us and our communities to hold steadfast to

**For our ancestors,  
community-based midwifery  
care was not “alternative”  
birth care—it was birth care.  
The midwife, well known as a  
healer in Black communities,  
came to the house and  
“caught the baby.”**

the legacy and vision of community midwifery and transformative spaces for collective care and collective courage.

### **“CATCHING THE BABY”—RECLAIMING OUR BIRTHING LEGACY**

“Birth centers are for crunchy white women,” she said, with an inflection that telegraphed *prove me wrong*. In many ways, this Black woman, surveyed as part of Neighborhood Birth Center’s needs assessment in Boston in 2016, was not wrong. The majority of planned community births (birth center and home births) in the United States serve white women.<sup>6</sup> Today’s midwifery workforce is predominantly white,<sup>7</sup> and more than 95 percent of the 384 established birth centers in the United States are owned and operated by white women.<sup>8</sup> This was not always the case. We need only look back one generation to understand the uniquely Black history of midwifery in the United States and the racialized policies that undermined it.<sup>9</sup>

At the time our grandparents were born, midwives, known in the community as “grannies,”<sup>10</sup> attended almost all the births.<sup>11</sup> For our ancestors, community-based midwifery care was not “alternative” birth care—it was birth care. The midwife, well known as a healer in Black communities, came to the house and “caught the baby.”<sup>12</sup> She and other women in the community tended to the mother and newborn—supporting breastfeeding, preparing meals, and harvesting herbs for teas and salves to facilitate healing.<sup>13</sup> The details of our grandparents’ birth stories had largely faded by the time we, the authors of this article, were of childbearing age. They were erased by government-backed campaigns to move

birth out of the hands of Black midwives and into the hands of white male obstetricians.<sup>14</sup>

In 1912, John Whitridge Williams, a professor of obstetrics at the Johns Hopkins University School of Medicine, published an article in the *Journal of the American Medical Association* titled “Medical Education and the Midwife Problem in the United States.”<sup>15</sup> One of the article’s key recommendations was to phase out the practice of midwifery in cities and rural areas. Williams joined the ranks of obstetricians who blamed midwives for infant and maternal deaths and discouraged people from trusting the midwives in their communities. The 1920s brought the Sheppard-Towner Maternity and Infancy Act, which legislated and designated funding for physician and nurse supervision and training and oversight of midwives. The Sheppard-Towner Act especially targeted Black midwives as too “uneducated and unclean” to provide healthy maternity care.<sup>16</sup> Moving into the 1930s and 1940s, white male obstetricians increasingly marginalized midwifery and pathologized childbirth, blurring the crucial line between “‘ordinary’ and ‘emergency’ practices” through the formalizing of med-surgical curricula and credentials,<sup>17</sup> establishment of authoritative medical societies,<sup>18</sup> and continued racialized smear campaigns.<sup>19</sup> Further, the passage of the Hill-Burton Act in 1946 resulted in funded “separate but equal” hospitals and health clinics for the underserved, leading more Black women in the South to birth in hospitals.<sup>20</sup>

This combination of legislated economic divestment and fearmongering wildly impacted the size and racial makeup of the midwifery workforce from that point onward and made hospitals the dominant settings for birth in the United States. Today, childbirth is the number one reason people are admitted to hospitals in the United States.<sup>21</sup> “In 2010, 98.8 percent of all US births occurred in hospitals,” and 86 percent of them were attended by physicians.<sup>22</sup>

The World Health Organization endorses midwifery as “an evidence-based approach to reducing maternal mortality,” and several studies “have found that midwifery-led care for women with healthy pregnancies is comparable or preferable to physician-led care in terms of:

- “Maternal (mother) and neonatal (baby) outcomes, including lower maternal mortality and morbidity and reduced stillbirths and preterm births.

- “More efficient use of health system resources, including lower use of unnecessary and potentially harmful interventions like C-sections for low-risk deliveries, epidurals, and instrument-assisted births.
- “Improved patient satisfaction and maternal psychosocial well-being outcomes, including those for postpartum depression.”<sup>23</sup>

The economic decision to undermine community midwives—mostly Black Grand Midwives<sup>24</sup>—and move childbirth into the hospital changed the entire maternity care system for everyone.

Even the American College of Nurse Midwives recently acknowledged that the United States has never redressed the divestment in midwifery.<sup>25</sup> Maternal health infrastructure, policies, and outcomes reflect this fact:

- US birth outcomes continue to pale in comparison to those of Sweden, Norway, France, and other European countries.<sup>26</sup>
- “[T]he U.S. maternity workforce is upside down relative to patient needs. . . .
- “Access to home visits after delivery varies in the U.S. but is guaranteed in other countries. . . .
- “The U.S. is the only high-income country that does not guarantee paid leave to mothers after childbirth.”
- Obstetricians continue to outnumber midwives nearly threefold in the United States.<sup>27</sup>

And our states, Massachusetts and Michigan, rank thirty-first and thirty-fourth, respectively, in midwifery integration—meaning that they lag far behind in incorporating the demonstrated effective midwifery model of care into their health systems.<sup>28</sup>

Birth center care is even less integrated and accessible, with physical access mirroring residential segregation and limited access to low-income families.<sup>29</sup> Out of the more than 384 birth centers in the United States, approximately twenty are owned or led by Black people, Indigenous people, and people of color.<sup>30</sup> Black people make up approximately 15 percent of the childbearing population, yet as few as 7 percent of that population give birth in a birth center.<sup>31</sup> Additionally, the

## Today, we face racially redlined access to midwifery that reflects our nation's deeply racist political, economic, and cultural history.

primary insurance coverage for more than half of births to Black people is Medicaid,<sup>32</sup> and most Medicaid-eligible families are unable to access birth center care, even though the Affordable Care Act requires that state Medicaid programs cover midwifery care.<sup>33</sup> The end result is that Black birthing people are among the least likely to have access to midwives and birth centers.

Today, we face racially redlined access to midwifery that reflects our nation's deeply racist political, economic, and cultural history. Obstetrics is the dominant maternal health practice, while cultural narratives overshadow the Black history of midwifery with one that is white, wealthy, and/or alternative/“crunchy.”

US studies of midwifery, as well as data from countries where midwifery is well integrated into the healthcare system, show improved outcomes for families, including lower infant mortality, increased breast/chestfeeding,<sup>34</sup> fewer interventions, and increased rates of vaginal birth after caesarean (VBAC).<sup>35</sup> It is shameful that the majority of people who have access to birth center care are white, cisgender, college educated, middle to high income, and insured or able to self-pay for services.

### COLLECTIVE COURAGE AND THE RISE OF THE BIRTH CENTER EQUITY NETWORK

“We ask for nothing that is not right, and herein lies the great moral power of our demand.”<sup>36</sup> As we write this article, we are reminded of this quote by Black artist and activist Paul Robeson—part of the canon of ancestral wisdom that buoys us up on hard days. The two of us are clear that without each other, what we are doing would feel insurmountable. After all, most birth centers—freestanding, homelike places where reproductive health and birth care are provided by midwives—are started by midwives, and these midwives are usually white. We are not midwives, and we are not white.

Of the nearly four hundred birth centers across the country, most are for-profit entities started by white midwives with resources from private practice, personal funds, loans, and family gifts.<sup>37</sup> In a policy and reimbursement context that has historically devalued midwifery, opening birth centers and ensuring that birth center care is accessible to families who need it most is challenging for everyone; and with outdated state regulations (or none at all) and abysmal or no Medicaid reimbursement, the sustainability of birth centers hangs in the balance. Layer on centuries of economic exploitation and

inequitable access to capital, and we understand that it is even more tenuous for Black people, Indigenous people, and people of color to build birth centers—especially when our commitment is to design with the most marginalized birthing people at the center.

Despite these obstacles and in the face of ever-increasing need, the two of us swing on a heavy pendulum between naiveté and boldness and scarcity and abundance, as we experiment with nonprofit community birth center models in two major metropolitan cities.

We are clear that the maternal and infant health crises in this country are not only problems of disparate outcomes but also of inequitable options. There are seven freestanding birth centers in Michigan and not one in the predominantly Black city of Detroit. There is one community birth center in Massachusetts and none in Boston. Why is this, when we know that birth center care improves the birth outcomes that healthcare professionals and politicians alike say are important (lower rates of low birth weight, fewer preterm births, higher rates of breast/chestfeeding, higher parent engagement); enhances the birth experience; and is cost effective? Studies have even shown that birth center care grounded in racial justice is protective for Black birthing people and improves autonomy and respect for all birthing people.<sup>38</sup> These benefits are attributed to care that “recognizes that the cultural identity of birthing people is a core part of the clinical encounter, incorporates a commitment to racial justice, and is grounded in the birthing person's agency and birth worker's cultural humility.”<sup>39</sup> Further increasing the number of Black midwives specifically in our communities is important, as “racially concordant care” (having a healthcare provider of the same race) is increasingly “associated with greater healthcare utilization, improved patient–physician communication, greater satisfaction with care, and reduced Black–White disparities in infant mortality.”<sup>40</sup>

It is time that community-based midwifery care be recentered in our communities. Recentering midwifery care would restore the sacred and social nature of birth. Black birthing

people would be honored, trusted, and supported to birth in our full power. Black midwives would once again be respected and revered healers, reestablishing the importance of community care in birth. We would no longer be forced to seek care outside ourselves and our own communities, because we would have the wisdom and expertise we need within our communities. Midwifery care that engages the whole family in pregnancy, birth, and postpartum care would support family engagement and nurture community kinship ties. Physical and emotional birth outcomes in Black communities would drastically improve with the high-touch, family-centered care midwives provide. And if all of these benefits do not appear enough to warrant large-scale investment, the cost savings alone justify significant investment. Cost analyses project “an annual savings of \$189 million with a shift of 1 percent of births from hospital to birth center.”<sup>41</sup> Midwifery care is high-quality, value-based care that saves lives and money.

Our courage as we do our work comes from the conviction that community-based midwifery care grows healthy and strong communities, from the power of being in this work together, and from the legacies of Black movement building. From abolition to desegregation to the birth of the reproductive justice movement, Black activists have a history of making the impossible possible. Our ancestors’ refusal to accept what is not right and not just led us to freedom. We refuse to accept highly medicalized birth and the racial redlining of midwifery. We aim to center Black midwives and Black birthing bodies as we grow exemplary models of community care. In her book *The Power Manual: How to Master Complex Power Dynamics*, Cyndi Suarez writes about liberatory power; in contrast to supremacist power, which focuses on domination and stems from scarcity, liberatory power is rooted in abundance consciousness and the transformation of what was once perceived as a limitation.<sup>42</sup> *The domination of obstetrics will someday be history, and midwifery will be the number one choice for birth care. Liberatory power is the power to create what we want to see in the world.* Thanks to our abolitionist ancestors, this power is in our blood. It is the substance of things hoped for and the belief in things not seen that fueled the underground railroad and the faith that pulsed through the civil rights movement and lives on in Black liberation movement activists of today.

We also share a commitment to caring for ourselves and each other as we work to make the impossible possible in

our communities. The day we met for the first time over Zoom, connected by our mutual public health mentor Dr. Renée Branch Canady, we were both working full-time jobs in public health and leading birth center planning on the side as volunteers. We agreed right then that overworking to the point of burnout to build sanctuaries for Black birthing people could not be the thing that “takes us out,” and that has been one of our mantras ever since. We started by sharing our stories of birth and becoming; why we chose midwives for our own births; and how we got to this place of leading teams of local birth advocates building birth centers. We talked about our families, our careers in public health, and what it meant to revere and work in service of community midwifery in this way—to embrace birth center development as persons who are not midwives. Between 2018 and 2020, we had countless virtual monthly coffee and tea talks, sharing ideas, budgets, strategies, tools, and wins and losses.

Our work is as much about the audacious goal of building birth centers where Black birthing people and midwives thrive as it is about healing and tending to the collective trauma of racism, scarcity, false histories, and limited thinking. During our combined thirty-five years of work in governmental public health, neither one of the big-city health systems we were involved with invested in the midwifery model of care—nor did the renowned schools of public health, where we delved into women’s studies and maternal and child health, teach the true history of the maternal health system in the United States. The public health field’s explicit focus in the early 2000s on “moving upstream,” so to speak, as a way to address racism as a social determinant of health,<sup>43</sup> had us, as young public health professionals, implementing programs that presumed that increased access to systems not designed for us would somehow improve our health outcomes.

The two of us also hold a mirror up for each other when our deeply ingrained government or nonprofit bias is showing—for instance, when we tensely move forward with the “well”-worn tools of funder-imposed urgency, perfectionism, and worship of the written word.<sup>44</sup> We make space for preparing and debriefing together as we practice being in radical relationship with each other, our funders, and our boards—growing shared leadership models and endeavoring to redistribute power within and outside our organizations. We remind ourselves often that there are enough resources available to meet our communities’ needs. Our greatest challenge

**Our greatest challenge is staying the course in the sacred design of the liberatory birth spaces of tomorrow while the structures around us are so deeply invested in the confines of today.**

is staying the course in the sacred design of the liberatory birth spaces of tomorrow while the structures around us are so deeply invested in the confines of today. Planning and strategizing together, we have felt “seen,” supported, encouraged—and stronger. In the face of uncertain funding, political will, and support—and with a commitment to centering values of safety, abundance, and liberation, and to birthing people who historically have not been centered—we understand that we are stronger and bolder together. We share a collective courage.

This leaning into each other in vulnerable ways is different from what we learned to do in “professional” settings and in our academic training, where white supremacy and heteropatriarchy call for staunch individualism. As we learned more about collective courage and the uniquely African American histories of economic cooperation and solidarity economies, we were brought back to a rich ancestral history. Black people on Turtle Island have always been discriminated against and marginalized, and therefore have always had to find ways to come together. Dr. Jessica Gordon Nembhard calls economic cooperation a stabilizing force.<sup>45</sup> Dr. Gordon Nembhard points to African American traditions of pooling resources to increase and democratize wealth; increase Black economic stability, group interdependence, and self-determination; and develop collective agency and action.<sup>46</sup>

In March 2020, as the pandemic locked down our communities and pregnant people scrambled for safe places to birth outside of hospitals overrun with COVID-19, we felt the call of Indian author and activist Arundhati Roy to recognize the pandemic as a portal. In April 2020, Roy wrote,

Historically, pandemics have forced humans to break with the past and imagine their world anew. This one is no different. It is a portal, a gateway between one world and the next. We can choose to walk through it, dragging the carcasses of our prejudice and hatred,

our avarice, our data banks and dead ideas, our dead rivers and smoky skies behind us. Or we can walk through lightly, with little luggage, ready to imagine another world. And ready to fight for it.<sup>47</sup>

A dear friend and advisor, Julie Quiroz of New Moon Collaborations—who helped spark the creation of Birth Center Equity<sup>48</sup>—invited us to expand our vision as we experienced what the twin pandemics of the virus and racism were revealing in 2020. Together, we dared to imagine (to remember, really) a different system of birth in the United States, centering midwifery-led community birth centers—this time, with abundant resources to flourish for generations to come. We coauthored “Birth Centers Are Crucial for Communities of Color, Especially in a Pandemic,”<sup>49</sup> and launched Birth Center Equity. BCE is rooted in the premise that, as a growing network of Black-, Indigenous-, and people-of-color-led birth centers, we can assess and set our priorities and collectively attract and direct resources at a level of scale and power that none of us could do on our own. BCE takes the principles of collective courage and solidarity economies<sup>50</sup> and aims to leverage collectively sourced resources (financial capital, wisdom, social capital, narrative) and allocate them for the betterment of the birth center ecosystem and, ultimately, improved health outcomes overall.

BCE was founded on values of safety, abundance, and liberation to grow and sustain birth centers led by Black people, Indigenous people, and people of color. Today, we are a network of more than thirty birth center leaders of color who—despite entrenched inequity and in active defiance of it—have successfully opened or are opening birth centers in our communities. Together, we are building community

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## **We are essentially reimagining the birth center model on local and collective scales by reclaiming ancestral principles of collective economics and bound liberation.**

among birth center leaders of color, growing efforts to transform the culture of birth, and stewarding capital to seed vibrant and lasting community birth infrastructure for generations to come. We are essentially reimagining the birth center model on local and collective scales by reclaiming ancestral principles of collective economics and bound liberation. Nwamaka Agbo, CEO of Kataly Foundation and managing director of the Restorative Economies Fund, puts it this way: “When communities come together to collectively own and manage assets, they can leverage their joint economic power to collectively assert their rights and exercise cultural and political power in a more impactful way than they would on their own.”<sup>51</sup> In liberatory economic models of birth centers, midwives—and communities—thrive.

### **OUR ANCESTORS' TOOLS**

Black lesbian feminist poet Audre Lorde wrote, “The white fathers told us: I think, therefore I am. The Black mother within each of us—the poet—whispers in our dreams: I feel, therefore I can be free.”<sup>52</sup> The two of us hold these words close in our work as a reminder of our origins and the depths of embodied wisdom within us. This assertion starkly contrasts with white supremacist ways of knowing, which routinely exclude embodied wisdom and Black women’s experiences from what counts as authoritative knowledge. Because white male obstetricians have historically dominated maternal health knowledge production in the United States, “authoritative knowledge” on the topic has long reflected their perceptions and interests. Maternal healthcare remains an area in which current evidence-based science from diverse sources is not fully reflected in practice, and Black women’s experiences continue to be deprioritized.

Our approaches to birth center development in Boston and Detroit intentionally center the lived experiences of Black birthing people and draw upon four dimensions of Black feminist theory or ways of knowing:<sup>53</sup> *lived experience as criterion of meaning*; *the use of dialogue in assessing knowledge claims*; *the ethics of caring*; and *personal accountability*.<sup>54</sup> We see these four dimensions as *organizing ethics*—moral commitments or principles that, when combined with the evidence base for midwifery care, have the potential to transform healthcare infrastructure development in our communities.

### **LIVED EXPERIENCE, DIALOGUE, AND KNOWLEDGE CLAIMS**

In *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, Patricia Hill Collins explains how knowledge reflects the interest and standpoint of its creators. Collins discusses how epistemology, or theories “used to assess knowledge or why we believe what we believe to be true,” is shaped by dominant power structures, highlighting that who we believe and why are rooted in accepted hierarchies of human value that devalue Black women’s voices.<sup>55</sup> Historically and traditionally in Black communities, lived experience is valued. Lived experience as a criterion of meaning is best understood in the saying “a heap see, but a few know.”<sup>56</sup> This saying differentiates observing from understanding, knowledge from integrated wisdom, reading and studying from living. In Black feminist epistemology, dialogue and connectedness (rather than separation and isolation) are essential parts of knowing that have African and African American roots. Dialogue builds community, call and response demonstrates understanding—and both require active participation of all people involved.

We drew on this tradition of living and connecting as a valid way of knowing as the basis of our community assessments, focus groups, and conversations. We started our birth center planning efforts by asking our communities about their birth experiences—their desires, their choices (or lack thereof), the outcomes.<sup>57</sup> From stakeholder interviews, focus groups, and community assessments in both cities, we learned that Black birthing people want more care choices, including midwives and birth centers. People shared experiences of not being heard and of feeling disrespected. People described what it felt like to go through the birth experience without birth care providers who looked like them, spoke their language, understood their culture and lived experiences, and truly cared for them and their families.



Birth Detroit organized a community launch-and-learn event, where cofounders shared our own experiences, midwife Jennie Joseph spoke about the midwifery model of care,<sup>58</sup> and we mirrored back what we heard in the interviews and assessments. We created large posters summarizing survey data, and made time for participants to do a “gallery walk” through the data, adding information, notes, and questions. It is essential to Birth Detroit as a community-born health initiative that Detroiters feel seen, heard, understood, and connected to birth center planning—and we created opportunities beyond the launch-and-learn for conversations about midwives, birth centers, and how we can reimagine birth care together, as a community. Birth Detroit provided toolkits and questions for kitchen table “birth talks” (small group discussions about midwives and birth centers), attended community health and early childhood education outreach events, and organized virtual provider and payor forums to introduce Detroit healthcare providers, private insurance, and Medicaid payors to the planned birth center and to invite questions.

Birth Detroit cofounders—a public health leader, a certified nurse midwife, a certified professional midwife, and a doula and health educator—also shared our personal stories of pregnancy, birth, and loss, and we made space for community voices and story sharing, legitimizing and centering our collective experiences and multifaceted view of maternal healthcare in our communities as actionable data. In addition to connecting with our communities and centering community voices, we stood in our power as established credible leaders proximate to the issue of birth care in our communities and with more than thirty combined years of experience caring for Detroit families. Birth Detroit’s birth center planning efforts since the community launch-and-learn event in 2019 have continued to prioritize connection and dialogue—even in the latest phase of birth center building design, where community members are invited to give input into interior, garden, landscape, and playground design.

## **ETHIC OF CARING AND PERSONAL ACCOUNTABILITY**

The spirit of care and leadership matter. The values that guide one’s speech, care, and leadership are essential elements of how healthcare and health systems leadership are experienced. The ethic of caring situates empathy, emotion, and personal expression as central to knowing. The ethic of caring has three essential interrelated components: *individual uniqueness and expression, emotion as a key part of*

*dialogue, and empathy.*<sup>59</sup> Put another way: *we are unique emanations of spirit; to be in touch with our feelings is a source of power; and where there is no empathy, there is no care.* In an ethic of caring, we are conscious not only of what is said but also of how it is said; not only that care is delivered but also in what spirit that care is delivered. Understanding the spirit of care and the ethic of caring helps us to understand why increased access to healthcare systems that devalue Black birthing bodies will never significantly improve maternal health outcomes in Black communities. Values of safety, love, trust, and justice fuel our birth center development efforts in Detroit and Boston; and Birth Center Equity is committed to growing birth centers that provide safe, culturally reverent, midwifery-led care for all.

Upholding an ethic of personal accountability means that we not only develop knowledge in dialogue with our communities—and share in ways that demonstrate respect and care—but also that we are accountable for our beliefs and to our communities for what we say and do with respect to what we know. In other words, what we speak of, represent, and create in the world are demonstrations of our “character, values . . . ethics”<sup>60</sup> and commitment to our communities.

From our experiences as public health professionals, we know that many initiatives survey and assess health behaviors and outcomes only to create interventions that act upon populations as the source of their own problems.<sup>64</sup> Far fewer interventions actually endeavor to disrupt white supremacy in the structure and leadership of healthcare and health systems. To date, most interventions that address Black maternal and infant health inequities aim to tweak existing systems with checklists, unconscious-bias education, and the integration of doula care—none of which fundamentally challenges obstetrics as the dominant care model or hospitals as the site for birth, despite compelling evidence of the need for these to change. Dominant strategies continue to center white people as the experts, financiers, decision makers, and institution builders of healthcare and beyond. It is not enough to declare a crisis or to say one cares about Black birthing people; such declarations must be reflected in an ethic of caring and translated into action—into real work toward a liberated future.

The economic model for birth care in this country has to change. The master’s tools do not work and have never worked for Black communities.<sup>62</sup> In sharp contrast to the 83 percent of US birth centers that are for-profit

businesses,<sup>63</sup> of the BCE network of thirty Black-, Indigenous-, and people-of-color–led birth centers (both established and in development), the majority are nonprofit. With the dominant financial model of birth center start-ups being personal savings or debt, the capital tools available to white entrepreneurs and the philanthropic investment given to white-led nonprofits have never been equally available to leaders of color. As such, many Black midwives have started their birth centers on shoestring budgets and been forced to choose between caring for themselves financially and sacrificing their personal salaries to provide birth care for their communities. Many developing BCE organizations have landed on the nonprofit structure as the only way to generate necessary start-up resources, leaving us to write endless grants, launch bake sale after bake sale, host backyard parties, sell bricks imprinted with donor names, and create crowdfunding and T-shirt campaigns to generate resources. It leaves even the most renowned and celebrated Black birth advocates—like our beloved mentor Jennie Joseph—to engage in endless fundraising efforts to solve for problems that we did not create and to care for our communities.

Personal accountability shows up in our work as not asking permission,<sup>64</sup> a bias toward action, and a commitment to leading our own care. GirlTrek, the largest African American women’s public health movement in the United States, says, “Never ask permission to save your own life”<sup>65</sup>—and history has consistently shown us that we cannot wait for others to respond to our needs. We cannot wait on the very healthcare-knowledge machine that delegitimized midwifery to champion it. Black people must reclaim midwifery now to save ourselves and our futures. Until the US healthcare system grapples with the true root cause of disparate maternal health outcomes—the legitimizing of knowledge and the distribution of money, power, resources, and opportunity based on a hierarchy of human value that privileges whiteness—interventions that maintain the status quo will continue to be funded and prioritized, and health systems will continue to be shaped by knowledge claims that devalue midwifery and Black bodies.

Linking Black feminist epistemologies’ assertion that Black women’s experiences can serve as a social location for “examining points of connection among multiple [ways of knowing]”<sup>66</sup> with the concept of targeted universalism (universal goals pursued by targeted strategies), we offer that improving Black birthing people’s experiences of birth care

can be the foundation upon which we examine and improve birth care for all birthing people. Consider: What would it look like to apply Black feminist epistemology to birth care as a whole in the United States? What if obstetrics and midwifery were both situated as valid standpoints of partial knowledge with the potential to make up a stronger whole? What if each group could consider the other group’s standpoint “without relinquishing the uniqueness of its own standpoint or suppressing other groups’ partial perspectives”?<sup>67</sup> What if true and authentic connections were attempted across historically entrenched lines of professional and philosophical division? What if we celebrated birth as a common thread, and made how we care for birthing people and families a shared moral, ethical, and economic priority?

## BELOVED COMMUNITY AND BELOVED ECONOMY

In his writing on centering Black epistemologies, Dax-Devlon Ross asks the visionary question, “Once we are liberated from the straitjacket of received histories curated to confine our imagination . . . what other options for organizing our affairs become available to us?”<sup>68</sup> We do not have to accept what is given simply because it is given. There is another way. It is time we move beyond the naming of the racist history, end the hold of obstetrics and hospital birth on our bodies, and courageously create alternative futures with midwifery and community birth at the center.

Neighborhood Birth Center and Birth Detroit are striving for ownership of ourselves, our care, and our futures. We are committed to working with community birth center leaders and philanthropic, investor, and policy partners to overcome capital and policy barriers and make birth center care equitable, accessible, and sustainable. We are committed to radical experimentation and investment in Black leadership to create a unique care system rooted in values of safety, abundance, liberation, and love.

Beloved community envisions cooperation, shared abundance, and collective thriving. Beloved economy invites us to consider what is possible when we decenter capitalism and center values of love, healing, and well-being. Rather than accepting that community birth centers are not sustainable economic models, we are broadening the conversation and asking: What if birth were at the center of a beloved economy? What if how we cared for birthing people and how we brought our babies into the world were a true

**We believe that when birth is held sacred, not only are individuals and communities transformed but also the public, the economy, and even the planet are healthier.**

moral, cultural, and economic priority? What is currently a boutique model of care available only to some should be a population-health strategy to heal our communities. From our own experiences, we know that childbirth is a portal through which people can be transformed—and we believe that when birth is held sacred, not only are individuals and communities transformed but also the public, the economy, and even the planet are healthier.

In a beloved community and a beloved economy, equity means ownership. Instead of retrofitting rented space in Boston and Detroit, our economic models involve buying sizable portions of city blocks to build from the ground up—including incorporating sacred spaces for collective care. We are working with designers, architects, city planners, and investors to build warm, inviting, beautiful healthcare spaces surrounded by community food and flower gardens and children's playgrounds. During our property search in Boston, a prospective seller gruffly asked why we insisted on buying when "it's so much work to own." He promised he would hold the risk as owner while we signed a multiyear lease to rent. Our response? "We want to buy for the same reason you don't want to sell. We want the asset." We cannot leave the sustainability of community birth to the whims of landlords or investors, or limit our growth by renting too-small spaces. Our big visions are to nestle our clinical care among movement leaders and care providers who provide holistic health and other services that build power; to include dedicated space for midwifery training, education, and student housing; and to work in solidarity with organizations and organizers who share our values and who are working toward a just and sustainable future. Midwifery and childbirth are the center of a beloved community and economy, and Boston's and Detroit's birth centers are love letters to our communities.

When we feel overwhelmed by the uphill battles ahead, we remember that "the Black mother within each of us—the poet—whispers in our dreams: I feel, therefore I can be free."<sup>69</sup> We think of the Grand Midwives of years past and the midwives working tirelessly today. We think of our grandchildren's grandchildren, and the world we are seeding for them—a world in which birth can be both gentle and empowering.

*How we birth matters.* Author and activist Alice Walker is said to have posited that "how we come into this world, how we are ushered in, met, hopefully embraced upon our arrival, impacts the whole of our time on this Earth."<sup>70</sup> Indigenous midwife Marinah Farrell offers that "reimplementation of birth as ceremony means babies can be born (and communities reborn) into an ancestral cultural ecology characterized by safety and cultural reclamation of healing."<sup>71</sup> Their wisdom delivers infinite possibilities.

A funder recently asked what the impact of our work would be. Rather than quantify the number of childbirth-ed classes taught or the number of babies born, we mused: What if we as Black birthing people were honored, trusted, and supported to birth in our full power? What if Black babies were born into rooms full of love and celebrated for all that they are and have the power to be? What will be the impact when midwives are once again revered as experts and healers in their communities? What will be the impact of Black midwives, Indigenous midwives, and midwives of color leading a reclamation of the tradition such that midwifery care is restored as the optimal care model in *all* communities? And we said unto that funder, "Fuck around and find out."

**Midwifery and childbirth are the center of a beloved community and economy, and Boston's and Detroit's birth centers are love letters to our communities.**

## ROOTED

by leseliey rose

we are bowls of light  
forgiving and remembering

we are mistresses of the moon  
keepers of stories, goddesses of the hunt  
becoming, remaking, reimaging—building together

we are mist from the heavens over gardens of holly  
womb holders of epic love stories past and futures deep  
we are flowers the sun never forgot

like the wisdom and roots of tall oak trees—we remember  
strong storms, righteous rebellion, journeys to new lands, resistance  
we dream winds of revolution  
we nurture the promise of safety and peace

we are descendants of underground railroad visionaries, masterminds,  
sojourners in love, joyful dancers and freedom songs  
we are ancestors seeding new worlds

we are bowls of light  
forgiving, remembering, and leading

we are curanderas, healers, and spirit-centered creators  
with backyard chapels and great-grand-basins  
from which to pour light and hold sacred space  
for babies, mamas, papas, families—and leaders—  
to be born in rooms full of love  
healing past, present, and futures

*born of radical love  
guided by the wisdom of Black women  
we are revolutionary leaders  
rooted in spirit, trust, joy, and vision*

*we are Birth Detroit*

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**LESELIEY WELCH**, a public health leader with a business mind and a visionary heart who holds love as a guiding value, a way of being, an action, and a politic, is cofounder of Birth Detroit, Detroit’s first freestanding community birth center, and Birth Center Equity, whose mission is to grow and sustain birth centers led by Black and Indigenous people and people of color across the country. Welch has nearly two decades of leadership experience in city, state, and national health organizations. She served as interim executive director of Birthing Project USA and deputy director of public health for the city of Detroit, and consulted in the development of Michigan’s first comprehensive LGBTQ health center. Welch taught at the university level for over fifteen years, contributing to the development of Wayne State University’s bachelor of science in public health program and creating courses on numerous health equity topics for undergraduate and master’s level public health students, medical students, and medical residents. Welch also lectured in the Women’s and Gender Studies Department at the University of Michigan, developing practicum courses on women’s leadership and nonprofit management, community engagement, and feminist practice. Welch has a BA in women’s studies, an MA in public health—with a certificate in women’s and reproductive health—and an MA in business administration from the University of Michigan. **NASHIRA BARIL** is the daughter and great-granddaughter of midwives, and birthed both of her children at home. Baril is the founder of Boston’s Neighborhood Birth Center—the first-of-its-kind community birth center—and cofounder and codirector of Birth Center Equity, a national strategy to rematriate full-spectrum capital to Black-, Indigenous-, and people-of-color-led birth centers. With a BA in women’s studies from the University of Massachusetts and an MPH in maternal and child health from Boston University School of Public Health—and nearly twenty years of experience designing and implementing public health strategies to advance racial equity—Baril brings a structural analysis and somatic practice to the design and implementation of public health strategies that advance justice and equity. Baril has worked at the Boston Public Health Commission, Harvard T.H. Chan School of Public Health, and Human Impact Partners.

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# Redesigning the Birth Experience of Native Parents

## A Case Study of Community Codesign

*by Adene Sacks and Thomas Both*

**T**he birth experience of expectant parents living in the tribal lands of rural Northern California can be harrowing. Everything from access to prenatal care to timing the journey to the hospital requires careful planning and savvy navigation of narrow roads and complex health systems. And that negotiation does not end at the hospital door. Rather, it shifts into a different sort of navigation: the too-common experience of being a Native person in a healthcare system that is mostly unaware of the historical trauma and cultural traditions that infuse the birth experience of Native people. Too often, the joy of a Native family's birth experience is tainted by fear, ignorance, and racial bias.

Over the last year, parents and leaders from tribal lands in and around Humboldt County in Northern California and medical practitioners from the local Providence St. Joseph Hospital have been working to better the birthing experience of Native parents.<sup>1</sup> This work emerged from the hospital's efforts to improve health outcomes for Native people in partnership with that community—an effort that continues beyond the story told here.

● The ultimate aspiration of this work is to redesign a more equitable healthcare system that will improve health outcomes for all. While we are far from claiming victory, we did land on a core belief that the work of changing systems occurs at the intersection of relational, actionable, and systemic work with those deeply embedded in the system itself.

## The work of changing systems begins with creating greater visibility of how a system functions, who it benefits, and who it harms.

Providence St. Joseph Hospital is a busy place. Like most hospitals across the country, it has been working intensely and relentlessly over the last three years of the pandemic to deliver care to those who live in and around Humboldt County. The hospital has a deep connection and commitment to the health of the community that extends beyond the doors of the hospital, and to the well-being of individuals. The hospital already had strong working partnerships with other communities, notably Latinx communities and also homeless populations, whose health disparities were strongly linked to their culture and existing societal inequities. This was not the case with tribal leaders and organizations, and the hospital's CEO understood that the hospital needed to establish trusting relationships with these groups before the work on improving health outcomes could begin.

From its base on the coast, the hospital serves Native people who live and work on land of nine federally recognized tribes and Rancherias, among other communities. Native people make up over 6 percent of Humboldt's total population, compared to just 1.3 percent nationally and 1.7 percent in California as a whole.<sup>2</sup> The preservation and vitality of Indigenous culture of the Karuk, Hupa, Tolowa, Wiyot, and Yurok people have benefited from the geographic isolation on this "lost coast" in Northern California. And while they did not suffer complete displacement, the Native communities here still experienced genocide, family separation, and repercussions for openly practicing their traditions.<sup>3</sup> It is only since 1978 that Native community members could openly practice their ceremonies and traditions in the United States.<sup>4</sup>

Before the "Better Birthing" team work began, Providence, which oversees St. Joseph Hospital, had made a significant financial and programmatic commitment to health equity.<sup>5</sup> Providence staff responsible for the health equity portfolio were exploring human-centered design as a way to integrate community needs and boost creative solutions to local health equity challenges. There was growing understanding at Providence that the path to improving community health outcomes was highly dependent on the involvement of those most impacted—in this case, Native patients. Providence St. Joseph Hospital in Humboldt County was selected to receive funding for this work in part because staff had

already recognized the need to increase relational trust with Native people on the path to improving health outcomes.

### HOW IT HAPPENED: THE PROCESS OF COMMUNITY CODESIGN

The core of the community codesign process that anchored the Better Birthing work will be familiar to those who know human-centered design.<sup>6</sup> It began with lived experience interviews, sensemaking of those interviews with an eye to identifying opportunities for change, and then moved into ideation and prototyping to create and advance solutions. Unlike more traditional design approaches, the Better Birthing design process viewed the community as the designers of new solutions rather than solely informing the work. This meant that the work involved multiple people and organizations at every stage and that the project team comprised key stakeholders in the perinatal care system. The work is messy, nonlinear, and ongoing. For simplicity's sake, we offer a high-level description of our learnings:

**Map the system you are trying to change.** All of us are constantly navigating multiple social systems: the education system, the healthcare system, our family system. It is challenging for anyone to see the full workings of any complex system. That is especially true if you are comfortable with your place in that system. The work of changing systems begins with creating greater visibility of how a system functions, who it benefits, and who it harms.

At the start of the Better Birthing work, Providence brought in an outside consulting team from the With/In Collaborative (the authors of this article) to map the systems that support a Native parent's birthing experience.<sup>7</sup> We spoke with dozens of stakeholders; discovered what organizations and people affect pregnant patients directly and indirectly; and, ultimately, created a visual of how these stakeholders are organized and connected to one another and to the hospital. We came to understand that the hospital was both geographically and physically distant from the birthing experience of many Native patients. Often, the hospital was the literal "last stop" for parents—who sometimes arrived at the hospital for the first time when already in labor—rather than a persistent player in the continuum of care during pregnancy.

## The act of interviewing Native parents as a team was a deeply moving shared experience that created a collective body of knowledge that was independent of any one person's experience or expertise.

**Build a team that mirrors the people from within that system.** The process of mapping the birthing system also helped to identify the people who should be intimately involved in the design work. The original Better Birthing team, nine members strong, included an obstetrician, a Native labor and delivery nurse, a Native childbirth educator, a community-based social worker, the head of the hospital's NICU, Native parents, and Native elders. The team's composition mirrored the tensions, power dynamics, and history that currently exist in the local birthing system. Native wisdom was put on an equal footing with medical expertise; and team members were recruited, in part, for their dissatisfaction with the current set of supports for Native parents and their ability to spur change across the community. By design, the team's dynamics were a microcosm of what would need to be navigated more broadly in the system itself.

From the start, there was warranted skepticism by Native team members about the motivations and commitment of Providence St. Joseph Hospital and the consultants. One Native team member described it like this: "I felt unsure about this project and if this was just another way an [organization] was going to come in and say, 'Oh, look at the great work we did,' and then call it a day. I was also nervous about having outside consultants come in to work with a team. This all made me question joining this group. Would I be a pawn of exploitation?"

It was no small task for the team to hold their fears and suspicions while moving forward together, but the design process helped to relieve some of the tensions. To begin with, the team members spent time sharing their personal stories and identities, including how their own experience of birth informed the work that they do. We invited the team to come to meetings as themselves rather than as their expertise or job titles. This worked to reduce some of the power differentials within the group, and created a path for building relationships. Later in the process, the act of interviewing Native parents as a team was a deeply moving shared experience that created a collective body of knowledge that was independent of any one person's experience or expertise. It

is also clear that the hospital's willingness to acknowledge its contribution to how systems at the hospital and in the community have created harm and perpetuated racial bias created goodwill in the team and the Native community.

That said, the tensions that existed at the beginning continued to show up in the team's work with one another throughout the design process. This reality fueled our learning, often changed our approach, and served as a constant reminder that pain, guilt, sadness, and bias remain ever-present in the effort to change broken and historically racist systems. Especially for the non-Native team members, it was important to continually acknowledge that non-Native people will never fully understand the experience of Native people, even when moving forward together.

**Deeply understand the stories of those most impacted by the system.** The guiding force of the team's work were the interviews that they conducted with eleven Native parents who had recently given birth. Starting with deep listening to personal stories anchored our understanding about the birth and perinatal care experience of Native parents and fueled our thinking about what needed to change.

What the team heard from Native families was that they often experienced disconnection and fear alongside the joyous overwhelm of birth. We heard stories of Native parents struggling to support Native birthing traditions in a hospital environment. And we heard too many stories that featured cultural ignorance and missed opportunities for comfort and care. We came to understand through these stories that the experience of many Native parents giving birth at a hospital is intimately connected to the devastating history of how the state and institutions have treated Indigenous people in the last two centuries. As our team retold these stories to one another, we also came to believe that the institutional birth experience holds the possibility of repair and connection.

As one team member reflected: "It was really hard to hear what things occurred to patients. I wanted to learn all that I could to fix the situation, and it took time for me to understand that some things [(traditions, ceremonies, and so on)]

## Native parents lean heavily on family and tribal support systems during their pregnancies and during the birth. They need advocates, doulas, and nurses who understand their community and traditions.

are not appropriate for me to know as a non-Native person. I also can't believe how I grew up and always lived in Humboldt County and never knew about the history and traditions of our Native communities."

**Move from stories to the parts of the systems you want to change.** The team spent many hours unpacking the experience of each birth parent and the systems and services that affect them. The hope was to understand the barriers to and opportunities for improving each parent's birth experience. Ultimately, the team's sensemaking created clarity about what threads of work to pursue. Honoring what the team now understood was important to Native parents, we articulated three strategic areas that the team felt might be most impactful for parents:

### ■ **Increase the personal agency of birthing parents.**

Often, parents struggle to be heard during their birth experience. Patients need their wants and wisdom to be heard by hospital staff. Ironically, the team realized that the hospital also struggled to communicate to new parents what decisions they could make. There was a communication gap that created misunderstandings and fear.

### ■ **Support the presence and voice of Native advocates at the bedside.**

Native parents lean heavily on family and tribal support systems during their pregnancies and during the birth. They need advocates, doulas, and nurses who understand their community and traditions. During the pandemic, when the hospital had to severely restrict who could attend a birth, Native patients suffered. The team saw an opportunity for the hospital to create a more inclusive and supportive environment for Native patients by supporting and expanding the role of Native advocates, especially at the bedside.

### ■ **Cultivate cultural responsiveness institutionally at the hospital.**

Native parents struggle to integrate Native birthing practices with hospital protocols. Many birthing mothers experience discrimination,

lack of cultural empathy, and pushback on practicing traditions from medical staff who are ignorant of their history. Birthing has the opportunity to be a moment of connection to culture and community support systems for Native parents. It is also an opportunity for the hospital to support that connection, instead of creating disconnection.

**Shape the Interventions.** Regarding the above three strategic areas, the team discussed and weighed multiple interventions to pursue. Some solutions were more clear and some less so. Some of the experiments moved forward but many didn't. Admittedly, there was a lot of ambition without full clarity at the time about how things would unfold. The team brainstormed how they might address each strategic area and also who else should be involved from the hospital and from the community, because the viability of each experiment was highly dependent on having partners in the community with time, capacity, and interest to join in the work.

One experiment the team was eager to try focused on redesigning the intake interview that all birthing parents experience when they first arrive at the hospital, before they are admitted and placed in a birthing suite. The hope was to promote the birthing parent's agency and the intake nurse's cultural responsiveness by rethinking what questions might improve communication from the start. This idea quickly shifted after hearing from labor and delivery staff about the many constraints of that intake interview from the hospital's point of view, including the realization that the interview was often conducted when the birthing parent was enduring the pain of labor. The experiment was redirected to focus on how we might educate both parents and medical staff about each other before patients arrive at the hospital. This early idea ultimately evolved into our redesigned birth plan (see below).

## WHAT HAPPENED NEXT: MULTIPLE EFFORTS AT EXPERIMENTATION AND IMPLEMENTATION

At this point, our original team of nine people became multiple teams that included community leaders and other organizations. There were about a half-dozen efforts under way

## With an eye to promoting better communication and cooperation between parents and the hospital, the Better Birthing team experimented with using a birth plan.

simultaneously as we did our work—some very structured and time bound, others more exploratory and longer term. What ultimately emerged was a commitment to projects that seek to provide the care Native parents want versus what they have experienced in the past.

Some of the projects that moved forward were focused on filling knowledge gaps about Native people in the healthcare system. We created a one-page internal document for medical staff that describes how the history and traditions of Native people may influence their approach to their medical care. We organized trainings with a local Native midwife for labor and delivery staff to learn about Native birthing traditions. And we worked to disseminate what we learned from Native patients to other important stakeholders in the birthing system (lactation consultants, childbirth educators, family centers, and so forth). Ultimately, the team focused most of its time and capacity on three major areas of work. These included:

**Changing California state law.** Until recently, California state policy required that all families register the birth of a child with the hospital by the tenth day of life. This practice often conflicted with the period of sacred ceremonial blessing and naming of a newborn in local Native communities on the tenth day.

The effort to change state policy emerged from the stories told to the Better Birthing team by Native parents and by hospital administrators. We heard from parents how offended they were by the constant requests by hospital staff to reveal their newborn's name before they left the hospital. In turn, hospital staff were frustrated that their attempts to prevent families from incurring the additional cost and paperwork involved if parents missed the ten-day deadline to register their child were experienced as ignorance and cultural insensitivity.

Changing state policy was not something that the Better Birthing team could do alone. Team members from the hospital recruited the government affairs team at Providence to determine the viability of this effort. The head of Providence's team then arranged for members of the Better Birthing team to present their findings to California State Assembly member Jim Wood, who agreed to draft the legislation and

steward the effort through the state legislature. Ultimately, the team solicited over forty letters of support from local and statewide tribes, healthcare organizations, and leaders before it went before the state assembly; and Native parents allowed the Native doctor and the tribal council member—who ultimately provided testimony to lawmakers—to tell their birth stories. As one team member reflected: "I liked that the hospital was able to use their power to lift up local Native voices and experiences, even though this action did not directly benefit the hospital."

On June 22, 2022, California Governor Gavin Newsom signed CA Assembly Bill 2176 into law.<sup>8</sup> This bill extends the time all families have to register the birth of their child, from ten days to twenty-one days.<sup>9</sup> This new law removes that irritant in the relationship between Native patients and medical staff; more important, it signals the willingness of the state to be more respectful of sovereign First Nations practices.

**Leveraging a parent's birth plan to cocreate a culturally responsive birth environment.** Many Native parents we interviewed described feeling unwelcome upon arriving at Providence St. Joseph Hospital, nervous about how they would be received and unclear about what choices they had regarding the birthing experience there. We heard from parents that they felt that traditional baby baskets, food, and medicinal plants were not welcome at the hospital. Others had concluded that the hospital was racist after being administered a drug test at intake—when in fact that test is administered to all birthing parents.

With an eye to promoting better communication and cooperation between parents and the hospital, the Better Birthing team experimented with using a birth plan. Birth plans, which typically express a parent's hope for the birth experience and make requests of the medical team, are not a new idea. But those hopes and requests are often out of sync with the hospital's requirements or the medical realities of that parent's birth experience.

The redesigned birth plan attempts to bridge the gap in cultural responsiveness and knowledge between parents and the medical team. We found that, typically, the medical staff present at a birth are unaware of how a patient's race,

## The hospital is continuing to build relationships with tribal leaders and Native patients on the path to addressing health disparities in the community together.

ethnicity, or religion impacts their decision making and preferences. The redesigned birth plan prompts parents to describe how their traditions influence their decision making around the birth experience. For example, if it is the Native parents' tradition to keep the placenta or umbilical cord, the birth plan prepares parents to bring a cooler for storage; sign a specific form of release; and designate a family member for transport. The birth plan is also an opportunity for the hospital to express its support of Native traditions by declaring, for example, that Native baby baskets and traditional medicinal plants are welcome in the birthing rooms.

Likewise, parents are often unaware of which hospital procedures are elective versus required. The birth plan makes explicit what is standard medical practice at Providence St. Joseph Hospital. It provides clear decision points, so that parents can decide on their preferences ahead of time—for example, to have either intermittent or constant baby monitoring, or whether or not to have an intravenous lock for medical interventions when it's not clearly warranted.

How to use and integrate the new birth plan is still a work in progress at prenatal clinics and at the hospital itself. And the team is interested in adapting the birth plan to also reflect the needs and language barriers of the Spanish-speaking populations in the community. Ultimately, the goal is for the birth plan to become a way for local care providers to express their cultural responsiveness and questions in a way that invites more collaboration with the birthing parent.

**Changing the hospital environment to reflect the communities it serves.** As luck would have it, the hospital had recently received funding to remodel its birthing unit just as the Better Birthing team began its work. This allowed the hospital administration to address early feedback the team had received from parents and members about what it felt like to be at the hospital as a Native person. Parents observed that the pictures hanging on the walls did not reflect the cultures of all those giving birth there, and that the birthing unit felt sterile and institutional.

The Better Birthing team, other Native leaders, and representatives of the local Latinx, Black, and Hmong community

worked with the hospital to create a space that was more representative of the community. They suggested that the hospital bring elements of the incredible rivers and trees of Humboldt County into the space for both inspiration and because it “felt like home.” The team selected pictures for the walls that were not only racially representative but show women breastfeeding and men nurturing their newborns. Finally, the hospital was able to purchase incredible artwork from Native local artists that reflects Native traditions.

### THE WORK CONTINUES

Beyond these concrete attempts to shift the birthing experience of Native parents, the hospital is continuing to build relationships with tribal leaders and Native patients on the path to addressing health disparities in the community together. Internally, the hospital is experimenting with how it can provide high-quality care that embeds more cultural responsiveness through staff training (especially staff new to the community) that prioritizes respect for patients and understanding of local populations. And externally, the hospital is looking to connect with parents before they arrive at the hospital to give birth. The hospital now sends two labor and delivery nurses at a time to clinics in Native communities to participate in prenatal care and education. This partnership was the idea of a local Native parent, who then brokered the partnership between the hospital and the clinic.

The work of the Better Birthing team is also continuing to evolve. Recently, the team received the 2022 Leighton Memorial Award by the CARESTAR Foundation for its success in addressing inequity in hospital care in a rural or tribal community.<sup>10</sup> Beyond the immense honor of receiving the award, it also funds the expansion of the Better Birthing work. The team has decided to focus the next chapter of its work on culturally informed postnatal care for Native parents.



The ultimate aspiration of this work is to redesign a more equitable healthcare system that will improve health outcomes for all. While we are far from claiming victory, we did land on a core belief that the work of changing systems

occurs at the intersection of relational, actionable, and systemic work with those deeply embedded in the system itself. To the Better Birthing team, this meant giving time and space to truly understanding the current and historical impact of our communal systems on those most affected; committing to building relationships through concrete work together; and aligning solutions with people's needs.

In the case of Humboldt County, the work of building relational capital and trust through deep listening and joint project work has begun to shift how Providence St. Joseph Hospital and the surrounding Native communities relate to one another. It has not gone unnoticed that the hospital used its power to lift up Native voices in the community and across

California. Native team members have reflected that this work has given them hope for a different future; but they also caution that this is just a small step of repair in a system that has perpetuated harm toward Native people for hundreds of years, and will mean little if it does not continue apace. To those in pursuit of just systems that equitably serve all, this is a reminder of both the hope and the realities ahead.

*In addition to the many tribes, Rancherias, organizations, and individuals who provided letters of support for AB2176, we would also like to thank K'ima:w Medical Center, United Indian Health Services, Two Feathers Native American Family Services, the Yurok Tribe, and the Native parents who provided guidance on the Better Birthing journey.*

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**ADENE SACKS** and **THOMAS BOTH** are members of the With/In Collaborative, which strives to work with and in communities committed to dismantling barriers to justice and redesigning a different future together. Sacks is a social systems designer and philanthropic advisor who happily wears many hats. She is cofounder of With/in Collaborative, program director of the New Leadership Network, and coauthor of *Leading Systems Change* (*Stanford Social Innovation Review*, 2020). Both is a designer and design educator, whose passion is helping people understand the practice of human-centered design—and people's ability as designers—in order to innovate how they learn, think, and solve problems. He is director of the Designing for Social Systems program at the Hasso Plattner Institute of Design (d.school) at Stanford University.

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# Living into a Childhood Commitment

## A Conversation with Cyndi Suarez and Kaytura Felix

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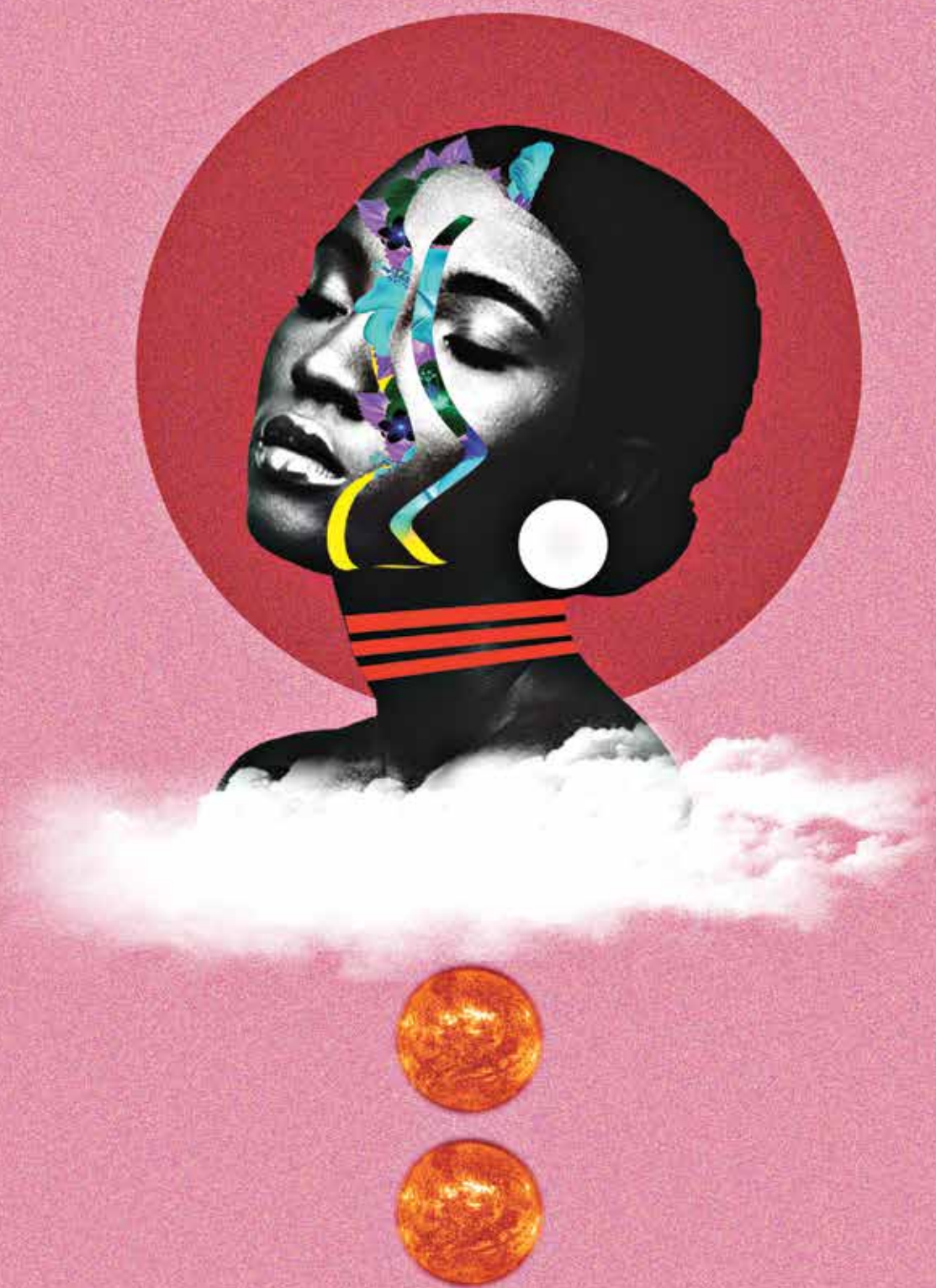
“What have I learned about health justice? I think what I have learned is that all of us have a part to play in it. You don’t think of the system as one focused primarily on health. Sometimes these systems do not support health. Health is very complex, and there’s what the system says it’s supposed to do and then there’s what the system is actually designed to do and what it delivers.”

*In this conversation between Cyndi Suarez, NPQ’s president and editor in chief, and Kaytura Felix, Distinguished Scholar, Department of Health Policy and Management, at Johns Hopkins Bloomberg School of Public Health, the two leaders discuss medical racism, health justice, and what it really means for a system to support people’s health.*

**Cyndi Suarez:** Thank you so much for taking the time to have this conversation with me, Kaytura. There is a lot that I want to dig into about your work, starting with something you said in an address at the Robert Wood Johnson Foundation’s Interdisciplinary Research Leaders fellows’ event. You said that you chose to become a doctor as a child growing up in Dominica and seeing inequities there. And I’m wondering if you can take me back to that time and paint a picture of what that little girl experienced and how it started you on your professional trajectory.

**Kaytura Felix:** That little girl saw a lot. And she saw a lot in a place where the mantra was that children should just be seen and not heard, right? My mother was a teacher; she taught in rural areas, and during the week we lived in a small hamlet in the mountains of Dominica—mother, father, three kids, and a housekeeper, who traveled with us. And I remember my father dropping us off at a clinic because my brother had some kind of skin infection on his ear. We walked into the building, and there was a bunch of doctors’ offices there, and she picked up the phone in the hallway outside the doctor’s office and said, “Dr. McIntyre, I’m here.” She then put down the phone, and we walked right in. The interaction took maybe five minutes. The doctor looked at my brother, wrote a prescription, and handed it to my mother, and we walked out. And when we were outside the building, she realized that she hadn’t paid him. So, we went back in and she called him again. And after a brief moment, she walked back into the office, trailed by her three children. There was an exchange of money—it was probably about fifteen dollars. I knew it was a





# “I said to her, ‘Mammie, when I grow up, I’m going to become a doctor. I’m going to become a doctor and provide free care.’”

lot of money. When we walked out, I noticed that there was a bunch of people waiting to be seen. They were poor, they were Black, and they were from the rural villages. They looked dusty and tired. It was between eight and nine a.m., and they had probably woken up at three o’clock in the morning to get to the doctor’s office, because the roads were bad. They would have had to drive long hours to get into the town. Even then, I understood that they were low down on the hierarchy within Dominica. So, after that transaction, I said, “Mammie, what happened there? Did you pay the doctor?” She said, “Yes.” “How much?” I asked, and confirmed the price. And I said to her, “Mammie, that’s a lot of money. How are those people, those poor people in there, going to afford to pay that kind of money?” And she was silent. And I said to her, “Mammie, when I grow up, I’m going to become a doctor. I’m going to become a doctor and provide free care.”

**CS:** And how old were you?

**KF:** Eight. And I kept the spirit of that stance. I went to medical school. And what has always been important to me is what happens to those on the margins. I was a financial aid student in medical school. I got grants, I got some scholarships. And you had to write thank you notes to your benefactors about the things you cared about. What I cared about was poverty, poor people, and those on the margins—those with less material resources. And that has guided my work. It guided me when I was an undergrad, and in medical school. It has also guided the choices that I’ve made—going into general internal medicine and then into research. I practiced briefly, but I realized that taking care of patient after patient wasn’t where the action was for me. I never practiced in Dominica. I immigrated to the United States in the mid-1980s, living on the East Coast. My undergrad years consisted of two years at Hillsborough Community College and then two additional years at the University of Florida. And then I went to [Weill] Medical College, Cornell University, in New York City—and I did a residency at Columbia Presbyterian Hospital in New York City. Then I did more studying at the Johns Hopkins schools of medicine and public health. But when I saw patients in Washington Heights, in New York City, Black and Brown people would come in about their blood

pressure—they were worried about the violence in their communities, they were worried about their grandchildren in jail. It was the violence in the streets, it was the family problems they were having, that consumed them. These are the things people brought to their healthcare providers. And there was no time for that. It was in and out. So, what I’ve been really concerned with is working upstream—just going as far upstream as I can so as to go deeply into the system and see what affects people. I mean, every part is important, but that’s the part that I most care about. *Upstream is where small, just actions can have big impacts on many people.*

**CS:** You’ve been a leader in this work for a long time, probably even before people were really talking about health justice in quite this way. It seems like you were seeing this landscape before it became what it is now: a field that people study in health justice. I noticed that you have held different roles within the Health Resources and Services Administration, and were an HRSA senior advisor and a director of the Office of Quality and Data. As a senior advisor, you launched the Community Health Applied Research Network—which I’ve read is “the first patient-centered outcomes research program for underserved communities”<sup>1</sup>—a network that centered under-resourced communities. You’ve also been chief medical officer within HRSA. You’ve consistently focused on minority health. You helped launch the National Health Plan Collaborative, aimed at reducing racial and ethnic disparities within large health plans, and you also contributed to the first National Healthcare Quality & Disparities reports.<sup>2</sup> I am wondering, as you keep moving upstream, what have you learned about health justice through all of this work that you’ve led?

**KF:** That’s an excellent question. What have I learned about health justice? I think what I have learned is that all of us have a part to play in it. You don’t think of the system as one focused primarily on health. Sometimes these systems do not support health. Health is very complex, and there’s what the system says it’s supposed to do and then there’s what the system is actually designed to do and what it delivers. The system is organized around sickness. Some describe it as a sick-care system. And it’s a transactional system that profits when people are sick. I tell people, “I didn’t learn

# “The way we engage with health right now is not about justice. That’s what I’ve learned.”

about health in medical school." I was saying this even while in medical school. I didn't learn about how to take care of my own health. I had to learn how to take care of my health by going outside the medical establishment. So, I'm probably not typical, in that I was in the system and was distrustful of the system, right? That little girl who saw that kind of injustice knew what that system was about. I couldn't articulate it, but I knew. I remember being in medical school, and I was very sick. My best friend (who is still my best friend) was saying that we needed to go to the doctor, and she kept on pressing me. And I wouldn't. She said, "This is crazy, you are sick, let's go!" I was rolled up in a little ball, and I blurted out to her, "I'm scared of doctors." She was like, "What?" And I was shocked that that was what actually came out of my mouth. And so where I'm going with that is that the system does not work for most people, and I believe that every part of the system needs to be reimaged. The financing needs to be reimaged, the delivery of care needs to be reimaged, the way care is evaluated needs to be reimaged—every part of the system. The way we engage with health right now is not about justice. That's what I've learned.

**CS:** In terms of having had to step outside of the system to learn about health, can you give an example of how you did that?

**KF:** One example is observing myself—observing my overall health, observing my weight—the space that I take up, observing even the stress in my life, right? Stepping out of the health system is learning practices like meditation. An important action of mine was moving toward Chinese medicine and acupuncture, looking into all these different traditions and modalities. So, I learned more about health by going into these different traditions—by taking a more active role in preserving my health through yoga or Qi Gong, for example; by being rigorous about the amount of sugar and flour in my diet. I felt comfortable going to these other traditions because when I was growing up, when we got sick at home, our first line of defense was what we called “bush tea.” My mother would make a tea for this, a tea for that, a tea for the other. And it was only when that first line of defense didn't work that we would go to what we describe as “the healthcare

system.” Moreover, I believed in my heart that God had given all the peoples of the world different healing knowledge systems. Healing knowledge systems could not possibly be limited to the Europeans, from whom our medical system arose. And the system we have right now is neither about health nor is it about care.

**CS:** I have very—apparently—good access to healthcare. But I don't use it often. I pay for my health insurance, which is pretty substantial, but I do a lot of alternative medicine, and I also do yoga every day. And when I go to the hospitals, I'm an anomaly for them. They're not used to people being healthy and knowing how to be healthy—it's not the norm for them. They don't know why I'm coming for checkups, because I'm fine. I had a doctor tell me that I don't have to come every year. The fact that I eat well and that I'm not overweight is just shocking to them. It shouldn't be an anomaly, but it is.

**KF:** But it is. And they themselves are struggling with their health. I've not met many doctors who are themselves healthy. Doctors are suffering from all the things that people are struggling with in the wider society. That is a hard reality. Doctors who know about health have developed that knowledge outside of the medical establishment. They are some of our heroes.

**CS:** Right. I got into Ayurveda pretty early on, and it was very interesting to know that there is actually a science of health, and that's Ayurveda. With colonization, it was driven underground, but it's making a comeback. I've been a client of Dr. Joshi, who practices Panchakarma, which is a super intense six-to-eight-week cleansing/detox. I learned about this whole other world. And there's a Chinese herbalist in Boston I go to, and I see a lot of people from communities of color there. It's translatable.

**KF:** People understand it. They get it at a fundamental level. I recently learned from Dr. Carolyn Roberts, a professor of history at Yale University, and from historians of colonization, that when the Europeans went to West Africa in the seventeenth century, they came into contact with an advanced system of healing that drew off of plants and herbs.<sup>3</sup> They drew on that “medical intelligence,” as Roberts described it,



**I consciously bring spiritual resources to my endeavor. This is not just about me, right? I live in a world where there are other actors—like you and me—who are aligned; but there are also actors in the spirit world, who support me and us. And I call on those actors.**

to maintain their health, and transmitted that knowledge, along with plant specimens, to British institutions such as the Royal Society of London and what today is the Royal Botanical Gardens, Kew. Historians and other social scientists are working to uncover what happened to that vast body of knowledge.

**CS:** You also talk about the power of leadership—and I know that when you went to the Robert Wood Johnson Foundation, your aim was to combine this work with leadership. Can you say more about how you think of leadership in this realm and what you did at Robert Wood Johnson around that?

**KF:** I'd been studying leadership for a long time when I joined RWJF. I was always very attracted to what was happening in the leadership space, and I was reading journals like the *Harvard Business Review*, and I was just really taken with the innovation that that journal was reporting on—people were actually thinking of solving problems. Now, mind you, what was behind that was how much money they were going to make—I recognized that; but I also recognized its significance, and that people were tackling big problems. And it just didn't seem that people wanted to do that in medicine. There was just the status quo, and people were unhealthy, people were sick and dying, but that was okay. Even in research, so many people were asking very small questions while the big questions were ignored. It was the early aughts. I felt that I didn't belong in that space. So, I very quickly abandoned that space and began my own practice of leadership, trying to be the change that I wanted to see. I read lots of books. Books like *Nice Girls Don't Get the Corner Office*, *The Seven Habits of Highly Effective People*, *The Effective Executive*, for example.<sup>4</sup> But I wanted more—not for myself, but for us poor people. *Black and Brown people. People of color.* And I was impatient. I wanted change and I wanted it now. I think sometimes people didn't understand that. People I worked with kind of *undersaw* what I was

doing—there was a perception that it was about my own personal ambition, about trying to get ahead. It wasn't.

**CS:** It seems like you're saying that even in these different organizations where you were working, there wasn't the understanding of leadership. That wasn't a thing.

**KF:** It wasn't a thing. And when I was at the university, for example, there were people advising me to take a big data set, write lots of papers, and get promoted. But that was not what I was about. That's never been what I'm about. And so initially, in many ways I failed as a scholar. And I failed as a leader. My first attempt at leadership was a failure. Why? Burnout. Unhappiness at work. I was hyperfocused on my goals and not really connecting with the people I was working with—because I had not as yet internalized that the means and ends needed to align. I had not yet learned how to embody the change that I wanted to see. There was a disconnect between what I wanted and how I was showing up every day with the people around me. I went through some jobs pretty quickly. There was just dissatisfaction. There was not a lot of joy or health for me in these roles. And I think a turning point for me came around when I turned forty. It just became so clear that what I was building and doing wasn't working. It was fragile. And my marriage collapsed.

**CS:** Where were you at the time in terms of your job?

**KF:** I was director of the Office of Quality and Data at HRSA's Bureau of Primary Health Care. But it was just clear that my life was not working. And I had a spiritual awakening.

**CS:** So, that was the next question. You call yourself a spiritual activist, and I'm wondering if you can share what you mean by that and how that informs your work.

**KF:** Last time we met, you said that your vision is so big that you're not overly bothered by what's happening *here*. I loved that. I consciously bring spiritual resources to my endeavor.

This is not just about me, right? I live in a world where there are other actors—like you and me—who are aligned; but there are also actors in the spirit world, who support me and us. And I call on those actors. I call on those ancestors. I invite them in, I talk to them, I seek their guidance. And I do this consciously. It's something—an aspect of African worldview—that is totally aligned with my faith tradition, which is that this world here is just a world, not *the* world. There are many worlds of God, and this is just one of them. So, when I understood that my time is endless, I stopped stressing over small shit, you know what I mean? Of course, I get treated like everybody else, I go through tough times like everybody else—but I don't overly stress. I never lose hope. Because I have time. There is time.

**CS:** What do you mean by that?

**KF:** If I don't learn what I need to learn here, there are other worlds. And the only thing I leave with is my consciousness. When I die, everything but my consciousness stays here. If I don't get it here, I'll get it elsewhere.

**CS:** How does that affect your leadership? How you approach leadership now? You said you had crashed a little bit and then you had this awakening. . . .

**KF:** I approach leadership now from a very different place. For example, it's no longer lonely. It's not competitive. People say it's lonely at the top—well, I'm not at the top of anything, you know? It's subtle—I mean, yes, I'm in a hierarchy at RWJF, but I don't engage it like I'm below anybody or above anybody. And I don't expect people to approach me like that, either. And that feels so radical to people. I don't expect people to bow down before me; I don't expect them to cater to me. And I don't expect to bow down or cater to others, either. I put my cards on the table, and I invite others to put theirs on the table so that we can figure things out together. I see my role as leader as holding the vision, holding what it is we're trying to do here and how we're going to do it together. Leadership is a process that I engage in, and not necessarily who I am.

**CS:** Is that when you moved to Robert Wood Johnson? Or just shifted more toward philanthropy and supporting leadership?

**KF:** It was a process. If you look at my CV, you can see I was chief medical officer for a year. And I was just losing my mind. The job was not working for me; it was killing me. It wasn't working for the organization either. Fortunately, at the request

of my boss, I moved to another part of the organization. And for about a year or two, my workload decreased dramatically. I read. I took a memoir-writing course. I was able to reimagine my life. It was the best. It was a much-needed respite, because for years I often worked in the office from seven a.m. to six p.m. I was often late picking up my daughter from aftercare. I was one of those mothers who had to pay late fees in aftercare or get caught speeding while rushing to pick up their child. It also helped me to connect more deeply with my daughter.

**CS:** That's amazing. What was the pivot?

**KF:** The pivot for me was around a different understanding of leadership. My mission became *not* being the person who needed to be on top so as to be able direct people to take action. You know, there's this idea that you have to get to a certain place for you to be able to take on that role, and everybody is always looking for who is the highest ranking person. I, too, had internalized that kind of striving—wanting to get to a place before I could be the change that I wanted. That is a joke, Cyndi. All of us have a role to play in this change, and we start now, wherever we are. So, I went to coaching school. Guided by my faith, I spent four or five years getting trained in ontological and generative leadership. I'm not talking about book learning only; I'm talking about *understanding what it means to be fully human*, unlearning the many unhealthy habits (competitiveness, thinking small, insecurity, disconnection from my body) that I had picked up over the years in school, in my family, and in wider society. And I began to see myself as somebody who serves. I remember the first time that I really understood that in my body. So, I had this pet peeve. Whenever I had to fill the paper cartridge before using the office copier, I would be rageful and resentful, thinking not only that I was doing someone else's job but that it was beneath me to do so. My time was too important. I remember one moment when I started with the rage and resentment drama and something inside of me softened. It shifted. I just let go of those two destructive emotions. I understood then that refilling the paper cartridge was no less important than being invited into a meeting with the highest-level person in the organization. It was all service to the mission. That was a powerful experience for me. I felt free, no longer bullied by rank and position. That's a big deal for someone who grew up in a colony. I began to pick up trash on the street, because I understood it was service. Service to others would become the criterion that I use to evaluate

**“Nowhere in my schooling did I learn about the importance of my emotional life and how to regulate it. But our moods and attitudes matter tremendously, because they determine whether we connect with each other, how we listen or don’t listen to each other, and whether we will share the space or try to dominate.”**

my actions. Who benefits? How am I contributing? became the defining questions of my life. I dedicated myself to supporting leaders in whatever context I met them.

**CS:** And how did you do a four-year course on generative leadership? Is that an established thing or did you design it for yourself?

**KF:** These are established schools of personal and organizational development. First, I did a Newfield Network’s ontological learning training program, which is about understanding on a practical level what is a human being. Then, I trained at the Institute for Generative Leadership, and there I learned a lot of distinctions that helped me to understand myself and learn how to work more powerfully with others in complex arrangements, such as organizations. For example, I learned that how I show up is more important than how much I know. That is a big one, because I got a lot of schooling, and schooling is all about what or how much you know. Nowhere in my schooling did I learn about the importance of my emotional life and how to regulate it. But our moods and attitudes matter tremendously, because they determine whether we connect with each other, how we listen or don’t listen to each other, and whether we will share the space or try to dominate or even annihilate each other. I learned how to listen to other people’s seemingly contradictory perspectives, hold them even when that created tension in my mind and body, and avoid othering people. I learned to speak my opinion not as demand but as an invitation for us to have a fuller picture of reality. I learned that I can always have “do-over” conversations. I applied these skills to my work at the foundation.

**CS:** What did you do at RWJF?

**KF:** I worked with a team of people who developed and managed a portfolio of programs that invested in people who

were committed to advancing health equity. Every year, we invested more than \$60 million in leadership programs. It was important work, but we learned quickly that there was a gap between the biggest challenges, such as structural racism or other structural inequities that these leaders wanted addressed, and the experience they were having. So, part of my and my team’s role at the foundation was first to help the foundation understand that gap and then to begin to reimagine what kinds of investment could begin to bridge it.

**CS:** What did you figure out while you were there? By the way, I think it’s amazing that a foundation is supporting leadership so specifically and in such a big way. It just seems like a big commitment, which I don’t see a lot in philanthropy.

**KF:** Yes! RWJF has a long-standing commitment to supporting people making change. It’s a huge commitment. They supported me from 1997 to 1999, while I was doing a research fellowship at Johns Hopkins. They invested in me. I was grateful for the support that they gave me. But I never thought I would work with them, based on what I knew of the organization at that time. They were very much interested in insurance and coverage, and while I think that’s important, it’s just not my jam. It’s not the thing that I was interested in. So, when they committed to a culture of health, and committed to leadership programs to address health equity, that’s when I raised my hand and said, “Hey, I can help you.” And they invited me into the organization.

**CS:** What did they mean by “culture of health”? Was it about promoting health, as in moving beyond insurance?

**KF:** Moving beyond insurance to what is called the “social determinants of health.” Understanding that there are barriers that are built into society that keep people from being healthy. And I think there’s so much injustice at the source. Injustice generates not just bad health and poor health but

also unhappiness and mental distress. Health isn't just what we are taught to think of as purely and directly physical. And even when people have diseases or medical conditions, social factors are often at the root of these problems. They play an oversized role in contributing to disease in that they are often ignored by the establishment. Those social forces place and maintain some people in toxic environments. The quality of the air that people breathe, the amount of green space they have access to, the toxins that they drink in the water that flows through the kitchen sink, how far they have to travel to their jobs, how safe or dangerous their jobs are, whether their children have access to environments that stimulate their learning, the number of jobs that they have to patch together to barely pay their rent. These conditions don't occur randomly. These conditions are designed to be that way with specific segments of the population in mind. And all these social factors exert a cumulative toll on human health. They undermine it. I love that RWJF is committed to that understanding of—and to addressing—health injustice. That's why I joined them.

**CS:** As we get to this high level ontologically in terms of how we are with each other, how do we address this?

**KF:** I think health is one part of a prism. The environment is another part. And I think how we address it is exactly where we are and what we are grappling with right now. Some people are working in organizations to disrupt these patterns of injustice, but other people are also reimagining what health could look like. I mean, why is it that Ayurveda—an approach to medicine that aims to restore the body back to health or balance, not just chase symptoms—is only available to a small, select set of people with resources? Why do you have to pay for it out of pocket?

**CS:** I remember wanting to find an Ayurvedic doctor in Boston and finally finding a clinic in Wellesley, which is a totally white, very wealthy, elite. I drove all the way out there, and they only had one Ayurvedic practitioner—and after a few minutes, she said to me, “I don't think I can help you; I think you know more than me.” And I just thought, How can that be so? I literally laughed with her at her not being able to help me. And then through my meditation community I met a woman who was an Ayurvedic practitioner. She had cancer and had gone to India and done Panchakarma repeatedly, and her cancer had disappeared. So, she became an Ayurvedic practitioner.

**KF:** What is Panchakarma?

**CS:** Ayurveda is very noninvasive. It's all about how you live, how you eat, how you balance your life—all the things and ways of living that promote health. Panchakarma is the most intensive part of the practice, and it was very subordinated during colonialism. People could practice it, if they knew it, informally, but there weren't many practitioners, because it is the most advanced part of the field. So, Panchakarma started to disappear. It has started to come back in the last few decades, I believe. Some of the families that had it in their past before colonialism decided to bring it back, and the Joshis—I mentioned Dr. Joshi earlier—are one of those families. But there are very few practitioners doing it. Basically, you travel to this retreat space, where you stay for between six to eight weeks, depending on your level of illness, and are treated with massages, oils, purges. They move all the toxins from your extremities into your body and your system, and then you expel it. You expel it through all your orifices. So, you're expelling toxins for six to eight weeks. And the woman from my meditation community said that it's very, very hard. You're alone, but you have five to ten people taking care of you, because it's very emotional. She said once all the toxins get into your system and are ready to be expelled—it takes about a week or two to move it into your system—you expel for weeks. And she said that when she was vomiting—when she got to the part of it coming through her digestive system—she was pulling out cords of tangled mucus and toxins. And while she was pulling it out, she felt like she was almost dying. Because all these emotions were caught up with it. It's not just physical, right? It's almost like a ritual—very intense. People have to be there to help you, because it's very hard to go through that. And then they give you massage. And the food that they give you is super pure.

**KF:** And you had that done?

**CS:** I've never had it done. It costs a few thousand dollars to do it. I was never sick enough to do that. A friend of mine went and did it in India. And there is one place here, in Arizona, I believe, that does a very light, surface-y Panchakarma—they don't even call it Panchakarma—over two weeks or something like that. But if you want a real one, you have to travel to India and be able to live there for six to eight weeks. So, it takes money. People don't usually do it unless they're really sick. Joshi does that in India and then he travels around the world. You can schedule meetings with him when he's in your location. I first met him and his wife, who is a reproductive doctor, after I had been diagnosed with migraines and the

headaches had been getting worse and worse. And I had had a few miscarriages. I didn't realize they were connected. The first time I went to see him, I had such a headache. And he started to tell me all these things like, "You can't eat bread." I was just like, "You don't understand. I'm dying. You're telling me to stop eating bread?" And he said, "No, no." I didn't understand that it was all related. His wife explained to me that in Ayurveda there are seven levels of health. And so when your body is not at optimal health, the first thing to drop is your reproductive health, because you don't need it. Ayurveda is organized around *doshas*, or bodily energies, and works on whole body balance and health.

**KF:** I'm learning about *doshas* now. I'm in a yearlong program studying and practicing the daily habits of Ayurveda.

**CS:** So, you've had this amazing trajectory with these shifting levels of consciousness as you keep moving into understanding how to even be in this work. What's next for you?

**KF:** My time at RWJF came to a close at the end of September, and I'll be joining the faculty at Johns Hopkins [Bloomberg] School of Public Health, where I'm being funded to study and write on medical racism over the next three years. I'm really excited, because I'm coming back to medicine. I'm coming

back to medicine to engage it from a place of really deep care and love for what medicine can be. And I think racism is part of what prevents medicine from being a more powerful force for healing. I believe medicine can be healing, but it's not as healing as it could be right now. Where I'm coming from here regarding racism and the experience that Black people have, is that it turns out that Western medicine and racism coevolved—so, you can imagine how toxic that is.

**CS:** I remember when I was at Boston College and I took a class with Mary Daly, and we read her book *Gyn/Ecology*, on how the gynecology field was developed from the Holocaust and experiments that were done on women.

**KF:** That's right. On enslaved women. J. Marion Sims, and all the big figures—Benjamin Rush and Samuel Cartwright—who built their powerful careers on biological racism, arguing that Black people were biologically different, aka inferior.<sup>5</sup> So, what does that do to a field? I want to write for a general audience on medical racism, so as to make the historical and the contemporary aspects of it more visible to everyday people. I'd like it to be narrative nonfiction, not a technical book. A book that women will read in book clubs, for example. I never imagined I'd be writing a book; I have the opportunity now to step into the unknown and bring my vision to light.

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# Evolving a Culture of Care Lessons from Third Root Community Health Center

by Vanessa Nisperos, Emily J. Kramer, and Julia Bennett

● Health disparities reflect systemic inequality rooted in racial capitalism. . . . For this reason, it is critical that those most impacted by health disparities in any community are at the forefront of healing efforts. Leaders living at the intersection of racism, classism, transphobia, and ableism are best able to articulate, envision, and lead practices that can truly heal a community.

*Healing justice . . . is a framework that seeks to lift up resiliency and wellness practices as a transformative response to generational violence and trauma in our communities.*

—Cara Page, cofounder, Kindred Southern Healing Justice Collective<sup>1</sup>

“W

e all belong. We are all healing. We are all welcomed in our wholeness.” These words were draped across our lobby wall until the closure last December, after thirteen years of service, of our Third Root Community Health Center in Flatbush, Brooklyn—the oldest cooperative holistic health center in New York City. With basic healthcare being stripped away—and communities already impacted by intergenerational trauma experiencing the ongoing trauma of a pandemic, the repealing of reproductive rights, and an epidemic of gun violence—we decided, as we closed, to share our reflections and learning. With the benefit of hindsight, we have a clearer picture of some key factors that allowed us to grow and prosper, as well as some understanding of what we wish we had done better. Our hope is that our lessons learned can help future healing spaces to be rooted in right relationship with community and sustainable.



## **Our opening, in August 2008, was the culmination of the dreams of healers who envisioned holistic healthcare access for those most in need.**

Healing justice is both a delicate and critical value to center in these times, for it can be a powerful guiding principle in moments of compounded crisis and trauma. Cara Page, cofounder of the Kindred Southern Healing Justice Collective, reminds us that the origins of healing justice lie in Southern Black Feminist practice and praxis,<sup>2</sup> and that an integral part of healing justice practice is the dismantling of oppressive systems. Third Root Community Health Center was created specifically to overcome historic inequities in health access,<sup>3</sup> and we understand healing justice as the increased capacity for individuals, families, and communities to experience wellness while righting historical inequality regarding access to economic resources and healthcare.

Our opening, in August 2008, was the culmination of the dreams of healers who envisioned holistic healthcare access for those most in need, and was built upon previous health justice work—such as the Black Panthers’ health programs,<sup>4</sup> the Young Lords,<sup>5</sup> and more recent projects like Working Class Acupuncture and Off the Mat, Into the World.<sup>6</sup> Third Root’s strategies for overcoming health inequalities were to offer sliding-scale holistic healthcare, herbal education, yoga, acupuncture, and massage for some of the most vulnerable residents in New York City. The founding structure was cooperative ownership with a consensus-based decision-making process. We began with seven founding members—Green Wayland-Llewellyn, Jacoby Ballard, Robyn Ji-Hye Choi, Angela Ueckerman, John Halpin, Romina

Rodriguez-Crosta, and Julia Bennett—a group of healers committed to equity, access, and cooperative ownership, who dreamed of a center that would be replicable across the world. Throughout Third Root’s lifetime, there were twenty cooperative owners (at its largest, the co-op had twelve worker-owners) and over one hundred and fifty staff, teachers, and volunteers whose contributions continuously evolved the culture of care.

### **CHALLENGES IN COLLECTIVE PRACTICE**

And yet there were challenges. While we did succeed in providing a steadfast resource that many long-term BIPOC community members relied on for healing and community building, bringing services into a community that had been historically marginalized did not in and of itself overcome cultural and access barriers. Although Third Root aimed to serve those most impacted by health inequality, we found ourselves situated in one of the most rapidly gentrifying neighborhoods in Brooklyn.<sup>7</sup> And because of historic gaps in access to holistic health modalities for working-class people of color, at least half of our patrons were white, and many were new city residents.<sup>8</sup> The irony—given our mission, given that the practices of yoga, massage, and Chinese medicine and acupuncture come from people of color, and given that the staff and owners comprised more than 50 percent people of color—resulted in pain and harm to the community and the BIPOC staff and owners. And yet our work held distinction and profound meaning for people of color, especially those at the intersection of multiple marginalized identities. While BIPOC people may have had many beautiful, connected, and important healing experiences here as patrons, practitioners, collaborators, and/or one-time visitors or longstanding community members, those truths don’t erase the fundamental challenges around racial equity at Third Root—challenges that are important, if sometimes difficult, to reflect on.

We strove to rectify these gaps by increasing affinity group programming, offering free and lower cost services to BIPOC folks via application, inviting community feedback,<sup>9</sup> and working internally with skilled facilitators to organize social justice training for all staff<sup>10</sup>—but challenging white supremacy in our own culture, language, and principles should have been a keystone of our founding and operations. As a holistic health business in a primarily Caribbean and Latinx neighborhood, the onus was on us to understand and undo our own privilege. From its inception, Third Root did plan and

**With New York City at the epicenter of the first US wave of the pandemic, our community witnessed firsthand how COVID-19 rapidly accelerated the gap between those with adequate healthcare and those without.**

budget for anti-oppression training, but we failed to make this work central to our organizational culture—a core failure for an organization helming a healing space in a diverse and increasingly gentrifying neighborhood.

For our collective to sustain a commitment to undoing racial oppression and white supremacy on an ongoing basis, we needed to develop sustainable business practices that would allow us to invest in antiracism while navigating the paradox of being an anticapitalist cooperative that must meet a bottom line. For example, we ought to have begun and sustained our venture with antiracism training for staff and community members from an organization such as The People's Institute for Survival and Beyond (PISAB);<sup>11</sup> without a core, unwavering commitment to challenging white supremacy, when resource scarcity comes up—as it does for many small businesses—decisions may be made that exclude, disempower, and disinvest from the most marginalized.

And this is exactly what happened at Third Root when we began struggling to cover our basic operating expenses. Sadly, although we had a clear guide to our sliding-scale model, clients consistently self-selected into the bottom tiers of payment even when they could afford to pay more. We believe this is rooted in the internalized nature of resource scarcity in a capitalist system. And because our economic model was not sustainable, antiracist training and practice became peripheral over time, eroding the integrity of our mission and vision as a healing justice center committed to racial and economic justice. Third Root held many concurrent truths about race, healing, and community that were both imperfect and profound. Ultimately, we had to face that we would not be able to sustain our business with this model, and that irreparable faults at the very foundation of the venture played a critical role.

### **A COVID NON-SURVIVAL STORY**

And then COVID hit. Amid the COVID-19 economic shutdown, there have been many stories about organizations that pivoted in the pandemic and thrived. This was not the case for us. Understanding that our self-selecting sliding scale model was not sustainable, in late 2019 and early 2020 we designed a new justice pricing model with clear qualifying parameters for subsidized care. The new model identified specific groups most in need, lifting up BIPOC, formerly incarcerated, immigrant, queer, trans, and disabled community members, as well as those receiving public benefits—all of

whom qualified for greatly reduced price services. High-income earners and those with intergenerational assets were asked to pay above-market rates, making accessible care possible for those most in need in our community. Tragically, the launch of the justice pricing model, complete with new marketing materials and web redesign, was timed for March 2020, just as the pandemic hit.

With New York City at the epicenter of the first US wave of the pandemic, our community witnessed firsthand how COVID-19 rapidly accelerated the gap between those with adequate healthcare and those without. BIPOC and working-class communities here and across the United States suffered vast, disproportionate levels of illness, death, and economic loss throughout the pandemic. Additionally, in the wake of the murders of George Floyd and Brianna Taylor, the same communities were impacted by the ongoing and intergenerational trauma of police violence on Black and Brown bodies.

In response, during the summer of 2020, we implemented our Collective Care Fund, which allotted donated funds to cover low-fee and free massage, acupuncture, herbalism workshops, and yoga services for community members most impacted by health disparities. But like many small businesses, we weathered the prolonged crisis with no financial reserves. To maintain operations, we pared down staffing to a bare minimum, qualified for and drew down

federal and state pandemic aid, and made many pivots in the model of service throughout the start-and-stop nature of repeated closures and reopenings.

We implemented online yoga and workshops, created an online marketing and outreach strategy, and offered outdoor services. Nonetheless, more than a year of sustained losses began to fracture an already tenuous financial situation. By mid-2021, faced with losing our lease and a long-shot option to relocate, we knew we could not shoestring our way out. Healing justice includes economic justice; and the confluence of challenges of running a business in New York City while aiming to pay a living and equitable wage amid a global pandemic led us to shutter our business.

We are honored and humbled to have had a vision and to have tried putting it into practice. Throughout our thirteen years, we centered the intention of “being with” change. Our growth and adaptation presented both obstacles and innovations, some of which are shared here. We know firsthand that mistakes can cause harm; they can also impart lessons when repairs are made.

## LESSONS LEARNED: SETTING THE STANDARDS FOR HEALING JUSTICE

As a collectively owned and managed cooperative, we pondered deeply what it would mean to our community and staff if we were to close our doors. We found ourselves navigating the important question of when an organization has reached the end of its life cycle. Through this process, we realized that there is a gap in support services for cooperatives—many organizations assist start-up cooperatives, yet few effective supports exist for midrange cooperatives, cooperatives navigating financial hardship, and cooperatives attempting to pivot to avoid closure.<sup>12</sup>

As we shuttered our center, we developed a healing justice map to direct folks to similar resources;<sup>13</sup> and below, we share our recommendations on healing justice practices for cooperatives and other businesses that are committed to racial, social, and economic justice.<sup>14</sup> It is our hope that a network of healing justice organizations and beloved practitioners will continue to thrive and serve those in our community in need of the deep care and healing that they found in our space, and that this network of care will hold them on the next leg of their journey.<sup>15</sup> (If you know of a healing justice business that you would like added to our map, you can submit it for consideration.<sup>16</sup>)

Based on our thirteen years of experience at Third Root, we offer healing justice businesses six recommendations for overcoming the effects of systemic inequality:

### 1. Ensure leadership by BIPOC and local community members

***Optical allyship is allyship that only serves at the surface level to platform the “ally,” it makes a statement but doesn’t go beneath the surface and is not aimed at breaking away from the systems of power that oppress.***

—Latham Thomas, founder, Mama Glow

Liberation practice’s definition of justice is *healing the root cause*. What *equity* means in liberation practice is *ownership of the soil one lives on and compensation that allows Black and Brown folks to become and own their role as the fabric of a community*. Like other institutional sectors, healthcare requires representation at the highest levels by people who share the lived experiences of those being served.

Health disparities reflect systemic inequality rooted in racial capitalism, leading to poor health outcomes and shorter life spans for Black and Brown people and BIPOC trans community members.<sup>17</sup> For this reason, it is critical that those most impacted by health disparities in any community are at the forefront of healing efforts. Leaders living at the intersection of racism, classism, transphobia, and ableism are best able to articulate, envision, and lead practices that can truly heal a community.

It is also imperative that allied organizations and resourced individuals support training and professional development that provide rising BIPOC leaders with the mentorship, healing, and support needed to develop sustainable and holistic leadership practices necessary for long-term change (meaning, there can be no space for underpaid roles and burnout culture).

### 2. Offer sliding scale, free, or scholarship options

***Life is very short. What we have to do must be done in the now.***

—Audre Lorde, *Sister Outsider*

Equitable pricing is a core aspect of healing justice that creates access for folks who historically have been priced out of or made to feel unwelcome within mainstream wellness spaces that cater to high-paying clients. Besides the

robust sliding scale Third Root maintained for all our programming for many years prior to the pandemic, our Collective Care Fund provided free and low-fee services to Black, Brown, and Indigenous people, the formerly incarcerated, intergenerational Brooklyn residents, trans folks, and disabled folks. We also offered a “no one turned away for lack of funds” option for many of our yoga classes, meditation classes, and workshops, as well as Community Care Days, which were free outdoor healing spaces.

### 3. Pay a living and equitable wage

***The economic system still depends on a profound racial hierarchy. It still depends on the degradation of Black labor and still depends on and develops tools to segregate and disenfranchise Black people and other working people.***

—Jennifer L. Morgan, chair, New York University  
Department of Social and Cultural Analysis

The labor of people who are Black and Brown, Indigenous, immigrant, disabled, trans, formerly incarcerated, elderly, and female is undervalued, underpaid, and overlooked. As at Third Root we were at least 50 percent BIPOC in our ownership, staff, and teachers, and majority women and queer, our commitment to remain accessible to our students and patients came into conflict with our ability to pay ourselves equitably. We knew that if we failed to uplift and sustain our healing justice providers, we would not survive long enough to provide care to our clients. It was an ongoing struggle to balance our anticapitalist values with our need to become solvent, and payroll was always our highest overhead cost. With the additional challenge of the pandemic, we simply could not pay ourselves enough to fulfill a fundamental principle of our work: *Healing justice includes economic justice.*

We envision that living wages in a healing justice cooperative would account for the varied needs of cooperative members who are impacted differently by structural inequality. For example, some bear the costs of child care as single or partnered parents, some sustain multiple family members on their wages, some live and work with disability, and some carry seniority and expertise as elder healers in our community. Staff like founding member Julia Bennett, who began her many-decades-long career in acupuncture and Chinese medicine at Lincoln Hospital and served the Flatbush community long before our cooperative began,

**Individual healing work never happens outside of collective healing work, and collective healing must include collective liberation—from generations of white supremacy, settler colonialism, capitalism, patriarchy, ableism, homo-/transphobia.**

should have been afforded a compensation package that included at least a modest retirement.

Additionally, in talking about equitable payment, it is necessary to name that within wellness communities there is work to be done to rectify the cultural appropriation and profiting from teachings that are not from the practitioner’s culture of origin. Monetizing healing traditions within white supremacist capitalism is problematic, especially when people from the cultures that developed these practices do not have equal access to the teachings and healing tools themselves. We recommend repatriating a portion of profits to healing organizations led by Indigenous practitioners of the relevant healing traditions as an entry point to righting this wrong.

### 4. Center social justice and racial equity

Individual healing work never happens outside of collective healing work, and collective healing must include collective liberation—from generations of white supremacy, settler colonialism, capitalism, patriarchy, ableism, homo-/transphobia. Communities of color, immigrant communities, queer and trans communities, and disabled communities continue to disproportionately bear the health impacts of our unjust society. At Third Root, we provided trauma-informed and affinity-group-based programming such as Brown Sugar: Yoga for Folks of Color, Yoga for Abundant Bodies, queer & trans yoga, and a QTIBIPOC meditation.<sup>18</sup> We provided herbal education programming that addressed settler colonialism and cultural

**We dream that new generations of healing justice businesses will center holistic reproductive healthcare, mental health and trauma support, and racial justice study as a wellness practice—all anchored in communities of mutual support.**

appropriation in relation to Native American plant medicine. Our physical space bore many accessibility barriers (for example, we had no ADA compliant ramps, restrooms, or access to the downstairs space), so we provided stopgap measures and aimed to communicate these clearly with accessibility statements on all our material. To maintain integrity, we created an anti-oppression code of conduct and led racial justice and equity meetings within our staff, teacher, and volunteer communities.

We recommend that any health justice facility prioritize full chair and scooter accessibility. We also recommend that healing justice spaces center, budget, and plan for ongoing racial and economic equity training, such as The People's Institute for Survival and Beyond (PISAB) Undoing Racism® workshop, and/or Resmaa Menakem's Somatic Abolitionism workshop, and engage consulting partners experienced in navigating equity within a business, such as Anti-Oppression Resource and Training Alliance (AORTA).<sup>19</sup>

Strategies to support such trainings financially can include an adequate budget line to cover training costs, engaging in external fundraising, and/or a stated expectation that owners and staff of European descent will take on participation in antiracism training on their own if the business cannot sustain these costs.

## 5. Actively participate in advocacy as a form of healing

*Dismantling systems of oppression is integral to building a world in which we all feel free and can fully live in our purpose individually and collectively. . . .*

*We are our ancestors' continued presence. We believe in our community's right and ability to heal.*

—Latinx Therapists Action Network

Healing justice asks us to actively right wrongs, and this means employing advocacy and organizing strategies to defend and strengthen healthcare access. It is not enough to promote individual healing and it is not enough to develop holistic health services absent an understanding of the impact of racialized trauma and systemic inequality on communities.<sup>20</sup> *We must be in action*—for in advocacy and action, we are also healing intergenerational trauma and the roots of institutional harm. As Dr. Anna Ortega-Williams writes, we heal our “collective self” when we involve ourselves in movements for social justice and safety for our people.<sup>21</sup> Not only is movement building cathartic, advocacy is central to healing justice.

What is needed to increase our collective tolerance for stress is equally as important as how to cultivate our collective experiences of joy—and sanctuary spaces where we can reset our nervous systems, be accepted, and receive care are vitally important.

If we were to start a healing center in these times, it would be one that embodies the practices and care that heal intergenerational harms. We dream that new generations of healing justice businesses will center holistic reproductive healthcare, mental health and trauma support, and racial justice study as a wellness practice—all anchored in communities of mutual support, so as to cultivate healing as an integral part of bringing into being all that is possible for our communities.

## 6. Cultivate stewardship of our spaces as owners

*Without community, there is no liberation.*

—Audre Lorde, *The Master's Tools Will Never Dismantle the Master's House*

When opening a cooperative in a community where you contribute greatly and where your work enhances the cultural capital of a place, *do what you can to own the space you occupy.*



While Third Root Community Health Center occupied a building in Flatbush and we contributed to the cultural capital of the place, we were renters, with no means of earning equity. In short, the community we helped build ultimately priced us out. We could not keep up with the pace of rent increases.

Inequitable access to home and land ownership is central to the perpetuation of racial capitalism. Redlining—the historic and ongoing exclusion of neighborhoods based largely on the racial makeup of a community—and the systemic denial of ownership opportunities and resources to these communities continue to accelerate the racial wealth gap. As Leah Penniman illustrates in *Farming While Black*, people of color in the United States perform over 80 percent of land labor, yet own and manage only 2 percent of farmland.<sup>22</sup>

Those who can leverage the capital to buy land or space for building healing justice centers can become stewards of care in the places where care is most needed. Anything less leaves us to gentrify ourselves out of our beloved communities. In practice, we envision this as being possible through financial education for BIPOC healers toward understanding the home- and land-buying processes. We also recommend the development of a robust profit-sharing model that includes a down payment match—allowing worker-owners to, over time, become permanent homeowners in the communities they serve. This creates the conditions to challenge systemic inequality by cultivating a long-term, intergenerational investment in the healing of a community.

## DARING TO DREAM

In a conversation with Geleni Fontaine, a long-time acupuncturist and Third Root member, they shared that “a lesson for me as a collective member at Third Root was to not be afraid to vision. To not be afraid to really expand the sense of what was possible. And doing that with other people—how thrilling that was.” Fontaine then asked the question, “What is this work?” Answering their own question, Fontaine said, “It’s the work that we’re getting paid to do. But it’s also who we are. It’s our lives. And those of our families and our communities. There couldn’t be a separation between doing the work of being in this collective and working on making it something that’s equitable and that addresses who we are as practitioners living our lives.”

Through this commitment to equitable and justice-centered healing practice, Third Root continued to be a sanctuary within the Flatbush Brooklyn community through the dual

pandemics of COVID-19 and racialized trauma. In response, besides the Community Care Days we offered to provide acupuncture, massage, and yoga in an outdoor setting to people in need of care, we also provided scholarship services to over three hundred Black, Indigenous, trans, and formerly incarcerated community members through our Community Care Fund. Collectively, the 160 healers and teachers who practiced at Third Root provided over one million unique services to over three hundred thousand people during our tenure. Many of those healers and teachers supported people who came from historically marginalized communities, some of whom felt safety in their bodies for the first time in our queer and trans yoga classes, in our affirming, trauma-informed services, and in being held by healers who looked like them and were trained to support people moving through trauma. These healers and teachers helped us to evolve and deepen our practices of healing justice, and now move through the world holding intersectionality and healing justice as central to their practice. We know many of these healers will go on to seed healing justice centers that continue evolving and building on the legacy we started together.



We, the former member-owners of the Third Root Community Health Center, recognize that we are in critical times that require all of us to pause and radically reconfigure. For some in the world of healing justice, the work that is needed right now is rest and wellness; for others, it is advocacy and action. Whatever one’s calling, we are in a moment to tap inward and listen. When we are well, we can dream what is next. When we are at peace and in equilibrium, we can see each other and connect.

“We all belong. We are all healing. We are all welcomed in our wholeness.” As we sunset our cooperative, it is our deep wish that these words and our lessons learned can seed the next generation of healers and healing justice practices.

*While our collective is no more, former worker-owners still offer consultations and insights via workshops and one-on-ones. If you have ideas and visions for healing justice, we’d like to hear them. You can contact [info@thirdroot.org](mailto:info@thirdroot.org) to share your reflections or for inquiries.*

## NOTES

1. “Statement on Healing Justice,” Third Root, accessed October 16, 2022, [thirdroot.org/2022/04/12/healing-justice-statement-map-third-root/](https://thirdroot.org/2022/04/12/healing-justice-statement-map-third-root/).
2. “Kindred Offering to this Moment,” Kindred Southern Healing Justice Collective, July 23, 2020, [kindredsouthernhjcollective.org/kindred-offering-to-this-moment/](https://kindredsouthernhjcollective.org/kindred-offering-to-this-moment/).
3. Ted Scheinman, “The Historical Roots of Racial Disparities in American Health Care,” *Smithsonian Magazine*, April 2022, [www.smithsonianmag.com/science-nature/historical-roots-racial-disparities-american-health-care-180979800/](https://www.smithsonianmag.com/science-nature/historical-roots-racial-disparities-american-health-care-180979800/).
4. See Alondra Nelson, *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination* (Minneapolis: University of Minnesota Press, 2011).
5. See Ed Morales, “The Roots of Organizing: The Young Lords’ revolution,” *The Nation*, March 24, 2020, [www.thenation.com/article/culture/young-lords-radical-history-johanna-fernandez-review](https://www.thenation.com/article/culture/young-lords-radical-history-johanna-fernandez-review).
6. For more on Working Class Acupuncture, see [www.workingclassacupuncture.org](http://www.workingclassacupuncture.org); for more on Off the Mat, Into the World, see [www.offthematintotheworld.org](http://www.offthematintotheworld.org).
7. See, for example, Kim Velsey, “The New High-Rent Districts,” *New York Times*, August 24, 2018, [www.nytimes.com/2018/08/24/realestate/the-new-high-rent-districts.html](https://www.nytimes.com/2018/08/24/realestate/the-new-high-rent-districts.html).
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9. Early on in our tenure, a member of our collective who was dedicated to outreach and organizational partnerships coordinated town halls in our space that accommodated between twenty and forty people per session, most of whom were acquainted with Third Root. The groups were racially and culturally mixed—roughly 60 percent white and 40 percent BIPOC. Ideas generated in these sessions would go back to meetings with the collective, in which we decided on how we would incorporate the feedback that was aligned with our mission and vision. Early surveys focused on what the community was interested in; later surveys focused on the accessibility of our services and on how the sliding scale worked or didn’t. During the first phase of the COVID pandemic, we surveyed extensively to help shape COVID-safe protocols and meet needs during that time.
10. For instance, Moksh Consulting (see [mokshconsulting.org/about](http://mokshconsulting.org/about)) and AORTA (see [aorta.coop/](http://aorta.coop/)).
11. See The People’s Institute for Survival and Beyond (PISAB), [pisab.org](http://pisab.org).
12. Cooperative Economics Alliance of New York City runs a comprehensive leadership institute for co-ops that we couldn’t manage the capacity to attend; nonetheless, CEANYC provided us with an emergency grant in 2018, when they learned that we were in big financial trouble (see [gocoopnyc.org/](http://gocoopnyc.org/)). Organizations that assist start-up cooperatives include New York City Network of Worker Cooperatives (NYC NOWC), [nycworker.coop/home/](http://nycworker.coop/home/); United States Federation of Worker Cooperatives, [www.usworker.coop/home/](http://www.usworker.coop/home/); and Green Worker Cooperatives, [www.greenworker.coop](http://www.greenworker.coop).
13. Third Root developed a healing justice map, which can still be found here: [thirdroot.org/healing-poc-brooklyn-new-york-practitioner-directory](https://thirdroot.org/healing-poc-brooklyn-new-york-practitioner-directory).
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16. Healers and healing spaces led by white people (people of European descent) can be listed on our Healing Justice Map if they have participated in racial equity training, such as PISAB-Undoing Racism: [pisab.org](http://pisab.org), and have built an achievable timeline to train and promote BIPOC and long-standing local communities into leadership and decision-making roles in their practice. See Third Root, “Healing Justice Map,” [thirdroot.org/healing-poc-brooklyn-new-york-practitioner-directory/](https://thirdroot.org/healing-poc-brooklyn-new-york-practitioner-directory/).
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18. See the following sites for more information: Brown Sugar: Yoga for Folks of Color, [www.brownsugaryoga.com](http://www.brownsugaryoga.com); Yoga for Abundant Bodies, [theshadowleague.com/black-girl-strength-creating-space-for-abundant-bodies-in-yoga/](http://theshadowleague.com/black-girl-strength-creating-space-for-abundant-bodies-in-yoga/); Queer & Trans Yoga—Virtual, [jacobyballard.net/product/queer-trans-yoga-virtual/](http://jacobyballard.net/product/queer-trans-yoga-virtual/); QTIBIPOC meditation, [thirdroot.org/2021/02/22/meditation-for-queer-and-trans-people-of-color/](http://thirdroot.org/2021/02/22/meditation-for-queer-and-trans-people-of-color/); and Love Circle Sangha, [www.facebook.com/groups/Lovecirclesangha/](http://www.facebook.com/groups/Lovecirclesangha/).
19. See The People's Institute for Survival and Beyond: PISAB, [pisab.org](http://pisab.org); Resmaa Menakem: Embodied Anti-Racist Education, [www.resmaa.com/movement](http://www.resmaa.com/movement); and Anti-Oppression Resource and Training Alliance (AORTA), [aorta.coop](http://aorta.coop).
20. For more on this, see "Free Racialized Trauma Course," Cultural Somatics Institute, accessed October 26, 2022, [courses.culturalsomaticsinstitute.com/courses/cultural-somatics-free-5-session-ecourse](http://courses.culturalsomaticsinstitute.com/courses/cultural-somatics-free-5-session-ecourse).
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**VANESSA NISPEROS** (she/they) is a social-justice-centered therapist and trainer who cultivated her passion for addressing systemic health inequalities in community-based mental health and youth service programs in New York and California. A longtime member of the Third Root Community Health Center, Nisperos directed center operations in the final years. As the associate director of the CUNY Academy for Community Behavioral Health, she now works to build pathways to intergenerational healing to help communities thrive. Visit [www.academy4cbh.org](http://www.academy4cbh.org).

**EMILY J. KRAMER** (she/her) is a mindful-movement practitioner offering techniques in yoga and functional training within a trauma-informed social justice framework. She provides a welcoming, embodied, and community-minded practice for all levels, genders, sizes, and disabilities. Kramer spent ten years serving as a worker-owner at Third Root, one of her greatest teachers. She lives in Brooklyn on Lenapehoking, Canarsie, Munsee land with her wife and toddler. Visit [emilyjkramer.com](http://emilyjkramer.com). **JULIA BENNETT** (she/her) was a founding member and co-owner of Third Root Community Health Center, is an acupuncturist, and is a longtime Flatbush resident. Bennett began her acupuncture training underground at the Lincoln Detox Center in the Bronx, treating individuals facing addiction and AIDS with the Black Panthers and Young Lords in the 1970s and 1980s. She went on to become a board-certified acupuncturist and herbalist trained in Chinese, Japanese, and Native American medicine traditions. Bennett's passion is community health concerns for women, especially those who have tested positive for HIV and AIDS. She believes that to address the health challenges of humanity, we must acknowledge wellness as a birthright. Bennett offers herbal health and wellness training and consultation to individuals and organizations.

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# Healing and Joy as Resistance

## Words of Wisdom from a Beloved Activist

by *Nineequa Blanding*

●

“Don’t compare your happiness with others. There’s no such thing as perfection. You create that for yourself, and you are responsible for your own happiness. You must create your happiness for yourself. Anything is possible—go out and get it. You must get up, get out there, and go get it.”

*Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare.*

—Audre Lorde (*A Burst of Light: Essays*)<sup>1</sup>

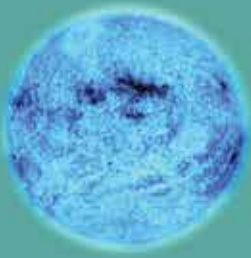
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hen I sat down with Dr. Lourdes Ashley Hunter-Fowler to discuss her healing justice work and two-decades-long journey as an activist for trans rights, we paused—at her request and to my delight—to take a few deep, synchronous breaths and ground ourselves before starting the interview. Dr. Hunter-Fowler is the founder and executive director of the Trans Women of Color Collective—an expansive coalition designed to uplift the narratives, leadership, and lived experiences of trans people of color while building toward the collective liberation of all oppressed people. She describes herself as a “Black, trans, nonbinary, neurodivergent, disabled—or ably different” individual. She also identifies as “a healer, orator, academic and educator, a dismantler of oppressive systems, a descendant of enslaved Africans, freedom fighters, and liberators.”<sup>2</sup> For Dr. Hunter-Fowler, living at the intersection of these identities grounds her work resisting systemic oppression and creates avenues toward healing and liberation.

A resounding theme, as we spoke, was the importance of incorporating self-care in one’s work to create positive change in the world. Dr. Hunter-Fowler illuminated throughout how cultivating healing and joy—critical dimensions of self-preservation and care—is an act of resistance. “Some people dream,” she declared. “I live. We should all be able to live out our dreams.”

### **A response to the fatal violence against trans people**

It was her vision as a healer that led Dr. Hunter-Fowler to start TWOC. In 2013, she joined forces with thirteen other trans women to establish the collective in response to the ongoing attacks of trans people, particularly Black trans women, and in particular the murder of Islan Nettles—a young woman who was fatally assaulted at the age of twenty-one. “We had to heal,” said Dr. Hunter-Fowler, as she



recounted hearing the news of Nettles’s murder and described the subsequent vigil that was held in her memory.

She [Nettles] was brutally beaten in front of a police station. *Nobody* helped her. She was twenty-one years old, in the prime of her life. A fashion student, just walking her dog. She told the man [who approached her] she was trans, and he beat her. And we say visibility is important, [and] we need to disclose who we are, but that can get you killed. The community came together. They had a vigil, but the vigil was led by cis people. They misgendered her, called her by her birth name, and they didn’t take into consideration the trans community. So, we had to heal from that trauma as we were also healing from [the death of] this young woman.

Unfortunately, the murder of Islan Nettles is one of many fatal attacks that persist today. The Human Rights Campaign—an advocacy group that is recognized as the largest LGBTQ political lobbying organization within the United States—has tracked fifty fatal attacks of transgender people in 2021 alone.<sup>3</sup> These fatalities represent a significant increase from when HRC started tracking the attacks eight years earlier, and those numbers may be higher: current records may not fully capture the extent of fatal attacks endured by trans people in the United States. The trans community has also faced political threats that include an increasing and unprecedented number of anti-transgender bills in state legislatures, as well as public narratives that are demeaning and stigmatizing. Tori Cooper, director of community engagement for the Transgender Justice Initiative at the HRC Foundation, has noted,

In 2021, we’ve seen the highest number of transgender and gender non-conforming people killed in a single year since we began tracking these deaths in 2013. These victims had families and friends, hopes and dreams. None of them deserved to have their lives stolen by such horrific violence. Most of the victims were Black trans women . . . an appalling trend of violence. **This horrific violence is fueled by racism, toxic masculinity, misogyny and transphobia. We need everyone to join us in empowering transgender leaders, building safer, stronger communities and reducing stigma.** We cannot rest until all transgender and gender non-conforming people can live our lives safely as our full selves.<sup>4</sup>

Dr. Hunter-Fowler—along with thirteen founding partners—recognized a need to create safe, affirming spaces for healing and also to uplift the experiences of trans people, especially Black trans women: “We had to focus on our own. We had to write [our narrative] ourselves, and we had to develop the tools.” She continued,

When we started [the] Trans Women of Color Collective, it was me and thirteen other trans women: Janet Mock, Laverne Cox, Nala Simone, Brooke Cerda Guzmán, Aisha Lyons, and many [other] trans women who were focused on healing. We started speaking at conferences. We started controlling our own narrative, having healing retreats. I remember [thinking] this is what we can do. We do not have to wait for somebody to do it for us.

TWOCC was created to provide economic opportunities and affirming spaces for trans people of color and their families to build community and engage in healing and restorative justice practices through arts, culture, media, advocacy, and activism.<sup>5</sup> The efforts of TWOCC center those “who have not had access to resources, opportunities and sustainable systems of support to live unapologetically in their truths.”<sup>6</sup> Dr. Hunter-Fowler describes her work as focusing on uplifting and celebrating the beauty and ingenuity that exists among trans people of color while also being responsive to their needs as a community. She explains:

Whatever the community says that they need, we provide. There’s no blueprint. There’s no curriculum. We ask the community what it is they need, and we provide it, whether it’s food, shelter, or a hug. At a moment’s notice. According to what the community needs, whatever I have, you should have it too. And let’s get it together.

This is an approach that aligns well with healing justice efforts—a framework used to respond to generational trauma, facilitate collective healing, and transform systemic oppression.<sup>7</sup> It proposes that healing and joy are essential elements of liberation. It is also the basis of TWOCC’s work—namely, the Healing and Restorative Justice Initiative, which is a signature effort under way to “shift the narrative [from] surviving to thriving” in trans communities of color and elevate those “who have had their voices stolen, usurped, commodified, silenced and exploited by cis gaze, colonization, anti-Blackness, imperialism and transphobia.”<sup>8</sup>

*“Our young people, they’re not waiting. They are stepping up. And it’s important for them to have direction, guidance, and inspiration. And it’s important for us to be that for them [while] also letting them find their own way.”*

—Dr. Lourdes Ashley Hunter-Fowler

For Dr. Hunter-Fowler, healing justice is . . .

. . . understanding how white supremacy, cisnet patriarchy, colonialism, [and] capitalism are embedded in every aspect of government and life. We need to create solutions outside of those systems. We don’t need to correct these systems [because] we didn’t create them. We don’t need to fix them, they’re not our problem. What we need to do is create modes and operations outside of those systems, so that we can heal from the trauma that they cause and restore ourselves back to who we were, back to who our ancestors were. And we can do that. It’s just going to take some time—and that’s okay.

### **Prioritizing youth leadership to create meaningful change**

As part of the work to create new systems of support, TWOCC engages in a wide range of activities in the areas of education and wellness, and disburses funds (including a COVID-19 rapid response fund) and financial resources to fulfill such community needs as housing, food, and clothing. In addition to providing those resources, TWOCC maintains a focus on supporting youth leadership in cultivating affirming spaces for communities to engage in healing and restorative justice. “We lean in with an intentional response to the trauma our community has endured by leading with the voices and leadership of our youth and young people.”<sup>9</sup>

“They’re our future,” said Dr. Hunter-Fowler, as she explained her rationale for investing in youth leadership and letting their voices drive TWOCC’s advocacy work. Alongside youth leaders, TWOCC has hosted initiatives in over forty states in the United States, and has global initiatives in Switzerland, England, Norway, Jamaica, and East Africa to facilitate cultural exchanges and anthropological studies with community organizers. These efforts are in service of curating a global platform to further the work of collective liberation.<sup>10</sup>

Dr. Hunter-Fowler explains,

Our young people are doing amazing things. A lot of times, people must go through these entry-level jobs

and work their way up. We make all our young people directors. We ask: “What is it that you want to do?” “What is it that you do well?” “You want to be the director of fashion?” “You want to be the director of art?” We give them [the] power to explore and celebrate our lives as queer folks, as folks from the African diaspora, [through] art and fashion. Our national director—Nyla Foster—won Miss Black Trans International, and she used her art and her talent to bring awareness to the lives of trans people. She’s also a youth counselor, and deals with housing insecurity in Kansas City. We’re helping young people realize their dreams, whatever it is that they’re dreaming to do. We’re not here to say, “Oh, you must go to college in order to be successful.” If they want to go to college, they can go, [and] we’re helping them through college; but you don’t have to go to college to be important, to follow your passion, to follow your dreams. We’re shifting that narrative, and we’re giving out the titles. Yes, I’m a doctor. That’s the path I took because society says titles [are needed] to be heard. But I get to use that power to create opportunities and curate opportunities for others.

Our young people, they’re not waiting. They are stepping up. And it’s important for them to have direction, guidance, and inspiration. And it’s important for us to be that for them [while] also letting them find their own way.

Dr. Hunter-Fowler’s human rights activism and her commitment to supporting youth leadership draws both from the inspiration of her parents and leaders like Shirley Chisholm—who paved the way before her—and from the challenging experiences in her life as a trauma survivor:

Life has not been easy. But it’s the journey and it’s your legacy that’s important. The journey was worth it. When I get phone calls and emails from parents of trans kids saying, “My child is going to be just like you,” I [respond], “No, your child is going to be greater than me.” The ability to sponsor and support young trans people through their art and through their ministry makes life worth living. It keeps me going every single day.

*“Every breath a trans person of color takes is an act of revolution.”*

—Dr. Lourdes Ashley Hunter-Fowler

I could remember at five and six years old, marching down Woodward Avenue with my mom. She was part of the United Automobile Workers (a labor union representing workers in auto, aircraft, and agricultural implement manufacturing, and other industries). She worked at Chrysler. My father worked at Ford. They're both retired. We were always fighters for the people. I was raised in service to the community, and as I began to get older—at seventeen—I started an organization called New Generations in Detroit, which was a space for LGBTQ youth. [As an adult,] I went to New York City with forty dollars in my pocket on a one-way ticket, and I was going to work at the shelter and figure it out. They (workers at the shelter) noted, You can't be trans here. So, I found myself in a men's shelter [and] having to get on welfare. I can remember being in the shelter, [being] sexually abused, raped, [and] violated. And I had a case manager. She said, You're getting out of here, and she helped me find my first apartment. So, there are angels out here, and I just want to give back this portion of what was given to me. For me, Trans Women of Color Collective is an extension of that history of service.

### **Maintaining self-care while in service of others**

Dr. Hunter-Fowler is a staunch advocate of maintaining self-care while working in service of others. She noted that as part of her effort to create positive change in the world, “I [also] need to focus on me, and make sure I am here for the next generation, for my family, for my children, for my husband, for my mother. I think we should all think about that as we are in service—that we are also making sure we're taking care of ourselves.” As she spoke, Audre Lorde's famous words, “Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare,” etched themselves into my mind. Her words are also reminiscent of those of longtime activist Angela Davis, who has said, “Anyone who's interested in making change in the world, also has to learn how to take care of herself, himself, themselves.”<sup>11</sup>

With healing and restorative justice as their mission, Dr. Hunter-Fowler and her husband have extended their homes—in Jamaica and Maryland—to others as safe and affirming communal spaces for trans leaders, in support of their artistic expression and leadership. Dr. Hunter-Fowler has created an artist residency fellowship and a mentorship

program for executive directors. While she and her husband live on the lower level of their home in Maryland, for example—which is also fully equipped with a gallery space and large, private yard surrounded by a forest for healing retreats—guests and mentees have access to residency spaces on the upper levels.

For Dr. Hunter-Fowler, this work to uplift and celebrate the voices and experiences of trans people, particularly Black trans women like herself, is a joy and a dream come true. The impetus for starting TWOCC—to create healing spaces in response to the fatal attacks of trans people—still holds precedence today. For years, with the ongoing violence coupled with systemic oppression, many Black trans women have operated under the notion that their life expectancy is no more than thirty-five years. As such, Dr. Hunter-Fowler states, “Every breath a trans person of color takes is an act of revolution.”

When I leave my home, I don't know if I'm going to return. My mother has already buried two of her children, and she has two left. I can't let her down. So, I know every breath I take is shaking the room. I have to take these breaths, because my life depends on it, my mother's life depends on it, my legacy depends on it, [as does] the legacy of Black trans women.

A breath shifts the narrative, because somebody didn't get to breathe today. And so many Black trans people—trans people overall—don't have access to opportunities. They're struggling. I used to be one of them.

So, I have to get up—and even if I lay down a little bit, that's fine, too.

I asked Dr. Hunter-Fowler to share her thoughts on what our future would look like if we all operated from a place of healing. Her response was one word: “Bliss.” In that moment, we paused and imagined what bliss means to us. For Dr. Hunter-Fowler, bliss means:

Flowers and rainbows and butterflies and unicorns and cheesecake. Fried chicken. Sunny days, starlit nights. And that's what I'm trying to create. We must start somewhere. That's what I think of when I operate from a place of healing. Walks in the park, picnics, tubing down the river, horseback riding. I can't wait for someone else to create it for me. Sometimes I just go



take a blanket, take my little Bluetooth speaker, and lie in the grass. I love all types of music. I particularly like gospel, and I love jazz music, symphony, Bach, Beethoven. I like ambient noise, even just the sound of the birds. The deer here are huge, and just going outside and seeing their footprints, [I say to myself,] I see I'm occupying your land. The birds have all types of little nests in my backyard, and I just listen [to their song]—happiness doesn't cost a thing.

Nestled against a backdrop of luscious foliage that fills a warm and calming section of her home, Dr. Hunter-Fowler radiated warmth and smiles across our Zoom connection. She ended our conversation with advice we can all benefit from:

Don't compare your happiness with others. There's no such thing as perfection. You create that for yourself, and you are responsible for your own happiness. You must create your happiness for yourself. Anything is possible—go out and get it. You must get up, get out there, and go get it. Even if it's a homemade pizza. Go ahead and make it. Even if it's the muffins that you like to bake. Go ahead and bake them. Be happy.

These words align with what activist Karen Walrond calls "lightmaking," which is defined as "any time you are led by your values to do purposeful action in the hopes of making the world brighter for other people."<sup>12</sup>

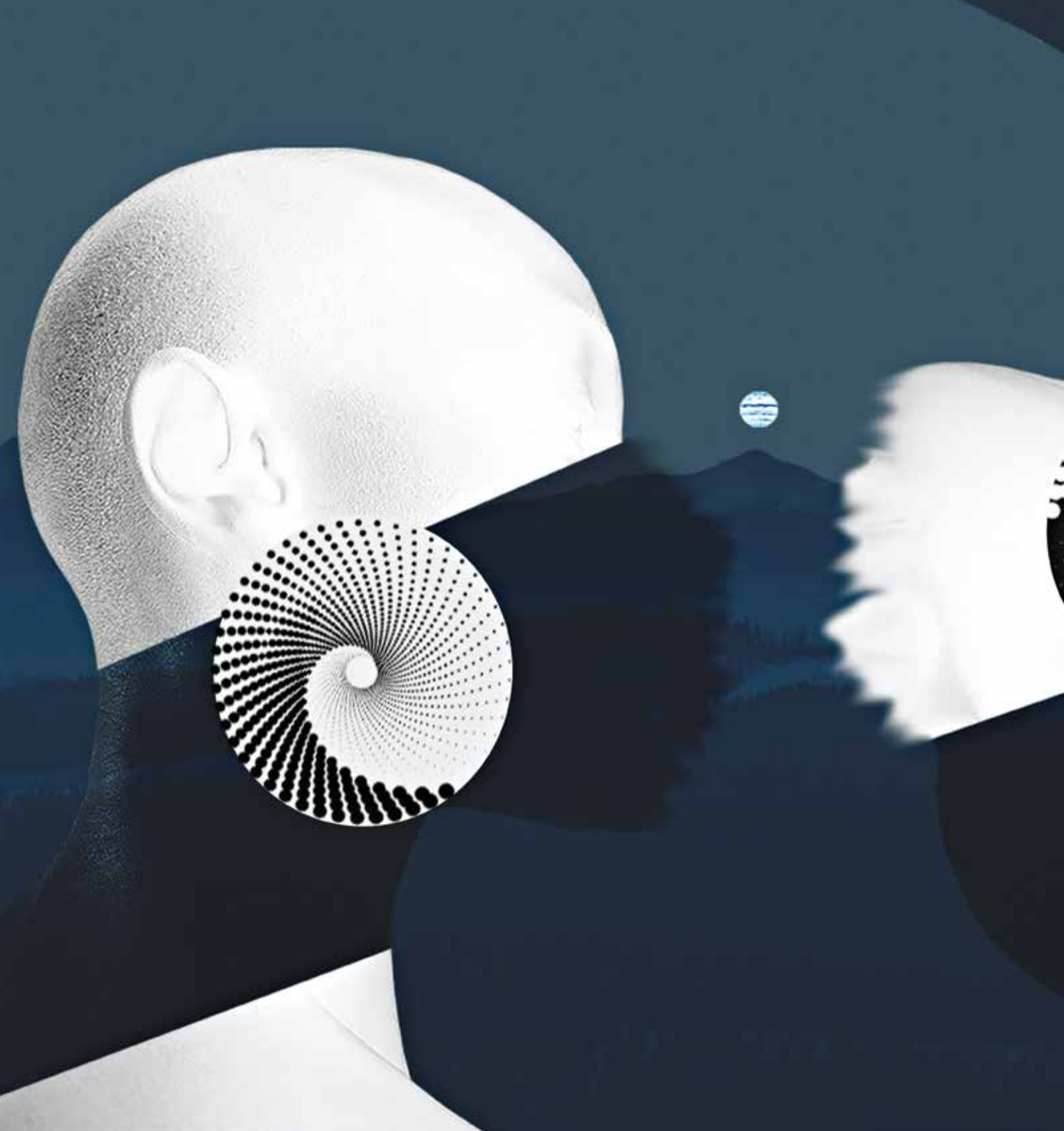
This is activism. This is healing. This is resistance.

## NOTES

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**NINEEQUA BLANDING** is *NPQ*'s senior editor of health justice. Blanding has dedicated the entirety of her career toward working at the intersection of health and social justice. Prior to joining *NPQ*, Blanding was vice president of Health Resources in Action, where she led the direction and growth of the organization's grantmaking services. Blanding was the former director of health and wellness at the Boston Foundation, where she applied her vision, leadership, and racial equity lens to develop, implement, and evaluate TBF's strategic priority to improve population health. Prior to her work at TBF, Blanding held senior leadership positions at the Boston Public Health Commission, where she led local and statewide strategies to advance health equity. She also held former roles with Mount Sinai School of Medicine and the New York City Department of Health and Mental Hygiene. She currently cochairs the Harvard T. H. Chan School of Public Health's Prevention Research Center Community Advisory Board. Blanding has a BA in psychology from Spelman College, and an MPH with honors from Long Island University, and she was previously funded by the National Institutes of Health to conduct postbaccalaureate research in trauma-related risk factors for post-traumatic stress disorder at Emory University and the Center for Cognitive Neuroscience at Duke University.

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“Part of the reason we are in the situation we’re in is because we didn’t trust women of color, we didn’t trust trans people of color, who’ve been telling us for decades that we need an organizing strategy, that we need to be doing movement building, that we need to be working in intersectional ways, not just on one issue.”

# “There’s No Such Thing as a Single-Issue Struggle”

## A Conversation with Kitana Ananda, Naa Amissah-Hammond, and Quanita Toffie

*In this conversation, Kitana Ananda, racial justice editor at NPQ, Naa Amissah-Hammond, senior director of Grantmaking at Groundswell, and Quanita Toffie, senior director of the Groundswell Action Fund, discuss the history and current state of the reproductive justice movement in the United States.*

**Kitana Ananda:** I’d like to start with talking about Groundswell Fund’s work in the context of the broader reproductive justice movement. At Groundswell, you fund reproductive justice organizing led by people of color. For folks who are newer to this movement and language, can you speak a little about what reproductive justice is, why it’s important, and what makes reproductive justice organizing different from other kinds of organizing around abortion rights and access or being “pro-choice”?

**Naa Amissah-Hammond:** Groundswell’s focus is on reproductive justice organizing, as you mentioned, and on intersectional organizing by women of color and trans people of color.

And we use our grantee partner SisterSong's definition of reproductive justice—one of the founding organizations of the RJ [reproductive justice] movement—who define RJ as a human right. So, it's grounded in the human rights framework—the right to bodily autonomy, to have a child, to not have a child, and to parent the children that you have in safe and sustainable communities that are free from state violence and also from injustice.

So what does that mean for us? We talk about reproductive justice as deeply intersectional. So, our grantees are Alaskan Native women organizing against toxics in the Arctic and the impacts that they might have on our health and also our environment. They are trans women of color organizing in New York for housing justice, and who look to abolition and also, in the meantime, reforms to policing and prisons to support trans communities. They are Latinx women organizing on the border, and in the Rio Grande Valley in Texas, for abortion access and immigrant justice. And we tie those issues into the conversation around reproductive justice. And I think the way that we talk about this work being different, and our grantees talk about it being different, is that it isn't a narrow focus. The pro-choice framework is a white feminist framework that singularly focused on the key issue that was really important to white women in particular in the '70s and '80s: abortion rights. And this is super important for our communities, right? It's an issue that all of our grantees work on. But it is not the only issue our grantees work on.

We often raise up Audre Lorde's words, "There's no such thing as a single-issue struggle because we do not live single-issue lives."<sup>1</sup> Our grantees are telling us over and over that we can't have this conversation about abortion in Black communities if we're not also talking about maternal health. We have to be talking about the full spectrum of reproductive healthcare. And we also need to be organizing in that way, because that's what brings the most people along in our fight. So, I think that's how we see our grantees' work as being different than just a narrow focus, such as the pro-choice framework, that very often will only be focused on a legal strategy or sometimes advocacy strategy, and doesn't look at all the many different strategies that groups are using to change hearts and minds and win reproductive freedom for the long run.

**Quanita Toffie:** To underscore what Naa already shared around reproductive justice being not just about choice, it's also about access—so, being able to afford to have an

abortion, afford the cost associated with traveling hundreds of miles to the nearest clinic, and so on—there is no choice when there is no access for our communities. The reproductive justice movement is rooted in racial justice. It is centered and rooted in the racial justice framework. And that is really critical, given the history of racism, classism, and sexism within the white feminist movement space—as is acknowledging that there were also women of color and trans and gender-expansive people of color affected by other things, like the history of forced sterilization, and acknowledging that the fight for reproductive justice is on a much broader scale and spectrum than just that choice framework.

**KA:** Particularly after the *Dobbs* decision, there has been renewed media attention on abortion rights, and there has been some discussion of reproductive justice more broadly. But I think there are still folks who are not familiar with the movement and the distinction between the two frameworks. What have you observed about how people are engaging with the movement after the *Dobbs* decision? Are you seeing new people coming into the movement? Are you seeing different kinds of coverage of the movement and how that's impacting the organizing that your grantees are doing?

**NAH:** I would say, yes, there's increased attention to reproductive justice just even in the mainstream conversation. We've had presidential candidates talk about reproductive justice for the first time, in the last few years; we've had larger organizations finally talk about reproductive justice, not just reproductive rights or health. And I think that we need to give credit where credit is due: This is happening because of the organizing that many of our grantees—who are grassroots people-of-color-led organizations—have done for a long time, saying, We cannot have this conversation about rights and health separate from a conversation about justice. You can have all the laws on the books, but if you don't have a base of people to protect them, if you don't actually address the root causes of why injustice is occurring, then it doesn't matter—those laws will be overturned eventually. Our grantees have often been the leading voice over the last twenty-plus years in terms of talking about how we need to have a conversation about reproductive justice that's rooted in a conversation about racial justice and economic justice and trans justice and immigrant justice—and I could go on and on—that is rooted in seeing the connections among these issues.

Our grantees name that they've seen many more people wanting to get involved, to volunteer, to donate. But I think

**“Even beyond this immediate moment, in the last five or six years there’s been an exacerbation of attacks on our basic civil and human rights across the board.”**

that oftentimes some of the larger national organizations with more access or communications departments and fundraising are the ones that get a lot of the attention—whereas the groups on the ground at the state and local level that are BIPOC-led and grassroots don’t often have the ability to get that access and shine, even though they have been the ones for years organizing in those communities and fighting to defend reproductive justice when nobody was talking about reproductive justice.

**QT:** An additional layer is that even beyond this immediate moment, in the last five or six years there’s been an exacerbation of attacks on our basic civil and human rights across the board—and with that, a politicization of many more individuals who weren’t necessarily involved in movement work or social justice organizing. We’ve seen these moments come up way more frequently over the last six years—around the Women’s March [2017], the Black liberation uprisings in 2020, the election in 2020—and there are newly politicized folks who are waking up to a reality that our grantee organizations have been awake to and on the frontlines about and organizing around for a long time. So there is definitely an interest in the work now that we haven’t seen in the past—but I want to underscore what Naa shared, which is that this work has been steady and consistent. The leadership and organizing of our grantee partners for the last couple of decades have paved that way for new folks to be welcomed into and introduced to and educated around what needs to happen. We put out a call to philanthropy earlier this year around investing in the infrastructure that already exists, to that end. And a lot of our role here at Groundswell is about ensuring that those new folks with interest and fervor around RJ know where to put their time, money, and energy. And to make the connection, too, with this election cycle—with the politicization of all of our rights to such a degree. There is also more interest and understanding that wasn’t there even four years ago around the connection between abortion access and voting rights at this moment.

**KA:** With the *Dobbs* decision and the end of *Roe* as precedent, we know that people have feared that there will be even greater criminalization of pregnant people, especially folks of color, for seeking access to comprehensive reproductive healthcare, including abortion. I’m wondering, as this year draws to a close, what you have observed about access to abortion and the state of reproductive healthcare in the United States in 2022.

**NAH:** At Groundswell, we have the privilege of supporting almost two hundred organizations a year, and over one hundred of those are focused on reproductive justice specifically, in forty-nine states—all except for West Virginia at this point; but we also support groups on the ground in DC, Puerto Rico, and the US Virgin Islands. This year has been a pretty devastating year for the RJ movement, even though I think RJ movement leaders have been warning for years that this day was coming—that *Roe* was never going to be protective enough, and that actually *Roe* is the floor and hasn’t protected many in our communities. Thinking about undocumented folks, thinking also about folks who couldn’t afford abortions in the beginning—so many of our communities have already been living in a post-*Roe* reality. But the Supreme Court decision—and how, very rapidly, other states followed suit by passing abortion bans—still stung for many of our organizations. We saw Texas last year being the front-runner there.

At the same time, we’re also seeing attacks on gender-affirming care, on trans youth and trans communities—and on voting rights, as well. And at Groundswell, we see all of these issues as deeply interconnected, as a way to mobilize opposition against the growing power of Black and Brown communities. We want to make that connection really clear to people, that these are not just separate attacks—they’re coordinated attacks, and they’re part of a fifty-year strategy that opponents of reproductive freedom have been pursuing.

So, I think in the immediate term, there has been a lot of shock and grief that people are experiencing at the same time that many of our grantee partners have had to spring into yet more action. They were already some of the frontline organizations that communities depend on to receive access and to fight for their rights. And now our grantees are being flooded with phone calls from communities who are terrified and confused and worried about what this means for their life if they’re seeking an abortion or if their child needs gender-affirming care in states that are now

**“Many of our grantees have had to step into supporting much more triaging and service provision, I would say, dealing with communities that are facing a lot of fear and panic—particularly communities with the least access already: undocumented communities, young people, Black and Brown people generally.”**

criminalizing care. Many of our grantees have had to step into supporting much more triaging and service provision, I would say, dealing with communities that are facing a lot of fear and panic—particularly communities with the least access already: undocumented communities, young people, Black and Brown people generally.

But I think what has been so inspiring is that our grantees have often been leaders in saying, “Okay, here are the solutions that we’re going to put to work regardless of what the legal landscape looks like.” I think abortion care has always happened on this land, and it always will happen, regardless of what the law says. Our grantees and others are part of how to maintain access for people. Thinking about self-managed abortion, thinking about how to access abortion funds to get people to care in other places if care is limited where they are now because of abortion bans, and helping to provide those networks of care so that our communities are not facing the brunt of these terrible bans and laws. And as Q named, one of the things that we’ve been watching out for is there’s been a lot of media attention around the criminalization of people seeking abortions and less attention to the criminalization of people seeking gender-affirming care. And that is really important. We also want to name that one of the impacts we’re concerned about is the criminalization of organizers and providers who work on reproductive justice and trans justice issues, because they’re key targets in the states where they work—in the South, Southwest, and Midwest, which are Groundswell’s key priority regions.

Foundations need to be thinking about how they are supporting organizations they fund to deal with this new legal risk and jeopardy, in addition to the work they do to support the communities that are bearing the brunt of attacks on abortion and trans rights. What’s been exciting is that most of our grantees are still focusing on the full spectrum of reproductive issues and trying to triage and find ways to do that if part of the work that they’re doing has been criminalized or is being criminalized in their states. One of our grantees in our

birth justice fund, CHOICES, in Tennessee, has a beautiful full-spectrum reproductive healthcare facility that they opened in 2020, and unfortunately they had to relocate the abortion services to Illinois because of Tennessee banning abortion care. But they’re still managing to figure out how to maintain their model of making sure no one is left behind—regardless of what kind of care that they need. And at the same time, they still continue to organize in Tennessee to change the laws and to build a base and to talk about how this is not going to be permanent, that we are going to fight for our people and our freedom even if it takes us the next ten years, fifteen years, to do that.

**KA:** Given that—and particularly the criminalization of organizers and providers as something that needs to be addressed, and that foundations need to be thinking about how to support organizations that are dealing with that threat—can you offer any examples of how people are dealing with this, or offer recommendations for best practices to support those who are on the movement’s front lines?

**QT:** I think one example is what Naa just lifted up, in terms of how much our grantee partners are holding in this moment by stepping into the gap to provide access to reproductive healthcare—which has never been a certainty for our communities—while also advocating for the laws and policies that are going to lead us to change, and holding on to that longer-term vision around building a world we have not yet seen.

I do think that this piece—local- and state-level organizing and building power such that communities can advocate and vote in their self-interest to gain the self-determination around bodily autonomy—absolutely necessitates a voting engagement strategy, as well. That is critical for seeing through the kinds of laws and policies that will change the material conditions for everyday people. So, one of the ways that we support organizations that are stepping into the gap and holding so many different elements and consequences of the *Dobbs* decision is to provide not just the funding but also the support for organizational resilience, such that

groups are able to mobilize hundreds of thousands of voters to turn out in key elections.

And we're providing—and have provided—the support for organizations to build the kind of infrastructure that can allow them to have a multipronged approach. That includes bringing new community members into the organization but also holding electeds accountable after a major moment like this. We know the work will only continue after the midterm election, and we will have to defend and protect wins. We're building that base of support where we'll always be out-moneyed but have the people power to ensure that we can make those changes and leverage the electoral moments for the sake of our communities, and be able to change things like district attorneys in our states who ultimately have power around how the criminalization of people seeking abortion will look.

Our grantees have highly expert and sophisticated approaches to holding all of these pieces while serving the communities and engaging in longer-term strategies such as around voter engagement—which needs year-round support, because engagement is happening in and out of the cycles. I can share in more detail why that kind of capacity is needed around the voter engagement strategy. One of our longtime grantee partners, Black Women for Wellness, is one of the organizations that received technical assistance around adopting a voter engagement strategy. They had been working on the full spectrum of reproductive justice around comprehensive sex education, dealing with the penalizing of Black women and girls—they're based in LA County—and they also work on the issue of Black maternal mortality rates. They have been building power over the

**“Holding elected officials accountable is so important, because we live in this strange reality where the majority of people in this country support reproductive justice and yet our elected officials do not—they do not reflect the ideas of the majority of people in this country.”**

last two decades with the community who they serve directly through connecting folks to access to healthcare, but have also been very successful in raising the visibility and importance of reproductive justice for the state of California. So, for example, when SB 8 [Senate Bill 8, the Texas law banning abortion as early as six weeks into pregnancy] was passed in Texas last year, California, now a reproductive freedom state, saw an influx of folks seeking abortion. There were something like from around forty thousand to a million within that short period of time. So, after building more power within their state to elevate this issue and bring along varying coalitions that represent different sectors of civil society in California, Black Women for Wellness were able to gain more power through their voting program as well, where they were responsible for getting several local-level progressive leaders in office with their c4 organization Black Women for Wellness Action Project. In the wake of SB 8 in 2021, they, along with other allied rights, health, and justice organizations, started the California Future of Abortion Council, to provide key recommendations and hold the state of California accountable to protect and expand reproductive healthcare and even provide a blueprint for other states. Several state legislators joined the Council once Governor Newsom announced that the state would participate. This didn't occur in a vacuum: Black Women for Wellness had been at the forefront of policy advocacy for a long time, and when they organized their constituents and began turning out voters on the issues they cared about over the last several cycles, this base of community members equaled people power that the state could not ignore.

**KA: Do you have other examples of what today's grassroots organizers are doing to fight for access to care within and across different communities? And who or what do you think needs more attention and support to be able to move forward with this work to fight for justice and provide full-spectrum care?**

**NAH:** Holding elected officials accountable is so important, because we live in this strange reality where the majority of people in this country support reproductive justice and yet our elected officials do not—they do not reflect the ideas of the majority of people in this country. So, our grantees are talking about how we need to talk about democracy and make sure that our leaders actually represent the majority of people in this country—that they are aligned with reproductive justice. I think one of the amazing things that our grantees are doing is galvanizing this moment as a base-building

opportunity—and as Q was naming, an opportunity to further engage our communities in this important conversation about voting and getting out the vote.

Groundswell has over the years been doing an annual evaluation of the reproductive justice movement so as to name for other funders the power that we see in this movement. And last year, when we surveyed our grantees, we saw that they had engaged over eight hundred thousand leaders to take action for reproductive justice across the country—in every single state. And in terms of long-term base-building, one of our grantees, National Latina Institute for Reproductive Justice, has been talking to us about not just its deep movement building work with the community but also its deep *listening* work—getting people engaged in this conversation around reproductive justice and helping them to understand as Latinx communities, as other communities of color, how this connects to all the issues that we care about, and helping to mobilize and activate people. So, I would name the deep base-building work, which is not a three-month or even a one-year project—it's a many, many years-long project. And funders need to support the work of base-building groups over the long term to be doing deep organizing in communities. This is a really important way that grassroots organizers are stepping into this moment. And I've heard our grantees talk about, "Yeah, we need a strategy that matches what the other side has been doing for fifty years." I think the advice to other funders is not, What are you going to do over the next two years? It's, How are we helping our grantee partners think about the next five years, ten years, twenty years? And really looking toward the future instead of always in these small grant cycles. So I'll name that.

I will also note that our grantees continue to do important policy advocacy work and systemic change work in every state. So, progressive states like California, as Q named, where Black Women for Wellness is active, where it's going to be really important in the next few years to continue to shore up laws that protect reproductive freedom, because it's no longer just for the communities in the states that are progressive—it's now for folks seeking care from neighboring states and from far away. I'm in the state of New York, and our grantees on the ground here are talking about how do we pass laws, how do we get things into the budget, so that we are supporting our neighbors who are coming from other states? And that's really important. But at the same time, we're a national funder that's deeply committed to the South,

to the Southwest, and to the Midwest as underfunded regions, because we know that liberation work needs to start—and will happen—in the places where there is the most reproductive oppression.

So, many of our grantees are still continuing to do harm-reduction work in states where abortion bans have passed, are trying to fight and think about how we can be proactive and defend reproductive freedom even in states where harmful laws are passing. Many of our grantees, such as the National Network of Abortion Funds, are super active in trying to support work to get people to care and provide practical aid on the ground for their member funds and communities seeking care. But many of our grantees are also thinking about how to create coalitions with other movements and to advance a reproductive justice agenda, knowing that now there are also a lot of people who've been mobilized in the wake of these terrible bans. And we've seen voters coming out in Kansas, for example, around that—voting very loud and clear that they do not support a constitutional ban on abortion. So, I think that there are unique opportunities there, and I just want to underscore that we're not abandoning any of the work in the South, Midwest, and Southwest. And in fact, that's going to be very important ground to continue to robustly support in the years to come.

**KA:** I'm hearing that there's a lot of work happening in different places, and that the needs are very different depending on whether you're in a state where the laws and policies support reproductive freedoms and gender-affirming care and voting rights or whether you're in a state or regions of the country where there are very repressive laws. What do you see as the future of grassroots reproductive justice organizing? Where do you see the movement headed in the next five and ten years?

**QT:** As Naa was speaking, it was sparking for me the ways in which our organizations have to use every tool in the toolbox right now, including really flexing and building even other entities to withstand these attacks and build toward a different future. When the *Dobbs* decision came down, our organizations that have been organizing and building their base for many years now pivoted to turn their base out and mobilize for reproductive justice. But because of their c3 status, they aren't able to fully leverage that power.<sup>2</sup>

And so, for example, our c3 organizations are doing the important work of educating on how and where to vote, helping folks get registered, helping folks change and update





their information if they've moved or been displaced due to hurricanes or other storms. Just the immense amount of infrastructural damage that has occurred in the South from storms creates barriers to the voting process. So, our c3 organizations are doing that—and then they have to stop short from actually saying to organizations, “We know this issue is important to you, so you've got to go out and vote on this issue this election.” This is where having a c4 strategy can make the greatest impact by ensuring that organizations can turn out those pro-RJ voters, because that is allowed.

But far and wide, because the ban is so very unpopular with the general public and so very much a politicized issue that the more extreme factions—the Republican Party and others—are fully using as their campaign agenda, it's hard *not* to touch this issue in any place, any state, right now. But our groups don't get the kind of funding that allows them to flex their power by using a c4 strategy or having PACs and other sorts of tools that allow them to tackle this issue head-on at varying levels. In order to do that, they would need the kind of funding that is unrestricted and that allows them to lobby as much as they can to ensure that whatever happens after this election, there will be opportunities to defend and protect vis-à-vis the laws and policies that come through while also building a more political infrastructure that will continue to grow between cycles.

So, our groups are hampered by the boom-and-bust cycle that exists and that will continue to exist. And we need to break that cycle, which is partly Groundswell's philosophy around our long-term, year-to-year deep investment in infrastructure building. What usually happens is that, after an election day, money dries up and campaign infrastructure has to basically go away. And that happens just as the legislative advocacy and lobbying opportunities are right there. You're essentially breaking up a needed infrastructure—an infrastructure that could help you to take that win or loss to the next level—and there's just not enough support that will ensure that groups are able to bridge those moments and then continue to build and learn from the wins and losses of an electoral cycle. So, c4 funding is very, very important—particularly in a year like this—and it doesn't flow fast enough. And there isn't enough even just *trust* in our organizations' abilities, in the folks who are actively building power independent of the political parties. I live here in Florida, where electeds on both sides of the aisle are making poor decisions about our lives. And our communities are very wise to that fact. Part of why we

need to ensure that our organizations have the mechanisms to build that political power is because they actually represent the needs of our communities. And our grantees have become, for many, political homes within their states, because there's a total breach of trust. These election cycles are about boom and bust—about using our communities for votes and then leaving, and the resources going away. So, our groups are building that infrastructure year to year, day in, day out. That support needs to come now *and* later *and* after this election cycle *and* all the way through, and in unrestricted ways such that our groups can determine the strategies that are needed—in this case, to achieve reproductive justice, particularly in this moment when there is a very practical and urgent need around it.

**NAH:** I will just name the thing that they're up against. Last year, we were trying to track how many bills were entered—I think there were something like 541 abortion restriction bills introduced this year across 42 states, and more than 300 anti-LGBTQ bills and 393 voting restriction bills introduced, as well. So, I think we are going to continue to see this intensify. And our grantees need, as Q said, that flexibility to be able to respond, because the attacks are coming on all fronts. And these issues are deeply interconnected—and if we give up the fight on one in one area, we're ceding ground for everything else. So, our grantees need that flexibility.

**KA:** You've been speaking throughout this conversation about how funders can support the future of grassroots reproductive justice organizing, and not only in the short term. It's clear that there is a lot of work that needs to be done with a more strategic timeline—especially since opponents have a half-century-long strategy that has been very successful for them. So, I'm wondering if you can say a bit more about what unrestricted funding would do to support grassroots reproductive justice organizers. Are there any particular examples of ways in which funders have already started to do that work that you would want to amplify? And are there any particular examples of organizing that could benefit from that kind of funding?

**NAH:** Q named a lot of the things that Groundswell tries to practice and that we see as best practices for the field around general support, long-term funding, allowing groups to do as

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much lobbying as they need to do and want to do. For me, as a funder, it has felt a little disheartening that, for years, reproductive justice leaders who are women of color and trans people of color have been waving their flag, saying, We’re going to lose if we keep going down this path of a single-strategy focus that isn’t doing deep organizing within communities, isn’t looking at voter engagement. And no one listened. These organizations have very small budgets—they’re grassroots organizations. Even some of our powerful organizations that we’ve named in this conversation have small budgets in comparison to some of the larger, white-led reproductive rights and reproductive health organizations. And yet, when the Supreme Court came out with its decision, I watched people turn and say, “Oh, my gosh, what are we going to do?”—everyone in the reproductive rights and health movement was suddenly looking to the women of color leaders as if to say, “You’ve been talking about voter engagement and about organizing? Can you do it? Can you fix this?” And I want to just name that that is the dynamic that also happens—that funders give very liberally to white national organizations, allowing them to fail, allowing them to experiment with things, allowing them to just do a strategy and it not work out and do something different, allowing them to staff up adequately. And when we talk to our grantees, 64 percent of them say that their work would be more powerful if they had enough resources to staff up.<sup>3</sup> They don’t have the staff that they need. And they’re constantly working on project grants that have a short grant term and that are not going to be renewed,

and they’re trying to piece together resources to build up their infrastructure. There’s an imbalance here. And I think it’s a racial justice issue and a racial equity issue within philanthropy around which organizations get imbued with funders’ trust. And “trust” meaning dollars, meaning flexible dollars, meaning multiyear dollars. Part of the reason we are in the situation we’re in is because we didn’t trust women of color, we didn’t trust trans people of color, who’ve been telling us for decades that we need an organizing strategy, that we need to be doing movement building, that we need to be working in intersectional ways, not just on one issue. So, I just want to name that. And many of our Black-led grantees talk about the need to Trust Black Women. We need to trust women of color, trust trans people of color—and that means put your money behind your trust and give in the same way that philanthropy has given to white-led organizations for so long.

**QT:** Thank you, Naa, you said that perfectly. I think I will just underscore that along with trusting Black women and trusting trans people of color, we must also trust the strategies of organizing. Invest in that strategy, invest in grassroots organizing. These are tried-and-tested strategies that have won many of the freedoms we enjoy right now in our lives that are absolutely being attacked. Investing in those strategies by the communities who are the most vulnerable and who actually have the solutions because of the impacts that they have had to face and navigate for so long—and trusting in those strategies and in those communities—is ultimately how we’re going to advance reproductive justice in this country.

## NOTES

1. Audre Lorde, “Learning from the 60s,” in *Sister Outsider: Essays and Speeches* (Berkeley, CA: Crossing Press, 1984), 134–44.
2. See “Comparison of 501(c)(3) and 501(c)(4) Permissible Activities,” Bolder Advocacy, A program of Alliance for Justice, accessed November 10, 2022, [bolderadvocacy.org/resource/comparison-of-501c3-and-501c4-permissible-activities/](https://bolderadvocacy.org/resource/comparison-of-501c3-and-501c4-permissible-activities/).
3. See *See us. Lift us. Fund us.: 2021 Impact Report* (San Francisco, CA: Groundswell Fund, 2022); and Kitana Ananda, “Organizing for Reproductive and Birth Justice: ‘Fund Us Like You Want Us to Win,’” *NPQ*, July 28, 2022, [nonprofitquarterly.org/organizing-for-reproductive-and-birth-justice-fund-us-like-you-want-us-to-win/](https://nonprofitquarterly.org/organizing-for-reproductive-and-birth-justice-fund-us-like-you-want-us-to-win/).

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# Eliminating Healthcare Debt A Liberatory Approach

*by Chuck Bell*

●  
A liberatory or emancipatory approach to eliminating medical debt begins with truly hearing the voices of one hundred million Americans who are struggling with bills they can't afford to pay. . . . The United States needs to fully recognize the scope and extent of medical debt as a systemic problem, and take responsibility for its harsh ongoing impacts—including the income and racial disparities it exacerbates.

# A

pproximately one hundred million people in the United States, or 41 percent of all US adults, currently have health-care/medical debt, according to a national survey report by the Kaiser Family Foundation.<sup>1</sup> Released in June 2022, the survey captured more debt than previous surveys, because in addition to counting unpaid bills from medical and dental providers, researchers collected survey data regarding credit card balances, debts in collection, and other types of loans for the purpose of paying off medical debt, including personal loans from friends and family.

The amount of medical debt held by individuals and families is substantial: \$195 billion in 2019, according to the KFF report. Of the respondents, 34 percent said they owed less than \$1,000 in unpaid medical and dental bills; 22 percent said they owed \$1,000 to \$2,500; 32 percent said they owed between \$2,500 and \$10,000; and 12 percent said they owed \$10,000 or more.<sup>2</sup> Fifty-nine percent of those polled said they expected they could pay off their medical debt in two years or less; 16 percent said it would take them three to five years; and 6 percent said it would take them six or more years. Eighteen percent said that they didn't think they would ever be able to pay off their medical debt.<sup>3</sup>



## One of the shocking aspects of the healthcare debt crisis is that most people who are struggling with medical debt have insurance coverage.

The impact of healthcare debt on individuals and families is staggering in its scope and severity:

- Sixty-three percent of respondents with current or recent medical debt said it caused them to cut spending on food, clothing, utilities, and other basics.
- Forty-eight percent of people with medical debt said that they had used up all or most of their savings to pay it off.
- Two-thirds of adults with medical debt said that they or a member of their household have put off getting needed medical care because of costs.
- One out of seven respondents said that they have been denied care by a medical provider because of unpaid bills.
- Eleven percent or so of adults with medical debt said that they had been forced to declare bankruptcy at some time in their life.
- Six percent of Americans with medical debt said that they have lost their home due to eviction or foreclosure at least in part because of that debt.<sup>4</sup>

### WHAT CAUSES HEALTHCARE DEBT? THE FIVE KEY DRIVERS

According to the national advocacy organization Community Catalyst, there are five key drivers of medical debt:<sup>5</sup>

**1. Poor Health Status and Low Income.** Not surprisingly, people who are sick or have chronic illnesses and disabilities are more likely than others to have higher medical expenses and go into debt. Families with a disabled household member, for example, are “two times more likely to have medical debt than those families where [there is] no disabled member.”<sup>6</sup> In addition, people living in poverty and from paycheck to paycheck are at much greater risk of

accumulating debt than higher-income households. According to the Kaiser Family Foundation, half of US adults do not have the cash on hand to cover an unexpected \$500 medical bill.<sup>7</sup> The problem is especially acute for people of color and people with incomes under \$40,000. Seventy-five percent of Black respondents and 66 percent of Latinx respondents said they would not be able to pay a medical bill or would go into debt to pay it.<sup>8</sup>

**2. Lack of Health Insurance Coverage.** While the Affordable Care Act expanded coverage to some thirty-five million Americans, “approximately 30 million people in the United States lack health insurance coverage.”<sup>9</sup> A primary reason continues to be the high cost of insurance and lack of either a job that provides it (or adequate financial assistance to purchase it) or eligibility to enroll in coverage through Medicaid (or not living in a state that even expanded Medicaid in the first place).<sup>10</sup> Because of historic practices of exclusion, “many of the uninsured people are immigrants and low-income people of color.”<sup>11</sup> The lack of insurance coverage is especially evident in “the twelve states that continue to refuse to expand Medicaid, eight [of which] are in the South.”<sup>12</sup> According to a study by the Stanford Institute for Economic Policy Research, “annual rates of new medical debt fell roughly 50 percent . . . in states that expanded Medicaid, but they dropped only about 10 percent in states that didn’t.”<sup>13</sup> Undocumented immigrants are ineligible for Medicaid or ACA Marketplace coverage, and Congress has not acted on proposals to expand either program. A handful of states have taken action to expand coverage for populations in critical need of coverage who would otherwise fall through the cracks, such as immigrant children and pregnant women.<sup>14</sup>

**3. High Out-of-Pocket Cost Sharing.** One of the shocking aspects of the healthcare debt crisis is that most people who are struggling with medical debt have insurance coverage. Insurance does not necessarily pay for all the expenses a person incurs when they receive medical treatment. Many consumers are enrolled in high-deductible plans that require patients to come up with substantial additional funds for deductibles and copayments. According to a 2019 survey by the Kaiser Family Foundation and the *Los Angeles Times*, 40 percent of people with employer-based coverage said they had problems affording their healthcare cost sharing, premiums, and medical expenses for themselves or a family member.<sup>15</sup> Many households do not

have enough liquid savings to pay for the typical deductible costs of \$2,000 for single-person households and \$4,000 for multi-person households.<sup>16</sup>

**4. Complicated Insurance Adjudication Process.** The medical billing process in the United States is extremely complicated and confusing, and many mistakes and errors are made that are difficult and time-consuming for patients and others to correct. Often, patients receive multiple bills and insurance forms for the same visit, which are hard to decipher and interpret, especially for non-native speakers. Providers and insurers go back and forth over whether a particular treatment or service is covered by the patient's insurance, and the patient is caught in the middle. Frequently, providers go ahead and send bills to collection even while they are still arguing with the insurance company as to whether the service is covered or not.

**5. Unfair Billing and Aggressive Collection Practices.** Patients are frequently hit with excessive charges by providers that amount to unfair price gouging. In addition, many nonprofit hospitals have charity care and financial assistance programs but do not inform eligible patients that they could qualify for free or discounted care. "Patients are often unable to negotiate to lower their bills or establish a reasonable repayment plan," leading to higher debts that are then sent to collectors and reported to credit reporting agencies.<sup>17</sup> Aggressive collection practices can therefore ratchet up the price of care far beyond the actual cost of delivering the procedure or service, and consumers are subject to additional interest charges on the debt that may exceed the value of the debt itself.

### MEDICAL DEBT MAKES PEOPLE SICK

Medical debt undermines the ability of individuals and households to have stable incomes, avoid financial stress and poverty, and achieve economic stability. In addition, medical debt *in itself* can cause sickness. "Medical debt and associated financial hardship are likely to be associated with substantial adverse health effects," wrote Dr. Carlos Mendes de Leon and Dr. Jennifer J. Griggs in a July 2021 recent editorial published in the *Journal of the American Medical Association*.<sup>18</sup> They continued:

Medical debt may compromise seeking or receiving appropriate medical care that may lead to delayed diagnosis of health conditions or exacerbations in

**Medical debt undermines the ability of individuals and households to have stable incomes, avoid financial stress and poverty, and achieve economic stability. In addition, medical debt *in itself* can cause sickness.**

preexisting conditions and may potentially contribute to increased risk of premature mortality. There is also clear evidence for a link of personal debt and financial hardship with poor mental health, which in the case of medical debt could worsen the adverse effects of medical conditions on mental health or vice versa.<sup>19</sup>

Healthcare debt can be thought of as a *negative externality* (to use an economic term), like air pollution. It makes people sick and stressed out. Further, it shifts financial costs from the healthcare system to patients and families and to the support systems in communities that exist to help support people when they are in crisis. Indeed, healthcare debt has negative impacts on other nonprofits in the community. For nonprofit housing, social services, and mental health providers, medical debt can create a significant added workload, because it undermines the stability and economic health of individuals and families and increases demand for a variety of services.

### WHO IS CARRYING MOST OF THE HEALTHCARE DEBT AND WHY?

According to the KFF report, Black adults are 50 percent more likely, and Latinx adults are 35 percent more likely, than white adults to be carrying medical debt.<sup>20</sup> Over a quarter (27.9 percent) "of Black households carry medical debt compared with 17.2 percent of white non-Hispanic households."<sup>21</sup> These racial disparities reflect long-standing gaps in healthcare access (17 percent of Black adults lack health insurance compared with 12 percent of white adults) but also gaps in wealth and income related to discrimination in jobs, education, and housing.<sup>22</sup> In some areas of the country, medical debt is particularly heavily concentrated in communities of color. For example, as the Urban Institute has reported, "Medical debt in Washington, D.C.'s predominantly

## The financial and psychological burden of medical debt falls most—and very—heavily on historically disenfranchised populations.

minority neighborhoods is nearly four times as common as in white neighborhoods.”<sup>23</sup> In other words, the financial and psychological burden of medical debt falls most—and very—heavily on historically disenfranchised populations whose living situations place them squarely at risk vis-à-vis the social determinants of health (SDOH). According to the Department of Health and Human Services,

Social determinants of health are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. SDOH can be grouped into 5 domains: Economic Stability, Education Access and Quality, Health Care Access and Quality, Neighborhood and Built Environment, and Social and Community Context.<sup>24</sup>

Medical debt falls clearly into at least three of these domains. First, it discourages and prevents people from seeking regular, ongoing, comprehensive healthcare, thus directly undermining *Health Care Access and Quality*. Second, it obstructs the ability of individuals and households to maintain stable incomes, avoid financial stress, and achieve *Economic Stability*. Third, it causes psychological distress and trauma, and impacts people’s relationships with friends, family, and community: the *Social and Community Context*.

At a time when hospitals, medical providers, insurers, foundations, and public health experts are urging increased attention to addressing and improving the social determinants of health, *eradicating the sources and impacts of medical debt* ought to be placed at the top of their list. This is an extremely effective concrete step we could take to improve the health and well-being of historically disenfranchised and economically stressed communities.

### THE PUNISHING CULTURE OF DEBT COLLECTION

Large portions of medical debt are being carried on credit cards (17 percent) or are being paid off directly to a doctor,

medical provider, or hospital over time through a payment plan (21 percent).<sup>25</sup> When people fail to make payments, the medical debts can be turned over to debt collection agencies, worsening what is already an intolerable situation. In 2022, the Consumer Financial Protection Bureau reported that 58 percent of all bills in debt collections and on people’s credit records were medical ones.<sup>26</sup> Medical debt is now the number one source of debt collections, surpassing debt in collections from credit cards, utilities, auto loans, and other sources combined.<sup>27</sup>

According to the National Consumer Law Center, hospitals and medical providers often place unpaid accounts with third-party debt collectors, who use frequent calls and other communications to pressure consumers to pay. “Many facilities and providers also authorize debt collectors to report alleged medical debts to credit bureaus” (and/or providers file collection lawsuits on the debts).<sup>28</sup> If they win and obtain a court judgment, they can then use a variety of onerous collection tools—depending on state law—such as “seeking liens on homes, wage garnishment, tax refund garnishment, attachment and seizure of bank accounts, and even . . . civil arrest warrants when debtors fail to show up for court proceedings.”<sup>29</sup> Typically, when the medical provider or hospital obtains a court judgment, the debtor is neither present nor represented by counsel to give their side of the story.

“About 1 in 7 adults who have had health care debt say they’ve been threatened with a lawsuit or arrest, according a nationwide KFF poll.”<sup>30</sup> Further, one out of twenty (5 percent) said that they had been sued by a medical provider, collection agency, or debt buyer for a past-due medical or dental bill.<sup>31</sup>

This punishing culture of debt collection further disenfranchises individuals and families already burdened by multiple inequities, and further erodes their ability to function in the societal system as it is set up.

### POLICY SOLUTIONS TO THE HEALTHCARE DEBT CRISIS

There are three basic tiers of potential policy solutions to the serious national problem of expanding medical debt. The first is to level the economic field so that all have access to comprehensive, high-quality medical care. The second is to achieve reforms in medical billing to reduce and eliminate the amount of debt incurred in the first place. The third is to prohibit unfair and needlessly harsh debt collection practices, such as wage garnishment and placing liens on primary



residences, and to give patients better tools for protecting and defending themselves against court actions.

The first tier, of course, is the bigger issue, and it won't be achieved in the short term; but there is substantial opportunity to make more immediate change at the second and third tiers. For example, reforms to limit the growth of medical debt and protect patients from its harsh effects can be achieved at the state level. The National Consumer Law Center has developed an excellent model state law to increase consumer protections for low-income patients against health-care debt and reduce the number of patients facing lawsuits or other harsh tactics.

The model law's provisions include:

- Requiring more healthcare providers—not just nonprofit hospitals—to have a financial assistance policy
- Setting a floor for those financial assistance policies to ensure more low-income people qualify for free or discounted medical care
- Capping the total amount of medical debt a low-income person can accrue at a hospital, capping monthly payments at 5 percent of a patient's income, and capping the interest rate that debt collectors can put on medical debt
- Incentivizing patients to sue healthcare providers who violate this law<sup>32</sup>

In 2021, state-based advocates were active in at least twelve states fighting for new protections against unfair medical billing and debt collection practices, according to Community Catalyst.<sup>33</sup> Eight states succeeded in passing bills to protect patients, in some cases incorporating sections of the NCLC's model law. New protections were enacted that require healthcare providers to:

- "Screen and provide free or discounted care to low-income patients regardless of their immigration status.
- "Clearly notify all patients about hospital policies regarding financial assistance programs, billing, and collections.
- "Limit hospital charges and extraordinary collection practices.

- "Comply with reporting requirements that aim to explore disparities.

- "Solicit feedback from patients and patient advocates on notification of patients' rights."<sup>34</sup>

A series of excellent case studies prepared by Community Catalyst highlights how patient advocates developed state-wide coalitions to curb unfair medical billing and debt collection in their states:

- In Maryland, advocates succeeded in "a ban on all lawsuits for medical bills under \$1,000, . . . prohibiting arrests for medical debt and liens on homes for all patients, prohibiting wage garnishments for low-income patients, and requiring hospitals to offer income-based repayment plans. . . . [The 2021 law also] require[s] hospitals to submit an annual report on debt collection activity" that includes the impact by race and ethnicity, to bring more public attention to racial disparities in collection practices. The bill was supported by End Medical Debt Maryland, a broad-based coalition of "unions, churches, and state and local community advocacy organizations representing approximately 400,000 Marylanders."<sup>35</sup>

- In Colorado, patient advocates helped pass a new law that requires hospitals to screen patients for participation in public insurance programs and hospital financial assistance programs. The bill also requires steep discounts on hospital bills for low-income patients who do not qualify for discounted care under the state indigent care program.<sup>36</sup>

- In New York, the statewide End Medical Debt Campaign initiated by Health Care for All New York succeeded in enacting reforms to cut the amount of time a hospital can sue patients from six years to three years; reduce the interest rate charged for medical debts from 9 percent to 2 percent; and close a loophole in the state surprise billing law that exempted hospital emergency rooms.<sup>37</sup> In 2022, the End Medical Debt coalition continued its advocacy and passed a bill to ban liens on primary homes and wage garnishments for nonprofit hospital debts that is now under consideration by the governor.<sup>38</sup> The coalition's

## Over the last several years, media coverage has highlighted the glaring contradiction between the role of nonprofit hospitals as institutions with a charitable mission and their role in aggressive medical billing and debt collection.

hard-hitting reports about medical debt lawsuits in different parts of the state resulted in several large hospital systems voluntarily announcing that they will no longer sue patients for medical debt.

The Medical Debt Policy Scorecard, developed by Innovation for Justice, provides a detailed score for each state based on its medical debt protection policies. “Only 7 states had a composite score of 50 points or higher”—indicating that while some states have taken significant actions to protect patients, many have barely begun to grapple with reforming the policies that leave patients vulnerable to unfair billing and collection practices.<sup>39</sup>

The Medical Debt Policy Scorecard lists nine different steps that states could take to limit the amount of debt incurred by patients in the first place, including: (1) expanding Medicaid, (2) mandating screening of patients for Medicaid and charity and/or discounted care, (3) requiring “hospitals or other providers to offer a reasonable payment plan before sending bill to collections,” and (4) “limit[ing] pricing for medically necessary care.”<sup>40</sup> Community-based advocates can press to adopt these important building blocks of a comprehensive strategy to limit unfair billing practices.<sup>41</sup>

### WHAT ABOUT NONPROFIT HOSPITALS AND CHARITY CARE PROGRAMS?

Over the last several years, media coverage has highlighted the glaring contradiction between the role of nonprofit hospitals as institutions with a charitable mission and their role in aggressive medical billing and debt collection. One study in New York found that fifty-five hospitals had sued over four thousand patients since the COVID-19 pandemic began, in March 2020.<sup>42</sup> A *ProPublica* report in 2019 found that Methodist Le Bonheur Healthcare, which includes Methodist University Hospital, “filed more than 8,300

lawsuits” over five years for unpaid hospital bills. Many of the defendants were low-income.<sup>43</sup> In addition, more than 20,000 debt lawsuits were filed by Virginia hospitals in 2017. More than 9,200 garnishment cases occurred that year, *and nonprofit hospitals were more likely to garnish wages than for-profit hospitals.*<sup>44</sup>

According to Community Catalyst:

Non-profit hospitals in the U.S. have a longstanding obligation to provide community benefit in exchange for savings that result from their tax-exempt status. Under the ACA, the IRS was directed to establish Section 501(r), requiring new community benefit, including establishing and publicizing financial assistance programs for low-income patients. In addition, hospitals are prohibited from charging patients who are eligible for financial assistance more than the amounts generally billed to insured patients. Finally, before engaging in extraordinary collection actions, hospitals must make reasonable efforts to determine whether a patient is eligible for financial assistance.<sup>45</sup>

Despite these requirements, the National Consumer Law Center reports that “hospital spending on charity care . . . varies from hospital to hospital. In 2017, hospitals spent \$14.2 billion on financial assistance (\$9.7 billion to uninsured patients and \$4.5 billion to insured patients), while generating \$47.9 billion in net income.”<sup>46</sup>

While charity care or hospital financial assistance policies help some uninsured patients from falling into debt, many hospitals “do the bare minimum to satisfy the ACA’s requirements and maintain their tax-exempt status.”<sup>47</sup> Further, some hospitals limit assistance to “patients with no insurance and extremely low incomes, excluding patients with any form of health insurance from receiving assistance,” even though such patients can be harshly impacted by high out-of-pocket costs for deductibles, coinsurance, and copayments.<sup>48</sup>

According to the NCLC report, “charity care policies fall short for several reasons:

1. Failure of hospitals to inform patients of their eligibility for charity care before commencing debt collection;

2. “Lack of specific guidelines and minimum eligibility criteria in the ACA’s financial assistance policy requirements; and
3. “Overall lack of effective implementation, enforcement and oversight of charity care programs.”<sup>49</sup>

If hospital financial-assistance programs were widely publicized, many patients could avoid going into debt in the first place. Advocates are responding to the issue by promoting state legislation to standardize and increase the availability of hospital financial assistance, and by encouraging federal regulators and the IRS to tighten the standards for provision of charity care. Advocates would also do well to hold nonprofit hospitals accountable for their billing and debt collection practices and invite them to be allies in the fight for greater health equity.

Under the Affordable Care Act, nonprofit hospitals are required to prepare and update Community Health Needs Assessments (CHNAs) every three years, by engaging in dialogue with stakeholders and the public to identify and analyze community health needs. The process provides a way for communities to prioritize health needs and to plan and act upon unmet community health needs. Many methods exist for conducting an assessment, but assessment generally includes stakeholder meetings, community focus groups, surveys, interviews with community leaders, and analysis of population health and other health-related data.<sup>50</sup>

Given the harsh consequences that medical debt imposes on individuals and the community as a whole—increased stress and anxiety, less access to medical care, risk of eviction, foreclosure and bankruptcy, and more—all CHNAs should include plans for preventing and reducing the risk that patients will incur debts for unpaid medical bills. At a minimum, nonprofit hospitals and other medical providers should avoid taking actions that undermine the financial well-being of residents in their community. In fact, they should help lead the fight to reduce the scourge of medical debt, in order to improve health status and outcomes.

## TAKING ON THE ELEPHANT IN THE ROOM

*I have my medical debt, and I try to pay it off, but then I can't pay my rent and my car loan, and all these other things. It feels like I can't get out of this hole. It stresses me out and worries me day in and day out.*

—Robert Parish, electrician from Tennessee<sup>51</sup>

**At a minimum, nonprofit hospitals and other medical providers should avoid taking actions that undermine the financial well-being of residents in their community. In fact, they should help lead the fight to reduce the scourge of medical debt, in order to improve health status and outcomes.**

A liberatory or emancipatory approach to eliminating medical debt begins with truly hearing the voices of one hundred million Americans who are struggling with bills they can't afford to pay. As a nation, the United States needs to fully recognize the scope and extent of medical debt as a systemic problem, and take responsibility for its harsh ongoing impacts—including the income and racial disparities it exacerbates and reinforces. Only then can we begin to realize the depth of policy reforms that will be needed to extend full protections against unfair billing and collection practices.

To fully protect people across the nation from bills they can't afford to pay, policy-makers and advocates will also have to take on the elephant in the room: The United States has the most expensive healthcare system in the world, yet for all we pay, it is failing to deliver safe, affordable, and efficient care—across multiple dimensions. Many of the worrisome practices are highlighted in Dr. Elisabeth Rosenthal's excellent book *An American Sickness*, based on her “Paying Till It Hurts” series in the *New York Times*.<sup>52</sup> One of the key problems is that Americans pay higher “unit prices” for almost all of the healthcare we buy relative to costs in other countries.<sup>53</sup> “While the United States medical system is famous for drugs costing hundreds of thousands of dollars and heroic care at the end of life, it turns out that a more significant factor in the nation's \$2.7 trillion annual health care bill may not be the use of extraordinary services, but the high price tag of ordinary ones,” writes Dr. Rosenthal.<sup>54</sup>

And there's also plenty of routine outrageous price gouging and profiteering. Hospitals and providers charge markups that greatly exceed the actual costs of providing care. For

**Unless bolder steps are taken to limit the health system's relentless drive to raise prices and shift costs onto patients, medical providers and insurers will continue to export additional costs to them, despite whatever reforms are achieved in the processes for billing and debt collection.**

example, a 2021 study found that fifty-seven of the largest one hundred US hospitals were charging patients more than five times the amount their care cost the hospital.<sup>55</sup> Nine hospitals marked up their prices more than ten times the cost of actual care.<sup>56</sup> Similarly, "it is estimated that hospitals mark up the prices of drugs for patients with private insurance by an average of 140% to 280%," according to one recent study.<sup>57</sup>

And the medical billing and collections system is itself fraught with financial and administrative waste. "For every office-based physician in the United States, there are 2.2 administrative workers. That exceeds the number of nurses, clinical assistants, and technical staff put together. One large physician group in the United States estimates that it spends 12 percent of revenue collected just collecting revenue. . . . Canada, by contrast, has only half as many administrative workers per office-based physician."<sup>58</sup>

While low-income patients are in the greatest, most urgent need of protection from medical debt, we should create firm rules to prevent patients from ever receiving medical bills they can't pay *across the entire healthcare system*. Otherwise, the system will continue to shift costs to other individuals, families, and employers, and postpone the day of reckoning for stamping out overcharges and creating a fairer, more rational system of pricing.

A key process reform would be to cap and strictly limit the amount of financial cost sharing for healthcare experienced by patients *across the entire marketplace*, so that almost all expenses are covered by insurance as a matter of course for all patients. The proliferation of high-deductible health plans has created a system whereby many patients are afraid to seek care because they are routinely charged more money

at the point of service for copays and deductibles. We can and should get rid of high-deductible health plans; but in doing so, it is imperative to implement sweeping reforms in the pricing and efficiency of care delivery, so as to limit the markups charged by providers and prevent price gouging for services that can and should be more reasonably priced.

Savings from innovations and improvements in care delivery and reduction in the complexity of billing and administration could then be clawed back to reduce the cost of care for patients. There is no doubt that savings of the annual national cost of \$195 billion for medical debt could be rapidly found in a \$3 trillion healthcare system *if* social movements demand these savings and *if* the United States finds the political will to look for them. The Institute of Medicine estimated in 2012 that \$750 billion is wasted every year in our healthcare system—literally 30 percent of every dollar we were spending at the time.<sup>59</sup>

Unless bolder steps are taken to limit the health system's relentless drive to raise prices and shift costs onto patients, medical providers and insurers will continue to export additional costs to them, despite whatever reforms are achieved in the processes for billing and debt collection.

Finally, a liberatory and emancipatory approach to medical debt would also include forgiveness and elimination of medical debts above a certain threshold. As advocates point out, no one takes on medical debt voluntarily. Refusing medical care because of financial factors is fraught with risk and danger to patients and their families. The nonprofit organization RIP Medical Debt has already purchased \$6.7 billion in medical debts from creditors for pennies on the dollar and released 3.7 million patients from the burden of paying it back.<sup>60</sup> The cost of buying debt from creditors is often less than the actual debt, because creditors don't expect to collect the full amount. "Every \$100 donation relieves \$10,000 in medical debt," the organization's website says.<sup>61</sup>

"The millions under the weight of medical debt deserve help, both because medical debt is a uniquely unfair form of predatory lending and because of its devastating effects on American families," Dr. Rosenthal wrote in a recent op-ed.<sup>62</sup> "Government could take action in the short term to relieve this uniquely American form of suffering by buying the debts for a modest price. And then, it needs to tackle the underlying cause: a healthcare system that denies millions of people adequate care while still being the most expensive in the world."<sup>63</sup>

## NOTES

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**CHUCK BELL** is the programs director for Consumer Reports, where he engages in advocacy regarding financial fairness issues and digital finance. Bell also serves as an advisor to We the Patients New York, which is involved in the statewide End Medical Debt campaign, and is on NPQ's board of directors.

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# Disability Justice—in the Workplace (and Beyond)

by *Sonia Sarkar*

●  
[Looking] at disability as a universal part of the human condition rather than an issue impacting just the few . . . enables us to imagine workplaces that are more caring, sustainable, and adaptive. At a time when establishing a new, equitable paradigm for work is more crucial than ever before, centering the voices of disability justice advocates can help blaze the path to achieving that reality.

# D

isability justice emerged as a framework in the early 2000s, as disabled queer folks and BIPOC activists reflected on and critiqued the Disability Rights Movement of the 1960s and '70s—which focused on advocacy for legislation and policy protecting the rights of disabled people.<sup>1</sup> The passage of the Individuals with Disabilities Education Act in 1975 and the passage of the Americans with Disabilities Act in 1990 were pivotal successes for disabled Americans, cementing access to accommodations, equitable education, and physical spaces. Focused primarily on themes such as independent living and individual rights, however, this movement did not explicitly centralize the needs and experiences of those who experience intersectional oppression<sup>2</sup>—for example, people with disabilities who are people of color, immigrant, trans or gender-nonconforming, among many other identities.<sup>3</sup>

In 2005, a group of disabled activists—predominantly, queer women of color who came from movement spaces that did not systematically address ableism—came together to propose a disability justice framework focused on intersectional identity and collective liberation. One of those activists, Patty Berne, has observed that the disability rights movement is “single issue identity based; its leadership has historically centered white experiences; . . . it centers people with mobility impairments, marginalizing other forms of impairment; and centers people who can achieve rights and access through a legal or rights-based framework.”<sup>4</sup> While the disability rights movement enabled an initial path toward justice, activists acknowledged that for many groups facing multiple forms of oppression, additional perspectives and approaches were crucial. Disability justice represents the second wave of the disability rights movement.

This second wave was the focus of a recent webinar hosted by *NPQ* on disability justice and its applicability in the workplace.<sup>5</sup> The webinar—featuring Adela Ruiz, program and grants lead at the NBA Foundation, and Sandy Ho, Disability Inclusion Fund director at Borealis Philanthropy—lays out the principles of disability justice and its intersectionality with other movements, including LGBTQIA+ rights, BIPOC justice, feminism, and immigrant justice. The participants also discuss how workplaces, particularly at this point in the COVID-19 pandemic, should be ensuring equity for people with disabilities.

“Disability justice really comes about because traditional disability rights movements did not center or didn’t center as well the experiences and perspectives of queer, trans, Black, Indigenous, people of color,





immigrants, and women. And that's important, and the list is long for a reason, because it is a call-in to members of the community that had not been in the leadership roles and the decision making in the public leadership as much. It's critical to have that leadership and opportunity component center folks that have been historically excluded," explains Ruiz. "People with disabilities deserve respect, dignity, and genuine inclusion."

Ho and Ruiz kicked off the panel by defining ableism as a "system of assigning values to people's bodies and minds based on socially constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness." These ideas are rooted in histories of oppression, from colonialism to eugenics, and have been integrated into our present-day systems and policies. As the panelists explain, one does not need to be disabled in order to experience ableism. A view of societal value that is based on an "ability to satisfactorily re/produce or 'excel' and 'behave,'" Ruiz explains, is inherently harmful to marginalized groups who may already be deemed as "less than" by the systems with which they interact.

In response to the critical need for anchoring the movement in the needs and realities of intersectional identities, members of the disability rights movement with those multiple identities created a framework of disability justice that centers ten principles not historically centered within the movement:

1. *Intersectionality*—applying the perspectives and analysis of multiple identities and groups to movement work
2. *Leadership of Those Most Impacted*—centering democratic leadership by those with direct lived experience with disabilities
3. *Anti-Capitalistic Politic*—applying a critique of the ways in which capitalism centers productivity and narrowly defines societal value
4. *Commitment to Cross-Movement Organizing*—engaging with other social movements to ensure mutual reinforcement and strategic alignment
5. *Recognizing Wholeness*—valuing all parts of an individual's offerings to the community and to movement work

6. *Sustainability*—building environments that are focused on long-term healing and change
7. *Commitment to Cross-Disability Solidarity*—preventing siloing within the disability justice movement and identifying shared aims
8. *Interdependence*—honoring communal exchange and relationships among individuals and movements
9. *Collective Access*—prioritizing access for multiple identities, geographies, and contexts
10. *Collective Liberation*—recognizing that struggles are interconnected and that working toward liberation for all is necessary<sup>6</sup>

These principles reflect an analysis of able-bodied supremacy as a form of oppression that is not unique to disability rights but rather is a root cause of other systems of exploitation, such as racism and capitalism. In centering white experiences, earlier phases of disability rights might have relied on corporate endorsements and strategies instead of grappling with the ways in which capitalism espouses a narrow definition of productivity. Similarly, a prior focus on self-advocacy for disabled people overlooks the ways in which *interdependence* and *collective liberation* are key to those with intersectional identities achieving shared visions for well-being.

As Berne observes, "A Disability Justice framework understands that all bodies are unique and essential, that all bodies have strengths and needs that must be met. We know that we are powerful not despite the complexities of our bodies, but because of them."<sup>7</sup>

## ADOPTING A DISABILITY JUSTICE FRAMEWORK IN THE WORKPLACE

Understanding the above ten principles that make up the disability justice framework is a crucial prerequisite to applying disability justice to the workplace (and beyond), particularly given a history in which these principles have not been centered. The panelists emphasize this need particularly in the context of the COVID-19 pandemic, which launched a major shift in national dialogue and practices surrounding ways of work. They share three major takeaways that have emerged out of the past two and a half years:

**“A Disability Justice framework understands that all bodies are unique and essential, that all bodies have strengths and needs that must be met. We know that we are powerful not despite the complexities of our bodies, but because of them.”**

—Patty Berne

1. Our country's public health policies, heightened in the context of a pandemic, manifest ableism by deeming some bodies as less deserving of equal access to health, well-being, and medical treatment than others. For example, Ho notes that “we have seen the ways that emergency rooms have done medical care rationing of ventilators when a person with a disability comes in and is deprioritized because of ableist beliefs that undergird our public health system and prioritize a nondisabled person's ventilator access.”<sup>8</sup>
2. Disabled folks, many of whom stand to be particularly negatively impacted during a pandemic, have had to advocate for services that enable them to experience ongoing quality of life, from home-based services<sup>9</sup> to vaccination.<sup>10</sup>
3. Workplaces across the country pivoted toward a more access-centered culture and workplace during the pandemic—from remote work to four-day workweeks and the opening up of positions that previously had criteria related to physical ability. Such access, however, has been bittersweet for those with disabilities, as many of the accommodations they had requested previously from their workplaces were denied or seen as a hindrance, but when those without disabilities requested the same changes, there was rapid adaptation.<sup>11</sup>

“The COVID-19 pandemic has [been a lens into] the ways that our country and at least some pockets of our community continue to dig deeper into equity and disability justice values [and] then really challenge what this idea of ‘normalcy’ is that we’re all suddenly trying to return back to. . . . A return to normalcy is a return back to ableism [and] ableist practices that we knew did not facilitate equity and equality [even] in some of our organizations that are more justice-aligned,” Ho reflects.

The panelists share several areas for workplace assessment within a disability justice approach:

**First is education, particularly around the concepts of intersectionality, cross-movement solidarity, collective access, and more**—ensuring that employees across a workplace are grounded in the history of disability and understand its intersectionality with other identities within the workplace. “It’s an addition, versus something that should be extractive,” Ruiz explains. “If you are working with young people, with Black and Brown people, with queer/trans people, chances are that a critical mass of your constituents manage disabilities in some way or another—so it’s important to understand what the historical connection is and how ableism shows up in their lives and in their experiences.”

**The second area named is hiring.** Reflecting on their roles in philanthropy, Ho and Ruiz share that funders are often unclear about how to build relationships with the disability community in order to broaden their hiring pool and inform their work. “Here’s the thing: you’re likely already doing disability justice work, even if you’re not calling it that. People with disabilities and ableism are present in every community, every issue area.” Engaging in equitable hiring practices requires breaking the myth that lowering barriers to access for employee candidates with disabilities is a compromise of quality, when in fact hiring people with disabilities into various levels of the organization—including leadership—is a way to bring unique perspectives into the work. Ruiz emphasizes, “People with disabilities can do a range of things. And actually, the research shows that disabled people excel, overperform. Not to reduce contributions to labor alone! But a lot of the excuses as to why folks don’t hire disabled people have to do with concerns around productivity, around not being able to accommodate, and it’s actually not the case. Disabled people are assets.”

Particularly in the context of valuing wholeness and honoring the leadership of those most impacted, hiring disabled people can add significantly to the overarching justice

mission of an organization. Practices in this space, particularly on the recruitment side, could include providing interpretation services and accessible interviews available in alternative formats, and ensuring that hiring qualifications are written in an open-ended way,

**The third recommendation centers on *discussion as an area to focus on, including hosting conversations with people with disabilities and listening to the community's ideas on ways to partner*.** Both panelists provide examples of inviting disabled people onto committees or advisory boards so as to incorporate them into organizational governance and advising. They also share instances of grantees they have worked with setting aside dedicated space for those with disabilities to raise their ideas—whether a lunch conversation, a suggestion box, a broader training. And they underscore that policies that benefit disabled people (such as remote work options) often benefit everyone.

**Lastly, the panelists recommend *engaging with the disability community—particularly with peers and nonprofits already engaging in this work*.** “It is hard to have one person—especially if this person is not in a decision-making role at the organization—take on all of that organization’s accessibility and disability justice journey,” says Ruiz. “So, the number one thing I would recommend is, find allies. You are not [necessarily] the only disabled person at your organization—one in four people have disabilities.” The panelists provide examples of identifying those organizations that have already adopted a disability justice framework, who are thinking about accommodations, and who can bring much-needed movement perspective to the work of organizations and funders who are similarly trying to support their employees.



“When we consider [work] with a disability justice lens, we are acknowledging that disability is a part of human diversity, it is across the lifespan, and that disability and ableism can happen to anybody, whether you identify as disabled or not,” Ho explains. This shift, rooted in the disability justice framework and lifted up by the panelists, looks at disability as a universal part of the human condition rather than an issue impacting just the few. This, in turn, enables us to imagine workplaces that are more caring, sustainable, and adaptive. At a time when establishing a new, equitable paradigm for work is more crucial than ever before, centering the voices of disability justice advocates can help blaze the path to achieving that reality.

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**SONIA SARKAR** is NPQ’s health justice editor. Sarkar has a background in health equity, democratizing capital, and social justice. Previously, she served as the director of social homes and health equity at the P3 Lab at Johns Hopkins SNF Agora Institute, where she partnered with social movement organizations across the country to conduct research on power building for health equity. Sarkar was also the chief policy and engagement officer for the Baltimore City Health Department, and the chief of staff/special advisor at Health Leads. In 2017, she was named a Culture of Health Leader by the Robert Wood Johnson Foundation; she is also a Social Entrepreneur in Residence with Common Future. Sarkar holds BAs in public health and international studies from Johns Hopkins University, and an MPH and DrPH from the Johns Hopkins School of Public Health.

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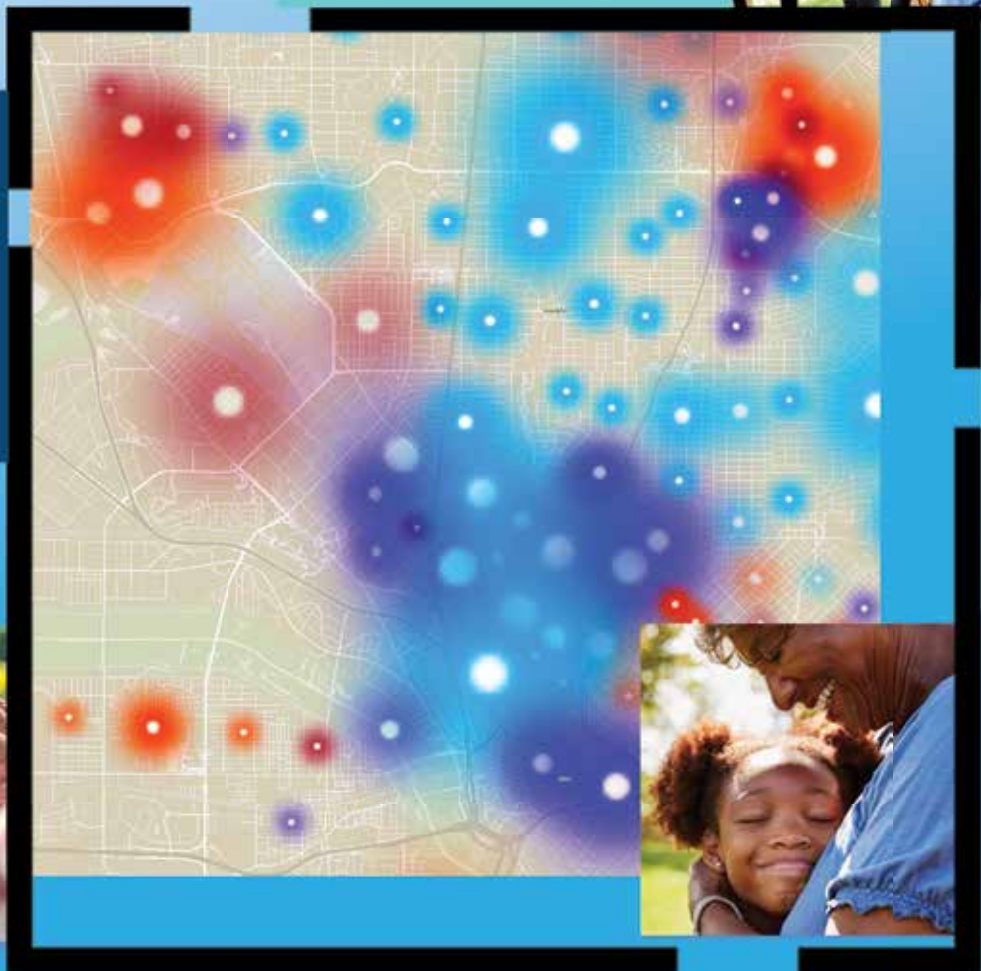
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## A Middle Finger to Oppression, a Road Map to Justice

by Shawn A. Ginwright

Rest is not just sleep or dormancy; it is an act of freedom—a middle finger to oppression that tells us to work tirelessly for the pleasure of capitalism. The idea that rest is weakness or a luxury has a long history in America, and it is still deeply rooted in white supremacist Western culture.

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**L**ately, I've been having trouble sleeping. I thought my sleepless nights would pass and that in time I would return to waking up feeling rested, revived, and refreshed. But that hasn't happened. My sleepless nights appear to be here to stay.

I suspect that some of my sleep habits come from my father. I can't recall a time in my life seeing my father sleep. Growing up, I never saw him in bed, because he worked the swing shift (4:00 p.m. to 12:00 a.m.). By the time I went to sleep at night, he was at work, and when I woke up in the morning, he would already be up fixing things around the house. He didn't believe much in rest, and sleeping for him was a "waste of good time." My father probably had problems sleeping because he worked so much, the night shift disturbed his circadian rhythm, and he was more concerned with feeding us than with the quality of his sleep.<sup>1</sup>

Many of us who work tirelessly to address social problems and improve the quality of life for communities do so without much consideration of the toll our work takes on our ability to rest. Whether you are a teacher, a community organizer, or a social justice activist, you are probably habituated to the stress, anxiety, and lack of rest your work creates. Creating and sustaining social justice movements and/or work in the field of care requires intense dedication and commitment that can cause burnout. Activist Yashna Maya Padamsee describes it like this: "We put our bodies on the line every day—because we care so deeply about our work—hunger strikes, long marches, long days at the computer or long days organizing on a street corner or a public bus or a congregation. Skip a meal, keep working. Don't sleep, keep working. Our communities are still suffering, so I must keep going."<sup>2</sup>

Leaders tend to devalue rest—which is dangerous for our movements, communities, and selves. Not only do we often devalue rest, we may also view rest as a sign of weakness. This message is everywhere, and every day we unconsciously take small bites of this poisonous apple. Take, for instance, the popular lyrics in "Ella's Song," by Sweet Honey in the Rock: "We who believe in freedom cannot rest. We who believe in freedom cannot rest until it comes." On the surface, the meaning is that we must remain committed and dedicated to our tireless work for freedom; but on a deeper level, it reinforces the idea that we can and should sacrifice rest in the name of justice.

Rest is not just the ability to get a good night's sleep. It's also the ability to not constantly worry—to have sustained peace of mind. A sustained peace of mind comes from the stability of a good job, knowing that your children are safe, knowing that you are not going to lose your home. These securities are not always available if you're poor, immigrant, Indigenous, or Black. The stresses that come from constant worry about

basic life necessities, concern over personal safety, and persistent cuts from racial microaggressions all add up and create yet another form of inequality we rarely talk about and only vaguely understand: rest inequality.<sup>3</sup>

Rest inequality refers to the gap in the quality, duration, and amount of rest people get depending on their status in Western culture.<sup>4</sup> This gap is created and maintained by structural inequality, not the result of personal choice, as some would have you believe. Researchers have found that the duration, quality, and frequency of rest in general and sleep in particular are shaped by income level, housing conditions, employment status, type of work, and race. Dr. Dayna Johnson, public health researcher at Emory University, has extensively studied sleep disparities and has shown that "racial/ethnic minorities are more likely to experience, for instance, shorter sleep durations, less deep sleep, inconsistent sleep timing, and lower sleep continuity in comparison to Whites."<sup>5</sup> Sleep is one of the most important aspects of rest, and more and more people are paying attention to the critical role that good sleep plays in all levels of physical and mental health from birth through old age, and its connection to learning, work, sound decision making, and so much more.

## **REST IS AN ACT OF FREEDOM**

Rest is not just sleep or dormancy; it is an act of freedom—a middle finger to oppression that tells us to work tirelessly for the pleasure of capitalism. The idea that rest is weakness or a luxury has a long history in America, and it is still deeply rooted in white supremacist Western culture. The uniquely American concept of "rugged individualism,"<sup>6</sup> for example, which emphasizes self-determination—combined with the Protestant work ethic that promotes the idea that hard work makes people more likely to go to heaven—helped to lay the ideological groundwork in the United States that devalued rest.<sup>7</sup>

Indeed, this idea that if you work hard, capitalism will reward your efforts is deeply rooted in the American belief system, and was fueled by the Industrial Revolution. And if America was built by the Industrial Revolution, then the Industrial Revolution was built on African slave labor. This meant that enslaved Africans were primarily, and singularly, seen as labor—the magic lever in the industrial capitalist machine that could produce the raw materials for the new industrial economy. Black bodies were and continue to be viewed through that lens. And despite four hundred years of free labor in sugar cane fields in the Caribbean and cotton or tobacco plantations in

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the South, the ridiculous term *lazy* is still hurled at Black people and other communities of color. The term is used to justify the sanctity of capitalism, and it serves as evidence as to why Black folks as a whole haven't yet benefited from capitalism—they apparently haven't worked hard enough.

African slave labor is just one of many examples of how the idea of rest as weakness permeates our society. It also applies to Mexican farmworkers in the Central Valley of California and Chinese workers whose labor created the transcontinental rail system. People of color, in the minds of white America, have primarily been seen as labor to exploit. Rest, for folks of color in white supremacist culture, has to be earned first by demonstrating unquestioned loyalty and dedication to sweat and toil; only then, after you have worked to maximum output, is rest considered permissible. But even then, rest is viewed as a way to “recharge” just in order to plug right back into the frenzy and hustle of work. Rest and leisure are reserved for the white folks, who supposedly earned the luxury. Rest and race are intertwined, and it all boils down to who has the right to rest and under what conditions rest and leisure should be granted.

### REST IS AN ACT OF CORE HEALTH

The role that sleep plays in learning, mental health, physical health, stress reduction, and so much more is gaining attention. A review of one hundred studies exploring the influence of sleep on health outcomes found that poor sleep often leads to a host of other issues, including cardiovascular disease, diabetes, decreased cognitive performance, and impaired mental health.<sup>8</sup> There is consensus among researchers that a significant “sleep disparity” exists in America that is clearly based in race.<sup>9</sup>

In the June 2015 edition of the journal *Sleep*, researchers published a study on the sleep quality of Black, white, Chinese, and Latinx adults in six cities across the United

States.<sup>10</sup> Participants in the study, which involved over six thousand people in order to better understand the impact of geography and race on sleep and sleep's impact on health outcomes, wore Fitbit-like bracelets that tracked the duration, disruptions, and overall quality and quantity of their sleep. Researchers found that African Americans were getting the least amount of sleep among the racial groups, and that on average, the sleep quality of whites was better than that of the other ethnic groups.

Rest inequality is not only about the racial and ethnic gaps in the quality and duration of our sleep; it also involves gaps in how we spend our leisure time, how we play, the quality of our recreation, and the amount of time we spend in pleasurable activities. For example, researchers have found that when compared to whites, racial and ethnic minority groups are less likely to engage in leisurely activities—such as taking a walk, dancing, gardening, sewing, or dedicated physical exercise such as jogging or yoga.<sup>11</sup>

Some of us refuse to believe this is a problem, putting the effects of sleep and rest inequality far below other inequalities that make up the injustices in our society. But sleep and rest inequality in many ways forces us to see the connections among all forms of inequality. As I've noted, rest inequality is tied to economic inequality, because quality rest is the result of peace of mind, a secure job, safe neighborhoods, effective medical care, and regular time spent with loved ones. Indeed, sleep and rest inequality permeates all aspects of our lives and requires that we rethink, reimagine, and readjust our connections to how we work, live, and play. Ask yourself: What is the quality of my sleep? How much rest do I get every day? How do I spend my leisure time? How much sleep and rest do I lose due to stress?

Another question to ask is whether your work is governed by a “grind” culture. Heather Archer, author of *The Grind Culture Detox: Heal Yourself from the Poisonous Intersection of Racism, Capitalism, and the Need to Produce*, shows us that grind culture permeates how we relate to one another and places a premium on getting the job done, even if it means working through the night, missing your child's soccer game, or postponing a night out with your friends, and so on.<sup>12</sup>

As a professor, I have supported numerous students with breaking their addiction to grind culture. I recall one student who, on top of her studies, was building a nonprofit organization in service to underperforming schools. She was also involved in organizing parents to reject the district's proposal



to close several schools in her city. All of this required an enormous amount of work. She had asked me for several extensions for her papers because her plate was overfull. When we met she looked tired—not tired like she had had a long day but *exhausted* tired, like she was holding on to a sack of bricks that was pulling her down to the bottom of the sea. She explained to me that on top of all that she was doing, her mother was sick, and she was the primary caregiver. Despite this, she believed that she had to grind it out for the community. I explained to her, as I do to all my students, that nothing is more important than one's health and well-being. I suggested that she take some time off and get someone else to take over some of her activities. We talked for over an hour, and she explained to me that she just couldn't imagine what people would think of her if she stepped aside, and she didn't want to let the community down. About a week or two later, I noticed that she hadn't returned to class, and I learned that she had been hospitalized after passing out from exhaustion. The following semester, she came to see me, and we talked about what had happened. She looked much better, her eyes were bright and alive, and I could tell she had turned a corner. She explained to me that being hospitalized was one of the best things that could have happened to her, because she had been forced to rest. She had also taken the time to reprioritize, and was incorporating regular rest and leisure into her life.

Grind culture is dangerous, and we have to learn how to rethink our deeply ingrained fatalistic ideas about how to engage in community change. We know from research that rest and leisure have numerous physiological benefits ranging from reducing stress, illness, and serious/chronic diseases to supporting creativity and boosting the focus and concentration required for deep listening to others—all of which are essential to our work for social change.<sup>13</sup>

We also have to build practices in which we prioritize rest and play—not as acts of self-indulgence but rather as critical components of our journey toward justice. This is why we have to understand rest as a *right*—not a privilege for those who can get and enjoy it. The term *self-care*, for example, has become popular among social justice advocates as a way to convey the need to take care of ourselves. But the term conveys the idea that caring for oneself is a privilege you can access if you have the time and money. Calling rest and other healthy behaviors “self-care” has resulted in separating them from health and from health for

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all—because when we think about care in this way, it's akin to saying, “My well-being isn't dependent upon yours.” It reinforces the idea that we are separate, disconnected, and independent from one another. We learned from the COVID-19 pandemic that our well-being is deeply interconnected, and that if one of us is sick, we are all at risk. So, I prefer the term *collective care*—not to discount the value of your massage, warm bath, or quiet walk in the park but rather to cultivate an awareness that caring for ourselves is deeply connected to, indeed, indivisible from, the well-being and concern of others. This is fundamentally what our movements for justice are based on, and there are no movements without shared concern and care for others.

### **REST IS AN ACT OF JUSTICE**

When I was growing up, my father would explain to me that crops that are grown in the same soil over time actually harm the soil. This is because overproduction of crops in the same soil drains the soil of key nutrients necessary for growth and flourishing. The soil is the most important factor in growing healthy plants, and without good soil, nothing you do really matters. Pops explained that wise farmers let the soil rest for a season, knowing that resting the soil would ultimately produce better crops. Resting the soil regenerates nutrients, replenishes important minerals, and restores soil quality.

We should learn from these wise farmers and prioritize the need to replenish. We all have the right to restore ourselves. Rest is an act of justice. When we rest, we call attention to the oppressive ways that capitalist culture devalues replenishment and tells us that rest is reserved for those who have “earned” it. We need to democratize rest and make it more available to those who need it most. This means rethinking our work hours and reimagining how and where we work.

## Rest is like food—and just as we must pay attention to how we are cultivating and replenishing our soil and ensuring that all have access to healthy and nourishing foods, we must also pay attention to our physical and spiritual replenishment.

The COVID-19 pandemic forced us to reconsider how we work, because so many of us had to work from home. Companies had to create new ways of working for their employees, and this opened a door to re-visioning work culture. For example, what if we reduced the forty-hour work week to thirty hours, or adopted a Monday through Thursday standard work week? Some US companies have already started exploring alternative ways to promote employee well-being. For example, the right to work remotely and unlimited paid time off have become popular among some industries.<sup>14</sup>

In the meantime, how can we exercise our right to rest?

*First, ask yourself, “What is my relationship to rest?”* This question will help you to identify the messages we hold about rest and identify the consequences these messages have for you. Do you think that rest is weakness, or that rest is not important? Where did you learn those messages? (Ask yourself the same questions in terms of your sleep.) These are just a few questions that can help you to identify your relationship with rest. Take some time to write down your responses. This is an important step, because by exploring these questions, you will identify the structural impediments and opportunities that shape your rest habits.

*Then, take an inventory of your sleep and rest habits.* Do you keep your phone charging in your bedroom? If your cellphone is charging up near your bed, it may well be draining you of your rest, because your brain will be attuned to that next beep or buzz of a notification—a pernicious result of capitalist culture. Take some time to make a list of how you sleep and rest over the period of a week. Begin with how you felt waking up in the morning, and list what you did during the day that you considered restful or not. Did you exercise or go to the farmers market? Did you respond to emails and crank out

the report that you’ve been avoiding? Just list a few activities that either enhanced or impaired your rest and sleep during the week. Once you have this list, you can ascertain if you are getting enough rest, what your favorite ways to rest are, what gets in the way of rest, and what supports your rest. Then, explore ways to reduce or eliminate those activities that impaired your rest, and try to add things that enhance your rest and sleep quality. By doing this, you create your own rest and sleep plan and reprioritize ways to enhance the frequency, quality, and duration of your rest and sleep.

*Finally, form a “radical rest” group among your colleagues at work or friends and family.* A radical rest group is just a small group of five to ten people who are curious about the significance of rest in their efforts for social change. This is not a support group for rest—a radical rest group works together on how to build systems of support for rest for everyone. Rest inequality is not a personal choice but rather a result of structural and cultural inequality. A radical rest group comes together to reimagine how to democratize rest in our society, and asks questions like: How can we reshape policies in workplace settings that give employees more time to rest? How might we reimagine the work week in order to provide more time to spend with friends and family? How might we cultivate a culture where rest is not viewed as a weakness but rather a strength, and is understood as a basic human right?



Everyone has the right to rest, and it is an important step in the pivot from our addiction to frenzy to an embrace of flow. *Frenzy* is a state of desperate, unending, unfocused effort that consistently fails to produce desired results. It is the dreaded treadmill to nowhere, and its consequence is a persistent feeling of being overwhelmed. *Flow*, on the other hand, is a state of tranquil, consistent, focused activity that consistently produces desired results. It is a state of awareness that is free of judgment, doubt, fear, and confusion, and is guided by a sense of effortless certainty.

Rest is like food—and just as we must pay attention to how we are cultivating and replenishing our soil and ensuring that all have access to healthy and nourishing foods, we must also pay attention to our physical and spiritual replenishment. Like the wise farmers who allow their land to rest, replenishing ourselves is the only real way to make the deep change we need in our world.

## NOTES

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**SHAWN A. GINWRIGHT** is a professor of education in Africana Studies at San Francisco State University. Ginwright is also the CEO of Flourish Agenda and former chairman of the board for The California Endowment.

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# How Can We Support Youth Mental Health?

by *Nineequa Blanding*

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Mental health is a human right, and our youth should be supported instead of criminalized if they experience mental health challenges. . . . A critical step forward is listening to young people, and letting their voices serve as guideposts in the development and implementation of policies and programs that support young people's mental health and well-being. Our future depends on it.

In Michigan, during the pandemic, a fifteen-year-old girl was sentenced to juvenile detention for violating her probation because she did not complete her online homework.<sup>1</sup> This young person required special education services while coping with ADHD, and—like many young people when schools abruptly closed—she struggled with the transition to online learning. Despite these factors, a judge deemed her a “threat to community” and stripped her of the foundational support she received from her school and community.<sup>2</sup>

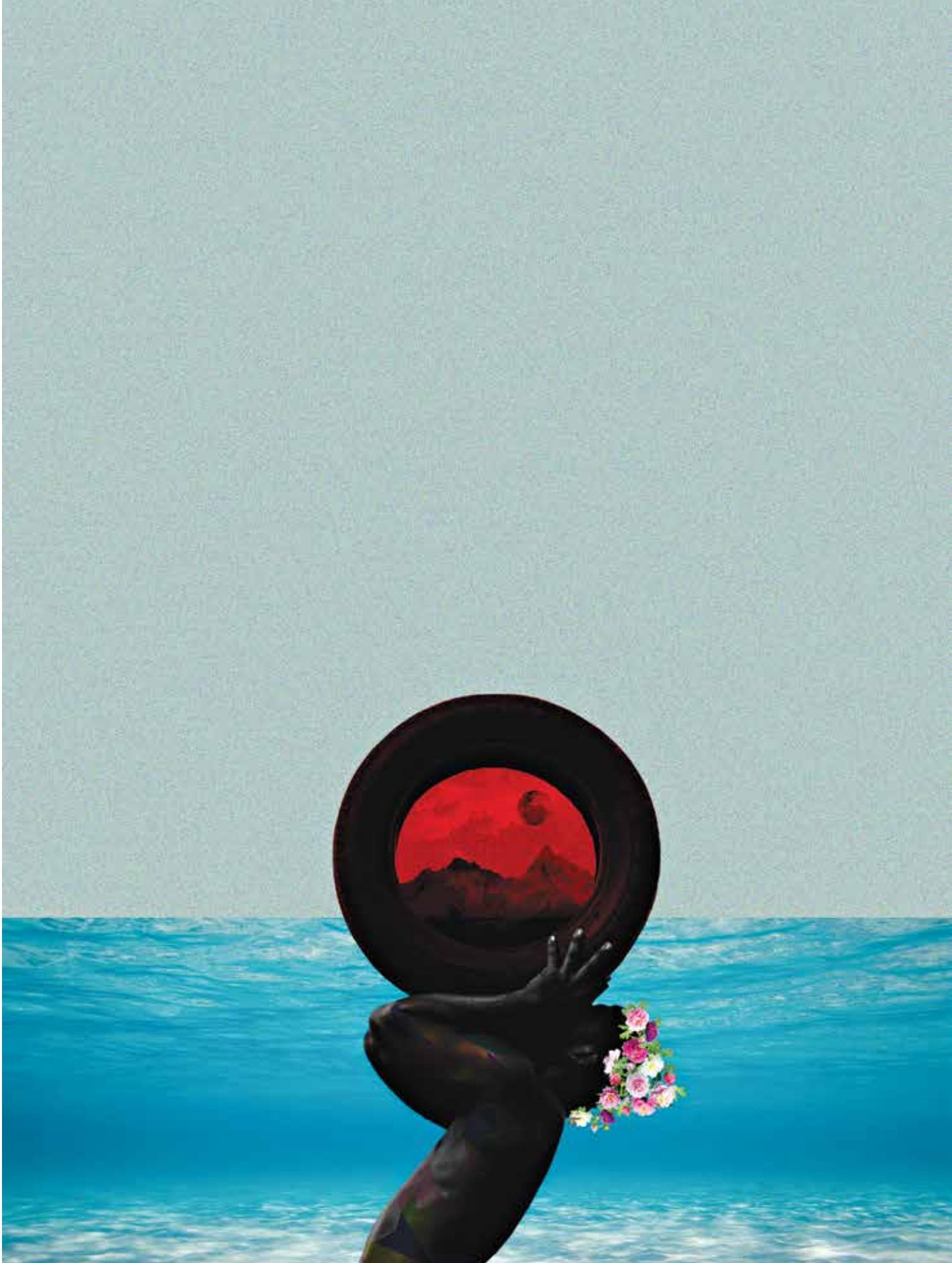
In Brooklyn, an eighteen-year-old trauma victim was rushed by her family to a local emergency room one evening after they learned she had survived multiple rapes that day. Although she was diagnosed with a severe intellectual disability at the age of four and was incapable of giving consent, the attending ER physician deemed otherwise by refusing to provide a rape kit; and responding police officers repeatedly asked the young woman whether she had invited the assaults. That same night, while in distress, she—along with her family—traveled several miles to another local ER that responded with the proper course of treatment, including a forensic exam.<sup>3</sup>

In Rochester, a nine-year-old girl suffering from a mental health crisis who verbalized suicidal thoughts was pepper sprayed by the police officers who responded to her family's 911 call for support. At the scene, as the young girl cried out to her father for help, she was told, “You're acting like a child” by officers, who then placed her in handcuffs, exacerbating her trauma rather than de-escalating it.<sup>4</sup>

“This isn't how the police should treat anyone, let alone a nine-year-old girl,” was the response of Governor Cuomo—and many others—after body camera footage of the Rochester incident was released.<sup>5</sup> Yet these stories represent the unfortunate reality of the ongoing mistreatment and criminalization of young people experiencing mental health challenges—not just in New York and Michigan, but across the nation.

## YOUTH INCARCERATION AND THE CRIMINALIZATION OF MENTAL ILLNESS

People coping with a mental illness are “three times more likely than the general population to interact with police and more likely to be arrested.”<sup>6</sup> According to the National Alliance on Mental Illness (NAMI), the criminal legal system in the United States incarcerates people with serious mental illness about 2 million times each year.<sup>7</sup>



Youth in the juvenile system have a high prevalence of mental disorders and severe psychosocial stressors. In fact, nearly 75 percent of youth arrested each year have experienced traumatic victimization either before the arrest or while in juvenile detention.<sup>8</sup> Further, approximately 50 percent of youth involved in the juvenile legal system develop post-traumatic stress disorder (PTSD).<sup>9</sup>

Structural racism and patriarchal misogyny leave youth of color, particularly Black girls, disproportionately impacted. Last year, the Annie E. Casey Foundation conducted a survey of juvenile legal systems across the country. Its analysis captured “trends from 144 jurisdictions in 33 states, representing more than 30% of the nation’s youth population (ages 10–17).”<sup>10</sup> The survey findings revealed that the population of Black youth in juvenile detention has steadily increased and, during the pandemic, reached the highest level it ever has, while the population of detained white youth declined. Indeed, from May 2020 to February 2021, the overall percentage of youth sentenced to detention rose by more than 6 percent, an increase largely driven by incarceration rates of Black and Latinx youth. Although the population of white, non-Latinx youth fell by 6 percent, the population of Black and Latinx youth grew 14 percent and 2 percent, respectively.<sup>11</sup>

Meanwhile, girls under the age of eighteen are the fastest-growing population in the juvenile legal system; and four out of five girls in juvenile detention suffer from a mental health disorder.<sup>12</sup> Black girls are disproportionately represented within this system: more than 40 percent of girls in youth detention are Black.<sup>13</sup> The stories shared in the opening of this article are those of young Black women and girls.

Other studies show an overrepresentation of LGBTQ+ youth in the juvenile legal system. A 2015 report on gender injustice produced in partnership with the National Women’s Law Center notes that 40 percent of girls in juvenile detentions across the country identify as lesbian, bisexual, gender nonconforming, or transgender.<sup>14</sup> Overall, researchers estimate that 20 percent of youth in the juvenile justice system are lesbian, gay, bisexual, gender nonconforming, or transgender, although they make up less than 10 percent of the nation’s population.<sup>15</sup>

The juvenile legal system is ill-equipped to accommodate LGBTQ+ detainees, leading to threats and trauma. The

report recounts a 2014 case involving the Connecticut Department of Children and Families and a sixteen-year-old transgender girl of color, named “Jane Doe” to protect her identity. DCF petitioned the court to place Jane Doe in Connecticut’s adult women’s prison, as the state does not have a separate facility for girls under the age of eighteen. Jane Doe, who had been abused and sexually trafficked, was charged with delinquency. Though this is a minor charge, under DCF’s direction she was placed in a maximum-security facility that houses women convicted of serious crimes. While detained, she was further “isolated in order to comply with federal laws mandating the separation of youth and adults.”<sup>16</sup> In response to “a months-long public outcry, Jane was moved to a treatment facility in a neighboring state and then to isolation in a secure facility for boys, in denial of her gender expression as a girl.”<sup>17</sup>

While detained, Jane Doe experienced further trauma—abuse, she says, perpetrated by DCF employees.<sup>18</sup>

Jane Doe’s story is unfortunately far from unique. As the *Gender Injustice* report notes, over the course of an eighteen-month period in Connecticut alone, “nearly 250 girls were placed in the [maximum security adult women’s] prison, many of them [like Jane Doe] for violations of probation, running away, or fighting.”<sup>19</sup>

## A NATIONAL EMERGENCY

Amid these systemic challenges, we are seeing unprecedented—and increasing—rates of mental disorders among young people in the United States. The American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, and the Children’s Hospital Association released a joint statement declaring a national child and adolescent mental health emergency. They note that the “worsening crisis in child and adolescent mental health is inextricably tied to the stress brought on by COVID-19, and the ongoing struggle for racial justice represents an acceleration of trends observed prior to 2020.”<sup>20</sup>

Young people in the United States are experiencing increasing exposure to trauma, whose effects are exacerbated by the COVID-19 pandemic. School closures and online instruction, social isolation, and the deaths of loved ones have compounded the complex challenges facing young people today. Such stress and trauma exposure are driving high rates of mental illness, with ADHD, anxiety, behavioral challenges, and depression

being some of the most common diagnoses among youth.

According to a data analysis led by the Centers for Disease Control and Prevention, approximately six million young people aged three to seventeen years old were diagnosed with ADHD and anxiety in 2019.<sup>24</sup> Within this same age group, nearly three million young people were diagnosed with depression—one of the leading causes of disability among adolescents and a major contributor to the overall global burden of disease.<sup>22</sup>

Moreover, since 2006, suicide rates have more than doubled among young people ages ten to fourteen.<sup>23</sup> To date, suicide is the second leading cause of death of people in this age group.<sup>24</sup> Despite these staggering rates, only one in two youth with a mental health disorder receives treatment. (These data do not account for undiagnosed cases.)

The World Health Organization notes that half of all mental health disorders start by the age of fourteen, yet most cases go undetected and untreated.<sup>25</sup> According to the University of Michigan's Health Lab, as many as one in seven young people currently suffers from an undiagnosed mental health disorder.<sup>26</sup> Criminalization of mental health disorders only widens the mental healthcare gap for young people.

According to the Office of Juvenile Justice and Delinquency Prevention, approximately 424,300 youth were arrested in 2020.<sup>27</sup> A significant number of these arrests were driven by mental illness and our society's responses to it: a congressional study concluded that every day, approximately two thousand youth are incarcerated because community mental health services are unavailable.<sup>28</sup> Yet, juvenile detention and correctional facilities exacerbate mental health challenges due to overcrowding, lack of available mental health treatment and services, solitary confinement, and separation from support systems such as family and friends.

## A PATH FORWARD

In a 2022 report, Surgeon General Dr. Vivek Murthy notes that “if we seize this moment, step up for our [young people] and their families in their moment of need, and lead with inclusion, kindness, and respect, we can lay the foundation for a healthier, more resilient, and more fulfilled nation.”<sup>29</sup>

We can seize this moment by deepening our understanding of the forces driving the staggering rates of incarceration among youth with mental illness, listening to the young people most impacted by it, supporting their leadership, and letting their voices shape policy and systems change. The National

Black Women's Justice Institute has done just that. NBWJI Executive Director Dr. Sydney McKinney notes,

The link between unmet mental health needs and Black girls' involvement in the juvenile legal system is undeniable. Therefore, dismantling pathways to confinement for Black girls requires a commitment to building and expanding the landscape of gender-responsive and culturally-affirming mental health services for Black girls and gender-expansive youth. Too often we look to adults for the answers when we should be asking [young people, particularly] Black girls what will best support their mental health and wellness.<sup>30</sup>

Given increasing rates of youth mental health disorders, the systemic criminalization of mental illness, and the disproportionate burden shouldered by young people of color, particularly Black girls, NBWJI joined forces with the Children's Partnership to form a youth-led policy council: the Hope, Healing, and Health Collective (H3 Collective). Dr. McKinney recounts, “We created a space and opportunity for Black girls and other youth of color to be the experts we know they are.”<sup>31</sup>

NBWJI reports that fifteen youth leaders and grassroots organizations with expertise in “community-based, trauma-informed care, healing-centered community engagement, and youth organizing”<sup>32</sup> convened to develop policy recommendations for meaningfully addressing youth mental health challenges and the systemic barriers to accessing “culturally-responsive and gender-affirming treatment.”<sup>33</sup>

According to NBWJI, their work “intentionally centers the experiences of Black and Latina girls, Indigenous youth and LGBTQ+ youth of color, who data show are disproportionately at risk for depression, anxiety, suicidal ideation and self-harming behaviors.”<sup>34</sup> The H3 Collective conducted six listening sessions with youth from across the United States to explore four key questions:

1. “Where were BIPOC youth seeking mental, emotional and/or social support before the pandemic?”
2. “How did the COVID-19 pandemic affect how BIPOC youth addressed their mental health and wellness?”
3. “What barriers impacted BIPOC youth's access to mental, emotional and/or social supports before and during the pandemic?”
4. “What can clinical mental health services learn from community-based strategies to improve the quality and effectiveness of services they offer BIPOC youth?”<sup>35</sup>

The findings from these listening sessions and subsequent policy recommendations are detailed in the recent publication *Youth-Centered Strategies for Hope, Healing, and Health*.<sup>36</sup> The report calls for an expansion of access to quality, affordable mental health care, and the creation of policies that ensure that instead of surveilling and disciplining BIPOC youth coping with mental illness and their often distressed families, the state offers treatment. Dr. McKinney writes:

US prisons and jails are filled with people who are trauma survivors, particularly Black women and girls. And those experiences paved the paths that led to their criminalization and confinement. [Those impacted] need opportunities and support with healing from the harm they have endured, not the punishment and violence the criminal legal system subjects them to.<sup>37</sup>

As such, the H3 Collective outlines several policy recommendations to reduce systemic harm and support young people in their healing as they cope with mental illness. The report calls for an expansion of treatment from professionals in the field—in schools and communities—who reflect the race and the cultural and community experiences of youth. Their recommendations include an increase in the number of therapists of color providing care and the creation of supportive “safe spaces” for all youth—particularly girls, transgender youth, and youth with immigration status concerns.<sup>38</sup>

Further, the collective demands an expansion of the scope of mental health services, investment in the capacity of youth leaders to provide peer support, and prioritization of the civic engagement of youth from historically marginalized communities. Ultimately, as the collective articulates,

In considering what serves young people well, it is imperative that we address these systemic barriers and develop innovative strategies, leaving space for healing outside of and in tandem with the traditional mental health system. We must be expansive in our thinking about what supports and strengthens youth mental health—inclusive of community-based strategies that mobilize, organize, and build power among marginalized youth—if our youth are to thrive.<sup>39</sup>

The World Health Organization defines mental health as “a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community.”<sup>40</sup> In other words, mental health is not the mere absence of disease—it is an

integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in.”<sup>41</sup> We must create conditions conducive to mental health and reform our responses to mental illness, because—as the WHO states—mental health is “crucial to [our society’s] personal, community and socio-economic development.”<sup>42</sup>



Now that youth mental health has been declared a national emergency, how might we galvanize efforts that center representative voices—including those of girls, youth of color, and LGBTQ+ youth—to develop practical solutions for meaningful change? How do we stop the criminalization of mental illness and create systems that enable all youth to thrive? Mental health is a human right, and our youth should be supported instead of criminalized if they experience mental health challenges. As demonstrated by NBWJI, a critical step forward is listening to young people, and letting their voices serve as guideposts in the development and implementation of policies and programs that support young people’s mental health and well-being. Our future depends on it.

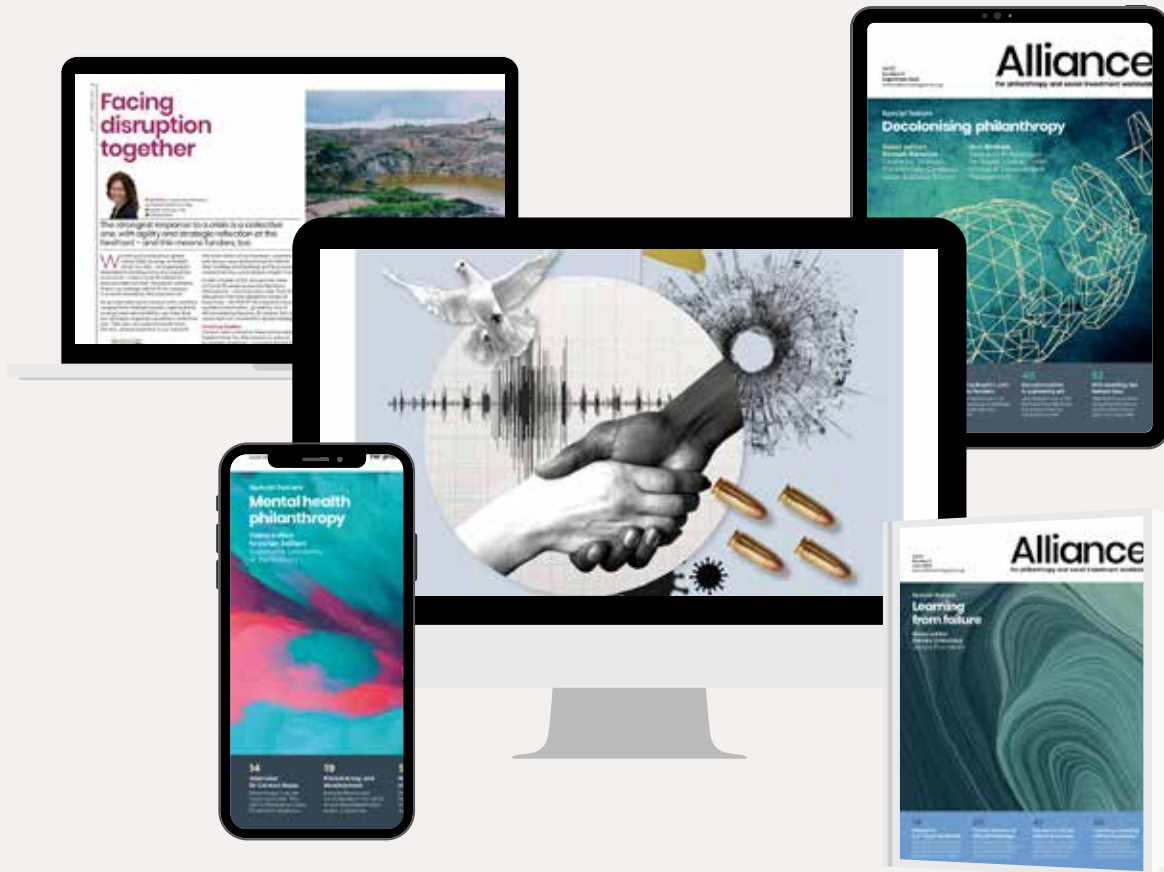


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**NINEEQUA BLANDING** is NPQ's senior editor of health justice. Blanding has dedicated the entirety of her career toward working at the intersection of health and social justice. Prior to joining NPQ, Blanding was vice president of Health Resources in Action, where she led the direction and growth of the organization's grantmaking services. Blanding was the former director of health and wellness at the Boston Foundation, where she applied her vision, leadership, and racial equity lens to develop, implement, and evaluate TBF's strategic priority to improve population health. Prior to her work at TBF, Blanding held senior leadership positions at the Boston Public Health Commission, where she led local and statewide strategies to advance health equity. She also held former roles with Mount Sinai School of Medicine and the New York City Department of Health and Mental Hygiene. She currently cochairs the Harvard T.H. Chan School of Public Health's Prevention Research Center Community Advisory Board. Blanding has a BA in psychology from Spelman College and an MPH with honors from Long Island University, and she was previously funded by the National Institutes of Health to conduct postbaccalaureate research in trauma-related risk factors for post-traumatic stress disorder at Emory University and the Center for Cognitive Neuroscience at Duke University.

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# Transforming Our Systems, Transforming Ourselves

## The Pivotal Role of Healing in Social Change Work

● We don't acknowledge everyone's trauma equally, and trauma as a field has been showing whose trauma matters over time. But trauma itself is an overwhelming event . . . and it is a condition that breaks apart or stunts our capacity to belong, to experience safety, and to experience dignity. And by many accounts, these are necessary for human survival and for our well-being.

*by Prentis Hemphill*

*The following was adapted from a talk given by Prentis Hemphill, founder and director of The Embodiment Institute and The Black Embodiment Initiative, at the Grantmakers for Effective Organizations (GEO) 2022 National Conference, in Chicago, Illinois.*

*Hemphill is a writer and cartographer of emotions, an embodiment facilitator, a political organizer, and a therapist who is unearthing the connections among healing, community, accountability, and our most inspired visions for social transformation. For the last ten years, Hemphill has practiced and taught somatics in social movement organizations and offered embodied practice during moments of social unrest and organizational upheaval. They have taught embodied leadership with Black Organizing for Leadership and Dignity (BOLD), and generative somatics. They served as the Healing Justice director of Black Lives Matter Global Network from 2016 to 2019. Hemphill's work and writing have appeared in the New York Times and the Huffington Post, and they are a contributor to You Are Your Best Thing: Vulnerability, Shame Resilience, and the Black Experience (edited by Tarana Burke and Brené Brown; Random House, 2022), Holding Change: The Way of Emergent Strategy Facilitation and Mediation (adrienne maree brown; AK Press, 2021), and The Politics of Trauma: Somatics, Healing, and Social Justice (Staci K. Haines; North Atlantic Books, 2019), and they are the host of the acclaimed podcast Finding Our Way. Hemphill lives in North Carolina on a small farm with their partner, two dogs, and two chickens, and is working on an upcoming book on healing justice.*





**H**ey, everybody, how's it

going? Thank you for inviting me to speak today. It is really exciting and sweet to be with you all—I haven't been out of the house in years at this point, so it's nice to be together. I have a lot of words, good words—and I will try to move through them and also stay connected to you all as much as I can. I want to extend a lot of gratitude and recognition to this land—to this place in which I am a visitor that has held me so well, and that I know has also held so many of our ancestors.

It was a challenge to put together my words for this talk on healing and social change just four days out of the massacre in Buffalo, in which Black people, and Black elders especially, were gunned down because of white hatred and white nationalist violence.

I feel overwhelmed—I just want to name that—by the barrage of seemingly endless brutality against our people and against our efforts for social change. And it's not missed on me that often, when I'm talking about healing and social change, I feel like I have to almost prove why healing and social change are important, even though we are living in these times when we're witnessing such tragedies.

It feels apparent—but it also reveals to me how accustomed we are in some ways to the suffering of poor and working class people, and the suffering of Black people in particular. So, sometimes these questions of how we heal and how we change can feel flimsy to me against that violence. And not to bring us down but to really ground us—we are in chaotic times generally: over one million deaths from COVID; the fascism that is gaining traction in our country making its intentions toward our bodies and our lives clearer and more realized each day; and climate change and war posing existential threats to all life. All of these, I believe, make it more and more critical that we deepen into and understand these questions.

I've been doing movement and social change work for two decades now. I started as a not very good organizer. But I was brought into abolitionist work and transformative justice models and frameworks, which pushed me toward imagining a world without prisons—which, if we take that a step further, had me think about and understand and feel into the question: If not a system that logically ends in prisons, what might we then build? If prisons and the carceral system became illogical to us, what institutions might we create? What might our communities look like? What might our relationships feel like? How might we be different with each other?

So, that's how I began my work around healing. Those questions led me to explore healing as a necessary component of social change, and I have been doing this healing work inside of movements ever since. I became a therapist—I became a politicized somatics practitioner—and I have been supporting trauma-healing political formations to understand the role of trauma and how it can impede our best efforts toward social change. And I recently founded an organization called The Embodiment Institute, where we are practicing building more just, embodied, relational habits with one another.

I don't think I encountered the words *trauma* and *healing* outside of talking about a wound until I was in college, or after that (and I mean a physical wound). I knew, for example—even though I didn't have the words for it—that what my parents had experienced in their childhood impacted how they showed up with me. I knew that their stories held something inside of them that could be activated, could flare up, and could create more or less threat or danger for us as children. I knew that my parents loved me, but I also knew that what they had to do to ensure our survival often stood in for the tenderness of love that I really longed for as a child.

I also knew that the things that we often did for reprieve, to buoy ourselves up, to remember and listen to the magnificence of life—our Saturday morning dances, our impromptu songs, our deep hugs—were connective rituals in our family. *Saturday mornings, you put the record on and you dance together.* And that helped us and brought us back into connection with each other and into life. So, I knew early on that wounds and memories and our experiences of healing were

**Trauma does not live neatly in one body.  
It necessarily spreads.  
It spreads relationally and it spreads across time.**

always with us—imperceptible to the eye but incredibly legible to the soul, if we knew how to listen to one another.

I want to briefly explain how I hold trauma, because I think it's important. And I know that this is one of those words that are both over- and underused, but I think it's useful for us to understand what might be happening inside of us. Trauma has always been a political term and a politicized term. Understanding trauma tells the story in some ways of how pain lives inside of us—in our bodies and in our behaviors. And who we identify as having experienced trauma tells a story about who we as a society allow to feel, and whose pain matters to us. We don't acknowledge everyone's trauma equally, and trauma as a field has been showing whose trauma matters over time. But trauma itself is an overwhelming event—that's what they say, an overwhelming event—and it is a condition that breaks apart or stunts our capacity to belong, to experience safety, and to experience dignity. And by many accounts, these are necessary for human survival and for our well-being.

What I really want you to understand about trauma is that *safety* is the internal foundation that allows us to be creative and collaborate with other people. If I'm safe enough, I can create and do things in the world. *Belonging* is our relational sphere. I belong to the species. I belong in my family. I belong in my community. I belong in Earth. *Dignity* is where our self-concept and our self-image lives, and it's often impeded and crowded by the experience of trauma and also by shame. So, safety, belonging, and dignity get broken apart inside of trauma.

And the residue—what lingers—is always inside our relationship with ourselves, and it's always present in our relationships with one another. It's inside and outside experience. We don't often talk about the break in relationality that trauma actually fundamentally is—and it's really important for us to understand that. Also, what I described to you earlier was *generational* trauma—how it gets passed and the meandering ways it wanders through our families and our communities and our lives. It is generational in that way and also epigenetic—as we're learning more and more.

The other thing I want you to understand about trauma is that it's not necessarily one catastrophic event. That's how the idea of trauma originally came about. We think about it as one event that happened, but it can also be conditions. The definition of oppression I often use is that it is *the concentration and distribution of trauma into certain bodies and certain communities*. We often think about it structurally, systemically, but what happens is that oppression concentrates experiences of trauma into certain zip codes, into certain blocks, and into certain bodies. You all with me? I'm packing a lot in, so I just want you to stay with me. So, what happened in Buffalo, for example, is devastating in so many ways. And it's devastating because of the lives of elders—especially—and community members being viciously taken. But it's also devastating because of how it impacts family members. This will have a lasting impact for generations. We're looking at something that will last across time. It spreads. Trauma does not live neatly in one body. It necessarily spreads. It spreads relationally and it spreads across time.

So, why is this important for social change? Why is it important that we're talking about this? In all of these spaces where we are attempting to cultivate and inspire social change, we still often find internal transformation reinstituting these capacities of safety, belonging, and dignity—of strengthening complex human relationships—mysterious. Mysterious, accidental, random—we don't understand it. But I believe—and what I've seen through movement—is that where our wounds are unaddressed, where our own story is not understood, is exactly the same place where the fractures in our organizations occur and the fractures in our movement occur.

I want to talk about mistrust and conflict as an example of that. I've worked with many organizations. I get called in a lot to facilitate conflict work. And if the conflict is not so acute, I usually come in and do a trust training first before I do conflict. Because trust—a trustful environment—is the environment in which conflicts can happen in a generative way. Trust is disrupted by trauma. I talked about how belonging gets ruptured in trauma, and that disrupts our ability to extend trust to one another—to believe that others are trustworthy,

## Healing . . . increases our capacity for authentic relationships with one another, and therefore opens us up to a power inside of our movements that we have not seen before.

for example. And we are experiencing, I would say globally in some ways, and especially in this country, a breakdown, an erosion, in trust—a failure of institutions and intentional manipulation or breeding of mistrust inside of the population. We’re experiencing a kind of growing suspicion and mistrust. But trust is so necessary. Trust is what makes things happen. It’s the lubricant for all social relationships, and especially for collaboration and coordination. So, we have to look at trust as one capacity that’s necessary to rebuild in our relationships and in our organizations, because nothing meaningful can happen without it.

I also want to say that the way power and privilege can operate is that if we’re used to having power over, it can feel really hard to extend trust to people who don’t have as much power. Not extending trust can be a way for us to hold on to certain power dynamics that reinforce who we imagine we are. (And I may or may not be saying this because I’m in a room of philanthropists.) But even that is a relationship to trust that needs to be healed and transformed, I think, in order to have meaningful relationships and to do meaningful and transformative work beyond what you know and understand currently alone.

In short, I believe it’s impossible for us to do what we set out to do around social change without understanding and being really skillful at the inner and relational lives that we have. It’s impossible for us to transform the world, transform our systems, without being equally willing to transform ourselves and to do that really hard, sometimes painful, deeply uncomfortable work of reckoning with what it is that we have embodied, the systems we have embodied, and the ones that give us identity and meaning that we may as of yet be unwilling to let go.

So, healing. I want to talk about healing and not just trauma. But healing—what is it? I don’t know if you experience this, but people talk about healing, and you can be like, What is that? And I know sometimes I struggle when talking with funders or folks in philanthropy about healing, because it can feel so abstract. But what I want to say is that if *trauma* is an overwhelming situation that breaks safety, belonging, and dignity, *healing* is any set of practices or processes that

restore a felt sense of safety, the capacity and desire to belong, and a sense of dignity as evidenced by a reduction of shame and an increase in agency. This is important for me as a practitioner. This is how I think about the work that I do with individuals and organizations. This is how I orient toward it. But healing opens up possibilities for our lives that we have not yet seen, that we cannot even feel, necessarily. Healing also increases our capacity for authentic relationships with one another, and therefore opens us up to a power inside of our movements that we have not seen before.

I think it’s important for us to pay really close attention now to the question of how we build the skillfulness to stay together in the midst of very hard things. That’s an important skill. Let me call it one of those soft skills—it’s one of those soft skills that everything is built on, to be able to stay together through the hardest of things, to build trust, to repair trust, to extend trust to one another, to move through conflict skillfully, to be vulnerable, to allow for intimacy, to vision beyond what you have seen, to look beyond the world that you have inherited and see something more. All of these capacities become more possible when we engage in deep transformative work—when we’re not just looking at other people to transform around us but are as deeply committed to our own transformation, as deeply committed to becoming *new*, as our expectation that the world change around us.

This morning, I went to visit an organization that I’ve worked with over the years and that I love, called the Chicago Torture Justice Center. The center works with survivors of state violence—torture perpetrated by the Chicago Police Department—and we’ve done embodied healing programs together. We were talking today about how important it is and how difficult it can be to talk about transforming along these axes—safety, belonging, and dignity—but how thinking about healing in this way transforms the very quality of an organization, of the relationships, the power, the effectiveness, and the clarity of the work.

So, what that means is that healing can look like a lot of different things. Healing can—and should—look like



**I invite those of you in philanthropy to choose to join us on this journey of being transitional characters, of transforming your own relationships in your own life, and especially in this domain in which you practice, by supporting this work around healing and healing justice and transformation.**

reparations. It can look like any opportunities for Indigenous and Black people to steward and inhabit land, to have a deep investment in our communities. It can look like creating healing spaces and trainings that give us a spaciousness to untangle the persistent stories and habits that live inside of us, and to have the space to practice new things, to embody new ways of being with one another, where we can experience this real safety, belonging, and dignity. It also means supporting these interventions and culture around social change—obviously, transformative justice, conflict transformation, restorative justice, and also the imaginative work of ritual creation—creating new cultural ways of being with one another and infusing the world more with meaning in terms of our values, so that how we come together is as important as what we do.

A framework that's been critical for our work at The Embodiment Institute is the idea of *transitional characters*. I borrow this term from family systems therapy, which looks at how people take on healing, the trauma that lingers in their lineage, how people who are willing to face and understand the route of violence or abandonment in their own family and then commit to learning new patterns in their own relationships change the course of their lineage.

I have always been really inspired by this concept of transitional characters, and I have also been really clear that we are not only embedded in family systems, we are also embedded in community systems, we are embedded in institutional systems, we are embedded in philanthropic institutions. And as these sites shape us—shape who we are, shape our habits, shape the way we talk, shape the way that we show up—they're also incredible sites for transformation. They are the places that we can shape back. We are shaped and we shape back—that's part of healing. We are shaped, and we learn through our shaping what didn't work, what stunted us, what stifled us. And we intentionally shape back to create more space for more life, more expression, more connection. That, for me, is the work of the transitional character in this moment. It's not only absolutely

transforming our family systems but moving beyond to transform *all* the systems in which we're embedded.

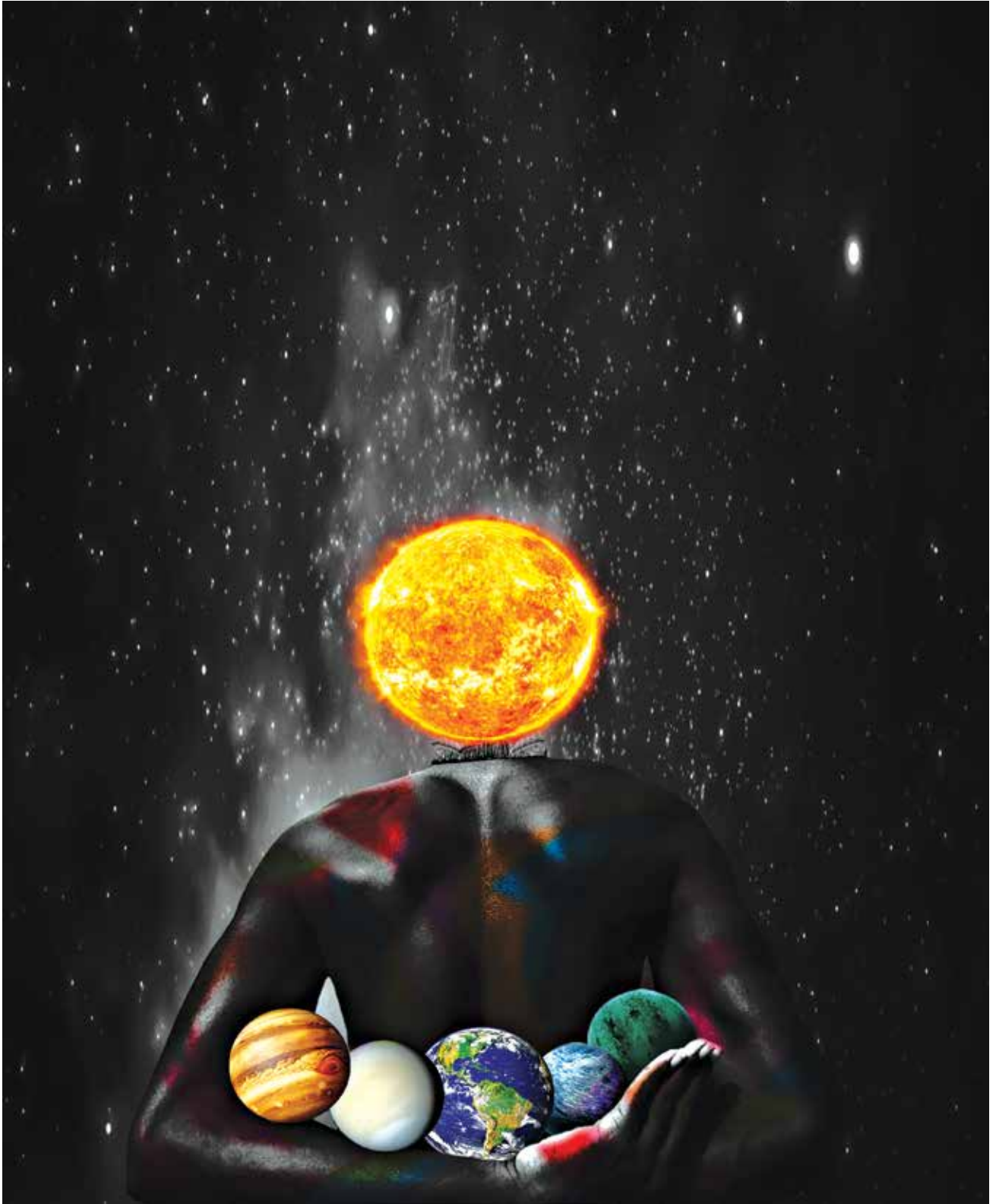
I think this is the time for all of us to understand ourselves in this way—that none of us exists as sideline characters or inconsequential beings in whatever it is that we're doing but that we are all transitional characters. And this means our work inside of every system we're in is to understand how to nurture life and creativity and connection inside of those systems—how to take the risks that are necessary, how to push where it's necessary while maintaining connection, how to transform what is necessary.

So, I'm charging you with becoming a transitional character in this moment and choosing to engage in that way. I'm sure that many of you already do, and are transitional characters. It is imperative that we be transitional characters in this moment—you, and me, and all of us. It is imperative that we have the opportunities to build the necessary skills that we need to do the transitional work that we need to do in order to know how to navigate conflict, to be able to be vulnerable with one another, to inspire trust and build trust among each other. This foundational culture work is what will make our movements strong and keep our movements together moving forward.

Lastly, I invite those of you in philanthropy to choose to join us on this journey of being transitional characters, of transforming your own relationships in your own life, and especially in this domain in which you practice, by supporting this work around healing and healing justice and transformation, extending trust and care to your own grantees and also being willing to do this work and to allow this work to be the site of your own healing—of expanding belonging, of increasing reflection—so that we can all grow and transform what is necessary for us to transform in this time. I'll end it there. Thank you so much.

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