NPQ

NONPROFIT QUARTERLY MAGAZINE

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We Thrive

Health for Justice, Justice for Health

The Psychedelic Renaissance: A Portal to Transformation

+

Healing-Centered Leadership

Learning from Black LGBTQ+/SGL Moments, Spaces, and Practices

From Big Pharma to Our Pharma

Indigenous Stories to Reclaim and Reframe Our Highest Health

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by Dana Brown

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“Rememory (after Walidah Imarisha)” by Amir Khadar/ www.amirkhadar.com. Republished from *Black Freedom Beyond Borders: Memories of Abolition Day* (Wakanda Dream Lab, PolicyLink, and The Big We, 2018, with permission)

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WELCOME

Dear Readers,

At the beginning of 2021, we made the decision to focus our content on four key justice areas: racial, economic, climate, and health. We realized that most of the important work of civil society today falls within these. Now, we finish the year with our winter issue, which takes a first look at the emerging field of health justice.

We partnered with Dr. Angel Acosta—a healing-centered educator who works to bridge the fields of leadership, social justice, and mindfulness—to invite an extraordinary group of leading-edge thinkers and practitioners working at the intersection of health and justice to write for *NPQ*'s first-ever edition focused on the topic.

From social psychiatry, urban policy and health, and African-American youth activism and development to Tribal whole-health care, Birth and Death work, trauma-informed care, and psychedelic-assisted psychotherapy, the range of inquiry at the heart of this collection is both unusually broad and deep. This is because health justice is the culmination of the other core justices at the forefront of societal activism and transformation, and because there is growing understanding that health and healing are key to thriving.

As we come to the end of the second year of the COVID pandemic, we hope that you take time to relax and regenerate. We offer this issue in that spirit.

Cynthia

Cyndi Suarez
President and Editor in Chief
NPQ

Psychedelic and Plant Medicines

A Portal to Transformative Realms of Possibility

by *Kasey Crown*

If anything has the potential to alter the grievous state of mental health and well-being and move us toward "visionary, transformative and liberatory realms of possibility," it is the psychedelic renaissance we are on the cusp of today.[1] The prospects for individual mental health and the transmutation of trauma alone are encouraging, but it is the potential for rebirth that keeps me engaged in and inspired by this work: the promise of our ego dissolving into its rightful place as steward of the soul; increased awareness of both our interconnection to one another and this planet, and thus the emergence of a more responsible, respectful, and reciprocal society; and expanded access to the creativity needed for systems change and eco-innovation. Psychedelic and plant medicines, some of which have been used in ceremonial contexts for thousands of years to transform consciousness, may be one of the only viable tools we have available that can properly awaken us from the illusions we currently occupy, keeping us stuck in the patriarchal, capitalistic, supremacist paradigms that govern our experience of life on this planet. Understanding and learning from plant-based or synthetic psychedelics is a quest to understand consciousness, the mystery of the universe, and our place within it.

Psychedelic and plant medicines, some of which have been used in ceremonial contexts for thousands of years to transform consciousness, may be one of the only viable tools we have available that can properly awaken us from the illusions we currently occupy, keeping us stuck in the patriarchal, capitalistic, supremacist paradigms that govern our experience of life on this planet.

“OUR STORIES OUR VISIONS SERIES #10” BY AMIR KHADAR/WWW.AMIRKHADAR.COM

Mushrooms are the fruit of a large subterranean organism, their underground growth reflecting the unconscious shadow material we are unearthing each time we ingest their medicine.

As a forthright advocate for the safe use of psychedelics, and psychedelic psychotherapy in particular, my hope is that we can reintroduce these healing modalities to society, with great care—making sure to avoid the usual profit-driven pitfalls that ravage our mental healthcare system and make "wellness" accessible to few. For health justice to succeed, we need to heal the past and step intentionally and attentively into new models and standards of care. This medicine space, like most other spaces that humans engage with, is ripe with opportunities for exploitation, misuse, and abuse, and it would be remiss not to address this fact.[2] The greatest harm caused rests on the shoulders of the policy-makers who relegated this work to the shadows in the first place, criminalizing the use of psychedelics, incarcerating countless humans (mostly people of color), suppressing research, peddling misinformation, and all but guaranteeing that much of this work would be conducted in secret, where unsafe usage and abuses of power run amok.[3] Few people question that the war on drugs has been a disaster of epic proportions, and it is our collective opportunity to encourage decriminalization, medicalization, and legalization of psychedelic and plant medicines, so that appropriate safeguards can be established.[4]

It is important for me to name at the outset that I am not a member of one of the many Indigenous communities that hold great wisdom on the topic of plant medicine; nor am I one of the experienced and revolutionary psychedelic guides who have been courageously practicing this form of healing underground for the last half century.[5] I am a white-bodied, cisgender, transpersonal psychotherapist and trauma specialist with extensive experience in community and private mental-health practice. Though I was once optimistic about our human potential to survive adverse experiences and thrive beyond them, my years of treating trauma within the confines of a limited and limiting mental healthcare system—combined with the increasing collective distress brought on by political unrest, gross inequality, climate crisis, and pandemic disease—have challenged my confidence. Despite mounting frustration, I hold out hope; and my commitment to finding creative solutions to the problems I see plaguing us has led me to psychedelic psychotherapy.

I began my training with the Multidisciplinary Association for Psychedelic Studies (MAPS) in MDMA-assisted therapy for post-traumatic stress disorder (PTSD), in 2018. MAPS, a pioneer in the field of psychedelic psychotherapy, conducts extensive research in the United States, Canada, and Israel; is engaged in drug policy reform; trains diverse cohorts of therapists; prioritizes health equity; and privileges public benefit over profit. Most important, MAPS is steadily moving the work forward using evidence-based research to establish the safest and most ethical legal "container" possible for working with expanded states of consciousness.[6] My training, the final elements of which require FDA approval, opened the door to a world of possibility and hope once diminished by the mental health system.[7] I have spent the three years since my initial training with MAPS ended continuing my studies with various educators and elders in the field—working to integrate and balance Indigenous wisdoms with the latest science, and learning and practicing in legal contexts to develop my skills as a psychedelic guide.

THE MUSHROOM AS A MIRROR

While there are a variety of molecules in the psychedelic category currently being researched in the laboratory, including but not limited to MDMA, Ibogaine, Ketamine, and 5-MeO-DMT, the psilocybin mushroom beautifully illuminates the potency of this work. A wise teacher of mine describes the various principles of the mushroom as a mirror. Mushrooms are the fruit of a large subterranean organism, their underground growth reflecting the unconscious shadow material we are unearthing each time we ingest their medicine. This organism and its underground mycelium, a network that connects all plant life and serves to transfer nutrients and minerals among them, reflects and teaches the interconnectivity of all living things and the idea that the exchange of love, care, and mutual regard are necessary for our health, well-being, and survival. Mushrooms are ephemeral—they fruit and die off quickly, reflecting and teaching the brevity of life and the impermanent nature of all things. They communicate to us the importance of letting go and embracing cycles of death and rebirth. Mushrooms are composters: filterers of toxicity that discard waste, they transform one

Psychedelics, known for their mind-expanding and often heart-opening qualities, create opportunities for us to zoom out and witness our humanity from a wider perspective.

thing into another in much the same way we in the healing professions work to transmute trauma and support the flow of grief as a means to make space for the integration of a renewed sense of meaning and purpose. While the mushroom provides us with plenty of useful metaphors, each psychedelic and plant medicine has its own unique spirit, and the molecules most aligned for one's growth can only be determined by oneself or with the support of a therapist or experienced guide.

Psychedelics, known for their mind-expanding and often heart-opening qualities, create opportunities for us to zoom out and witness our humanity from a wider perspective—an otherwise tall order for a person contracted by depression, anxiety, and/or traumatic injury. Furthermore, psychedelic medicines can induce powerful mystical experiences or glimpses into realms of the unknown, the contents of which have the potential to initiate the reorganization of our perception of reality and liberate us from the injuries that confine us.

INTENTION, PREPARATION, SET AND SETTING, AND INTEGRATION

The singular act of ingesting psychedelics, however, is not where the real magic unfolds. It is in several other important elements of this work that the conditions for transformation are created: *Intention*, *preparation*, *set and setting*, and *integration* are necessary agents when working with psychedelic medicines for the purpose of healing. Without these cornerstones in place, the experience lacks the container to yield truly meaningful results, and, in some cases, harm can result.

I once read the words "Be careful where you are headed, or you may end up where you're going"[8]—a humorous but cautionary reminder of the importance of establishing an intention when doing any kind of healing work. We must first know why it is we are taking these medicines—what it is we seek to heal, change, or understand about ourselves, our relationships, the universe. *Intention* aligns the journey with purpose and grounds the journeyer. Journeying with intention almost always leads to insights directly or symbolically related to the intention itself, and can serve as a powerful anchor point to return to when traversing difficult terrain and when engaged in the integration process.

Preparation is the practice of preparing the journeyer (client) and establishing trust between journeyer and guide (therapist). The guide starts with a thorough intake and client history, assessing for potential contraindications. Once it is determined that a client can safely move forward with the journey, the client's mental, emotional, physical, spiritual, and environmental situation is explored, and the guide shares details of what to expect within the journey space. It is important that the client be of sound mind and have sufficient ego strength to enter an expanded state. They must be capable of creating space inside themself for the journey and for the process that follows.

Set and Setting refers to both the mindset of the journeyer and the container within which the journey itself takes place. Insofar as mindset is concerned, the journeyer must be prepared to surrender to the experience. While nervousness is inevitable, excessive fear and anxiety about the journey itself may interfere with a client's capacity to loosen their grip and give way to the process. If conditions have changed and an acute crisis or life challenge has emerged between the prep sessions and the intended journey date, a person's mindset may be compromised. Ensuring the client is stable and resourced enough to enter the journey space is essential, and will be evaluated in preparatory sessions and on the day of the journey.

It is the guide's responsibility to establish a safe container and to communicate what that entails. The therapist or therapists (the MAPS protocol calls for two) communicate standard rules and steps for the journey, prepare music, control environment, temperature, and other such details, and monitor client needs throughout the process. Most important, the guide will have two feet in this dimension of reality, creating a safe space for the client to surrender to the effects of the medicine and retreat into the unconscious. If the therapist or client emerges from a particular lineage/culture and/or wishes to include a ceremonial- or ritual-based practice in the session, space is made to honor whatever spiritual or earth-based wisdom tradition that calls to be honored.

In addition to establishing trust with the guide and being of sound mind, the environment is an exceptionally important aspect of creating a safe container for the work taking place.

We have all the necessary instruments at our disposal for a radical shift in human consciousness and the cultivation of a more harmonious human family.

Journey spaces and treatment rooms should be tranquil, calm, and inviting—safe sanctuaries with limited outside interference. Natural environments can also provide a deeply healing and supportive cocoon for this work. In many cases, access to nature is limited, and some studies are incorporating digital content as a way of simulating an experience of the natural world. According to renowned cinematographer and *Fantastic Fungi* director Louie Schwartzberg, a current study being conducted at the Pacific Neuroscience Institute on the use of psilocybin for alcohol abuse is incorporating elements of his *Moving Art* nature cinematography in sessions with subjects.[9]

And lastly, there is *integration*. By far the most important aspect of this work, integration is the key to ensuring that a psychedelic journey leads to meaningful change. Integration is the process of both embodying and "actionizing" the insights derived from a journey. It is one thing to adventure off to a supernatural world that defies the boundaries of this dimension of reality, and quite another to make use of that experience in a way that enhances the quality of our lives and benefits those around us.

Because psychedelic experiences often reveal information symbolically and have the potential to open difficult doors, it's important that a competent and well-trained therapist provide a solid container of love and compassion as the client works to interpret the content of their journey after the fact and heal whatever material may have surfaced in the journey space.

As a therapist, I know all too well how slow the healing process can be, especially as we contend with increasingly complex trauma and an overmedicated and underresourced population. Psychedelic therapy cuts through many of the interpersonal and neurobiological self-protective mechanisms established in response to injurious experience. Those default modes are barriers to our healing and often need a powerful interruption to initiate change.[10] Inducing a non-ordinary experience can speed the healing and life transformation process along, producing insights within hours that might otherwise take years to access in traditional psychotherapeutic models. In that way, a journey is like a wormhole, or passage through space and time. The insights and experiences clients emerge with then require attentive exploration in service of organization and integration.[11] Integration grounds us back into our bodies and physicalizes the spiritual or ethereal wisdom we touch. Without integration, a psychedelic experience is just that: an experience—and the degree to which it is useful is up for debate. Integrating a psychedelic experience with psychotherapy or other mindfulness-based integrative modalities helps us to lay new cable and create healthier connections in the brain and extended nervous system, and in our relationships.[12] This work, if done intentionally and integrated effectively, is extremely powerful and fast acting. It can liberate a person from pain and restore vitality, creativity, and a sense of meaning.[13]

■

As this work travels from its Indigenous birthplaces to the Wild West underground to the laboratory to the therapy room, it continues to evolve—and so, too, does our understanding of how to best be in a responsible and respectful relationship with these modalities. Recognition that traditional mental health models continue to fail our most vulnerable populations helps to build momentum and support for alternative approaches like psychedelic psychotherapy. Many questions remain unanswered around how this work can be conducted safely, cost-effectively, and at a scale that provides the greatest benefit for all. However, with the second phase 3 clinical trial for MDMA-assisted psychotherapy in process (MAPP1 is complete; the second trial, MAPP2, is underway) and studies being conducted all over the world at leading research institutions, it is only a matter of time before this is an accessible treatment option and self-actualization tool.[14] Psychedelic medicines will not work for everyone, but we can do better where whole health is concerned. We have all the necessary instruments at our disposal for a radical shift in human consciousness and the cultivation of a more harmonious human family. I continue to look to organizations like MAPS that are learning from the past and leading the way with intention to a future where visions of equitable access to mass mental health are realized, and health justice prevails.

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KASEY CROWN, MA, LMFT, is a transpersonal psychotherapist, clinical supervisor, consultant, wellness educator, and activist. Her work challenges old mental health paradigms and suggests instead that true well-being lies in our ability to balance scientific and spiritual perspectives. For more than a decade, she has served as a facilitator of the healing process for adult individuals, couples, and groups, working to upend trauma, transform emotional injury, repair relationships, and unlock vital wisdom to connect people with who they truly are. Crown holds an undergraduate degree in philosophy from the University of San Diego and a master's degree in spiritual and counseling psychology from the University of Santa Monica. She has completed postgraduate advanced clinical trainings in relational studies, interpersonal neurobiology, culturally competent trauma-informed care, and harm reduction, and is a California-licensed marriage and family therapist, trauma educator, and embodied mindfulness facilitator. Crown is a 2020 to 2022 Garrison Institute Fellow, working with a diverse cohort of scholars, artists, and activists to blaze a new trail in the field of collective healing, drawing upon and engaging with the science of interconnection, generative action, and awareness-based contemplative wisdom. To learn more about Crown, visit www.kaseycrown.com.

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About the Artist: Amir Khadar

(They/Them) is a Sierra Leonean–American artist, designer, and educator from Minneapolis, Minnesota. Their main mediums are poetry, fibers, and digital art. They are actively experimenting and growing as an artist through establishing relationships to ways of making, but their practice has always been grounded in afro-futurism, gender theory, beauty, and ancestral practices. They have done extensive art/design work with Black Alliance for Just Immigration, Parenting for Liberation, Wakanda Dream Lab, Forward Together, and the Astraea Lesbian Foundation for Justice. Khadar is currently a student at Swarthmore College working toward a BA in Black Studies.

HEALTH JUSTICE

The Power of Self-Care

A Bridge to Communal Care

by Shelly Tygielski

In recent years, a growing uneasiness and an undercurrent of anxiety have emerged in the United States. Psychologists, therapists, social workers, and doctors across the medical spectrum agree that we are in the middle of a genuine national mental health crisis. A time like this can serve as an impetus for reclaiming self-care as a movement, which could have a profound and lasting impact on this country and the world. As the late beloved activist and writer Audre Lorde said, self-care is not "self-indulgent" but rather an act of "self-preservation."[1]

Self-care reaches beyond the individual. In Sanskrit, the term for self-actualization and individuation is *samadhi*, which means *enlightenment* or *union with the divine*. This word recognizes that we are more than just our individual selves: we are a sum of all the parts that surround us. Every life is of value, and we are all connected; when we recognize this, we can embark on the healing work that addresses the traumas of our culture.

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Today, we are seeing calls for change and transformation of our world. We are seeing people rise up in their power to assert that their lives are important, valuable, and worth fighting for. We are also showing solidarity by giving our friends and loved ones messages of strength and support as they dismantle systems that are oppressive and archaic. By starting with the inner work, we address many of our root issues and work our way through them. If we all simultaneously commit to healing ourselves and healing our trauma, our own healing becomes a contribution to the health and wellness of our communities, our descendants, and the world.

Take a moment to imagine the power of a self-care movement—a wave of kind care connecting communities, healing our bodies and minds, sustaining our energy and momentum, and helping us all live healthier, happier, and more balanced lives.

SELF-CARE AS A MOVEMENT

As a movement, self-care has a rich and radical history.[2] It was born at the intersection of the women's liberation movement and the civil rights era—a time when courageous individuals and communities fighting relentless prejudice and discrimination created the first formalized communities of care, which allowed them to stand strong together in the face of seemingly impossible challenges and unspeakable treatment. In fact, a core piece of what civil rights activists were and continue to be fighting for can be seen as the basic human right to self-care—for when the government turns its back on its people, self-care literally becomes a matter of life and death. Often denied medical treatment at hospitals and healthcare centers in the past, and facing any number of dangers stemming from unequal and unjust treatment in the present, part of what people of color are fighting for is the freedom, time, money, and resources to care for themselves. In this exhausting battle, often the only support they find is with one another and within themselves. Thus, civil rights leaders made healthcare a priority. As Martin Luther King Jr. said, "Of all the forms of inequality, injustice in health is the most shocking and the most inhuman."[3]

What has been true for the civil rights movement has also been true for the women's liberation movement. Women across the board have viewed controlling their own health as a corrective to the failures of a white, patriarchal medical system to properly tend to their needs. Self-care, as described by Natalia Mehlman Petrzela, an associate professor of history at the New School, in New York City, became "a claiming [of] autonomy over the body as a political act against institutional, technocratic, very racist, and sexist medicine."[4]

In this age of the industrial wellness complex—an era of bath bombs, drop-in meditation studios, and self-help quick-tips lists—capitalism ignores that for populations most in need, self-care is neither frivolous nor easy. As a movement, self-care and communal care make the declaration that we don't just deserve to be alive, we have the right to live our best lives. Genuine self-care and communal care are long and hard paths. They require diving beneath the surface problems, which are just the symptoms of the deeper, more enduring traumas that all of us carry. What we need, and what this movement seeks, is—to use a concept coined by Ghanaian playwright and journalist Esther Armah—*emotional justice*.[5] Emotional justice can provide us with a steady undercurrent, like a river flowing beneath the exterior crust of the Earth, as we embark on dismantling and rebuilding social systems that don't work for us. Emotional justice depends upon our commitment to doing the inner work; it cannot exist without it.

This type of work can show up in different forms, like healing from an offense that was never recognized by the offender or by society, or having the courage to speak up for ourselves and write our own stories. Individual inner work is not enough to support a movement. In social and political movements, commitment to community care, which means our own and others' emotional justice, is a fundamental building block. What defines any movement—including the self-care movement—is people coming together with a shared purpose to create change that benefits everyone. Movements need people with skin in the game and the energy and desire to move the needle and drive change.

STANDARDS OF SELF-CARE

I define self-care as the practice of taking an active role in protecting one's own well-being, pursuing joy, and having the ability, tools, and/or resources to respond to periods of stress so that they don't result in imbalance and lead to a health crisis. Ultimately, every person should have access to the caregivers, transportation, treatment, and funds needed to properly address their health. Building a self-care movement—one that can support every other movement in turn—requires incorporating it into our communities and workplaces so that communities of care become part of our culture.

The slow adoption of self-care in our culture is in large part due to a lack of definition. Standards for self-care have never been clearly established. Creating a well-defined vision for self-care grounded in clear principles and standards is a good first step to take, because defining the standards and providing a clear road map for people to follow helps to legitimize the cause. It allows people to create plans, measure progress, and make changes based on realistic and achievable goals rooted in sustainability, which in this hyperproductive capitalist culture is rarely if ever prioritized.

In terms of movement work, exhausted leadership is poor leadership. The reward for productivity should not be the assignment of more work—whether for leaders, paid employees, or volunteers. Exhaustion leads to shorter attention spans, increased emotional volatility, and poor decision making. If movement leaders burn out, that will be replicated by others in our sphere of influence—coworkers, staff, volunteers, children, and so on.

Social transformation work begins with the self. Imagine advocacy work as a series of peaks and valleys. The peaks are where advocacy work happens, and the valleys are where we rest, celebrate, and reflect, gathering our strength to climb the mountain ahead. If we conduct our lives this way and model this workflow in our organizations, we can build resilience, make sure that we keep people engaged, and ensure that none of us falls victim to burnout.

The modern self-care movement can embody practices that avoid burnout rather than merely being a response to it. The movement must demand that individuals put their health and wellness first without feelings of guilt for doing so. If we all collectively share our plans for self-care, we declare boldly that our needs, our state of mind, our body, and our overall health matter. This gives others permission to invest in themselves and take the courageous step to acknowledge that they have needs, that their needs are important, and that those needs deserve to be met.

Social transformation work begins with the self. Imagine advocacy work as a series of peaks and valleys. The peaks are where advocacy work happens, and the valleys are where we rest, celebrate, and reflect.

There are key reflective questions we can ask ourselves and those on our teams and in our communities at every turn and with every incremental step forward that can improve our actions and build momentum to climb the next peak. For example:

- How does the quality of my leadership diminish due to lack of my own self-care?
- Which habits negatively impact my self-care, and what new behaviors can I substitute for them?
- Do I have a self-care plan in place to ensure I follow up on new behaviors, and have I shared this plan with others who will hold me accountable?
- How will I track my progress along the way?
- How can I best support others in their self-care endeavors?

Such questions will help us to integrate self-care with community care and social movements, paving the path forward to achieve balance among all three and to cease having to choose one over the other.

When we work on the self, we do not need to abandon the world. When we begin the process of care with ourselves, we begin the journey of working to heal our community and the world. It is my hope that we each show up, fractured or whole but always beautiful, with our unique talents and skills to create the world we envision. No action is too small, no voice too quiet, and no person too insignificant to make a change. *May we realize that our investment in the inner work awakens awareness to something else, something radical and liberating: a possibility.* We matter, our voices matter, our lives are precious, and we have many gifts to offer. When our inner work is deeply embodied in the collective life of those working for social transformation, this creates resilience within the group, so that when natural bumps or boulders in the journey arise we don't give up. Instead, we stay the course, adjust course, or shore up our reserves and capacity. We celebrate and introduce play, creativity, and lightness into our efforts. We remember the purpose, meaning, and inspiration behind what we're doing, and it supports us in moving forward.

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My eldest uncle, a very pious man, would often share with me wisdom from the Old Testament and the Talmud (also known as the Oral Torah). One of the verses that he shared when I was barely thirteen has been a guidepost for my work: "Do not be daunted by the enormity of the world's grief. Do justly now, love mercy now, walk humbly now. You are not obligated to complete the work, but neither are you free to abandon it."[6]

Movements are not goals. There are no finish lines. Movements embody incremental gains that require consistent forward motion born out of actionable intentions. Creating sustainable movements requires widening our perspective of self-care—shifting it from a purely individual pursuit to one that embraces the entire community and uses the entire toolbox of best practices and resources. While self-care and communal care are movements in themselves, they also provide the primary infrastructure that supports every other movement, whether for equity, justice, peace, or freedom. In order to sustain forward movement—even if it's millimeter by painful millimeter at a time—the pillar of societal care must be championed.

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NOTES

1. Audre Lorde, *A Burst of Light: Essays* (Ithaca, NY: Firebrand Books, 1988), 130.
2. See ibid.
3. Dr. Martin Luther King Jr., speech at the second convention of the Medical Committee for Human Rights, Chicago, March 25, 1966, quoted in John Dittmer, *The Good Doctors: The Medical Committee for Human Rights and the Struggle for Social Justice in Health Care* (New York: Bloomsbury Press, 2009).
4. Aisha Harris, "A History of Self-Care: From its radical roots to its yuppie-driven middle age to its election-inspired resurgence," Slate, April 5, 2017, www.slate.com/articles/arts/culturebox/2017/04/the_history_of_self_care.html.
5. The Armah Institute of Emotional Justice, www.theaiej.com/about-aeij.
6. Originally attributed in the Pirkei Avot (Ethics of our Fathers) 2:16 to Rabbi Tarfon, and then repeated in the Talmud.

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Dimensions of Thriving

Learning from Black LGBTQ+/SGL Moments, Spaces, and Practices

by Dr. Kia Darling-Hammond

Beyond resilience, we need to create the space and the conditions to design a much better now and a much better future. . . . Hardship is not the only story.

In order for me to thrive as a person I need to be doing something that I love and be surrounded by people that I love and have a community that I can call my own.
—*Lara*[1]

Thriving means having your identity supported, your identity affirmed . . . being in a situation where you can learn, fail, make mistakes, and still understand yourself as someone who will be capable of greatness and is worth greatness.
—*Dante*[2]

Humans have imagined thriving across our entire history, from *Iwa* (living virtuously) to *eudaemonia* (good spirit) to contemporary theories of flourishing.[3] Models abound. They often reflect the voices of those empowered to articulate and record such ideas (scholars, philosophers, politicians), who, in turn, reflect the power structures of the societies in which they reside.

There is no single accepted model of thriving. Some people approach it with a physiological focus, or a psychological one. Sometimes, people use *resilience* and *thriving* interchangeably; some call it *flourishing*.[4] My research focuses on intersections of race, ethnicity, gender, sexual orientation, age, and ability. And in doing so, I have been able to advance an inclusive, intersectional, and developmentally grounded model. However, within the minuscule pool of scholarship that centers Black LGBTQ+/SGL youth and young adults, for example, there is almost none attending to their lives beyond surviving oppression. Select another intersectional suite of identities and you'll find the same. Disabled trans women? Native girls? Nonbinary Latiné adults? If anything has been written, it is most likely hardship centered. This is understandable (we want to end suffering), but insufficient.

REJECTING THE DEFICIT APPROACH, THE MEDICAL MODEL, THE STATUS QUO

We need to suspend "'damage-centered' research . . . that intends to document peoples' pain and brokenness to hold those in power accountable for their oppression" but "simultaneously reinforces and reinscribes a one-dimensional notion of . . . people as depleted, ruined, and hopeless."[5] Under our dominant medical model, people under duress whose coping or survival behavior is pathologized must be "fixed" so they can fit in. Psychologist Martin Seligman calls for the "[curtailment of this] promiscuous victimology," elaborating that "in the disease model the underlying picture of the human being is pathology and passivity. . . . The gospel of victimology is both misleading and, paradoxically, victimizing."[6] Focusing too narrowly on problems and what writer and professor Edward Brockenbrough calls "victimization narratives" gets in the way of building something visionary and liberatory, something that needs to be, and is already being, shaped by marginalized people themselves.[7]

> *I feel whole when I really . . . nurture my sense of spirit, which is in my creative outlets, which is in nature, which is in cultivating just the little things, cultivating gratitude and positivity.*—*Sailor*[8]

The tendency to focus on adversity and pathology leaves little space for a concept like pleasure. It then fails to recognize the immense power that Black LGBTQ+/SGL people have called upon for generations in the face of oppression.

We're putting most of our energy into making people "fit" into systems and institutions that are fundamentally flawed—violent, even—and, in the process, reinforcing the belief that these sociopolitical structures are natural. They are not. It's not a flex to participate for the sake of participating in a society that's designed to destroy us. Assimilation, compliance, compromising personal needs, and becoming smaller than we authentically are all require rejection of one's true self. We activate our precious energy for survival instead of passion, pleasure, fulfillment, and innovation. We also find ourselves increasingly disconnected from one another. Laurence J. Kirmayer and colleagues note that "Aboriginal values and perspectives emphasizing interconnectedness, integration, and wholeness can provide an important counterbalance to the ways of thinking about resilience . . . that tend to dominate current scientific writing."[9] By considering "the whole state of the person," as well as the communities and systems within which they exist, an "Aboriginal perspective [moves] resilience away from a simple, linear view of risk exposure, resilience, and outcome, toward a more complex, interactional and holistic view [that] . . . includes the role of traditional activities, such as spirituality, healing practices, and language in dealing with change, loss and trauma."[10]

Beyond resilience, we need to create the space and the conditions to design a much better now and a much better future. Here, I highlight what Black LGBTQ+/SGL communities have taught us about the dimensions of thriving, offering a way to move forward. Hardship is not the only story.

> *So, when I go out with a bunch of queer folks of color and we're all together in that space, but also then . . . being able to see all these other queer folks of color who I don't know, but I feel this connection with, and see them joyfully losing their inhibitions and finding joy, in ways that I see queer folks of color not really being able to completely find joy in their daily interactions . . . there's a beauty and a joy that I find there.—Dante*[11]

Black LGBTQ+/SGL people have crafted moments, spaces, and practices of activism, belonging, wellness, beauty, and possibility, even as they have revealed and pushed back against heavy challenges. L. H. Stallings talks about the "imaginative, agentive, creative, performative, uplifting transitional space[s] established and occupied by queer youth of color"[12]—while Bettina Love celebrates identity formation and expression grounded in "performance of the failure to be respectable" and the freedom granted by "contradictory, fluid, precarious, agentive, and oftentimes intentionally inappropriate" *ratchetness*.[13] The act of claiming joy or pleasure, especially when in defiance of norms of respectability, is healing work. The tendency to focus on adversity and pathology leaves little space for a concept like pleasure. It then fails to recognize the immense power that Black LGBTQ+/SGL people have called upon for generations in the face of oppression. *More than simply being self-accepting, insisting upon self-expressing (often ratchetly) is a crucial, adaptive facet of thriving—really, for any oppressed community. It is holistic stress relief.*

Consider James Baldwin's 1956 novel *Giovanni's Room*, which he was initially told to burn due to its "homosexual" content.[14] Consider Street Transvestite Action Revolutionaries (STAR), founded by Marsha P. Johnson and Sylvia Rivera in 1970.[15] Consider the Ballroom culture so lovingly portrayed in the films *Vogue Knights: A Short Documentary on Ballroom Culture in Hell's Kitchen* (2014) and *Kiki* (2016), as well as the scholarship of Marlon M. Bailey[16] and activist scholarship of Michael Roberson (and his Ballroom Freedom School).[17] Consider the work of Alexis Pauline Gumbs, like her chapter "Something Else to Be: Generations of Black Queer Brilliance and the Mobile Homecoming Experiential Archive," written with Julia Roxanne Wallace in 2016;[18] the dynamic catalogs of Janelle Monáe and Me'shell Ndegeocello and Lil Nas X;[19] and the visionary Afrofuturism nurtured by adrienne maree brown with Walidah Imarisha and a slate of activist-writers in the collection *Octavia's Brood* (2015).[20] These imaginative products and others like them must be taken up as dynamic blueprints for a different kind of future—one in which the grand metric for success is thriving among people currently faced with disproportionate struggle.

Bringing these innovations to light is part of how we locate hope. It's as important as understanding how large social forces make things difficult. More so. A critical perspective that resists the hypnotizing pull of the status quo lets us attend to strength, desire, and love; our pasts, presents, and futures; wisdom, hope, and joy. Especially, the ways they are complex.

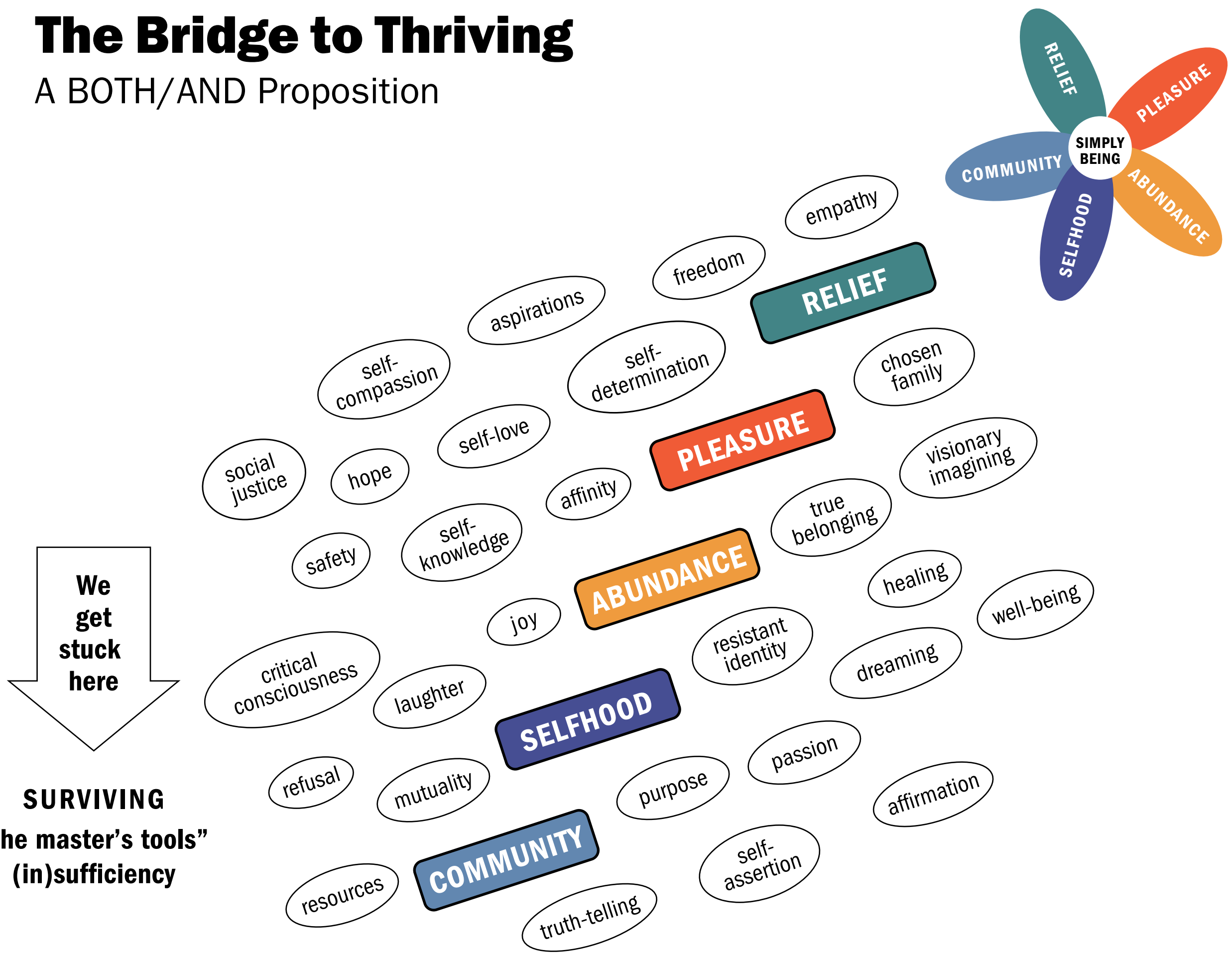
PURSUING A BRIDGE TO THRIVING

The Bridge to Thriving Framework© (BtTF©), which was born out of conversations with Black LGBTQ+/SGL youth and young adults, explores three big ideas: (1) Surviving Encounters with Oppression, (2) What Thriving Can Be, and (3) What's on the Bridge to Thriving (i.e., healing, chosen family, etc.).[21]

Although thriving is not a permanent state of being—and people can thrive in some aspects of their lives more strongly than in others—it is possible to increase one's capacity for and duration of thriving, and return to it over time. Some of this is on an individual level, but ultimately it is a community- and society-wide project.

Surviving Encounters with Oppression

Violent, oppressive systems shape our lives. The United States imprisons more adults than any other country. In fact, we have numerous states that "lock up more people at higher rates than nearly every other country on earth."[22] Politicians choose cost savings over human safety, as we heard and saw



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The urgent focus of so many efforts on resilience and survival makes sense. Too many of us don't survive our encounters with oppression, particularly where complex marginalization is at play. Still, there is more to life.

loud and clear in Flint, Michigan. Quieter is that the EPA estimates there are 7.3 million lead pipelines nationwide servicing as many as 10 million homes. According to the CDC, roughly 24 million homes in the nation contain deteriorating lead paint and 4 million of them house small children.[23]

Almost half of the children in the United States are impacted by adverse childhood experiences (ACEs), which can be linked to systems of economic exploitation, patriarchy and the misogyny that shores it up, anti-Blackness, racism, xenophobia, and so on. "One in ten children . . . has experienced three or more ACEs" and are, in many cases, being raised by adults who have themselves experienced adverse childhoods.[24] The Centers for Disease Control and Prevention (CDC) ACEs resource page lists such potential long-term effects as autoimmune disease, cancer, pulmonary disease, liver disease, memory disturbances, depression, and more.[25] The more ACEs a child experiences, the higher the risk that they will develop a chronic condition later in life. These issues disproportionately impact disabled communities, Native, Black, and immigrant communities, and LGBTQ+/SGL communities.

Lives are cut short from mental and physical anguish, through accumulated toxic stress resulting in illness, through acute violence at the hands of police and other state and institutional actors, and so on. We are ranked and sorted during our earliest, most impressionable years, internalizing ideas about intelligence, worthiness, rightness, and goodness. We are taught to ignore our needs, including our joy.

Creating the conditions for thriving requires attending to threats to survival—emotional, spiritual, and physical. This can include teaching children how to communicate with adults and authority figures in a way that reduces risk to the young person. It includes learning how to demonstrate "knowledge" in order to have one's work "taken seriously" or counted. It includes helping people remain attuned to their authentic self and needs, despite the powerful forces encouraging them not to. It requires social justice activism, from marches to lawsuits to boycotts to unionizing.

Researchers[26] recommend such individual-level interventions as improving one's amount and quality of sleep,[27] avoiding psychological distress,[28] increasing optimism,[29] improving self-esteem,[30] eating a nutrient-dense diet,[31] finding social support,[32] and engaging in regular physical activity.[33] In fact, high levels of social-emotional support and excellent sleep are particularly powerful. They can protect against and even repair damage caused by toxic stress. Research suggests that when people belong to a community in which their stigmatized identities are celebrated[34]—where they can find pride in their community's history, legacies, stories, and triumphs[35]—they experience a kind of protection from psychological threat, which has physiological implications.

The urgent focus of so many efforts on resilience and survival makes sense. Too many of us don't survive our encounters with oppression, particularly where complex marginalization is at play. Still, there is more to life; and, as Michael Roberson points out, we have to claim our "divine right to exist."[36]

What Is Thriving?

A framework for thriving that centers marginalized communities goes beyond resilience or integration. People experience thriving when they:

- have supportive, affirming communities (particularly affinity community focused on applying critical consciousness to advancing social justice);
- can come to know their true selves, love themselves, and self-assert in a self-determined and empowered way;
- have not just economic stability but also abundant resources for thriving, including time, space, funds, and—crucially—hope, aspirations, and dreams;
- can engage in pleasurable activities (with or without others), pursue their passions, and be joyful; and
- can heal and experience relief from stressors like unsafety, erasure, economic hardship, and social isolation, among others.

"I had mental and physical confidence. I had a swagger . . . not like, 'I'm the shit!' but just, 'I am me, and I'm comfortable with my skin.'"

In particular, people describe an optimal state of thriving—one in which all five "petals" of the thriving model are activated—as "simply being," or being able to exist fully and wholly. This requires an ability to know and value oneself, which calls for activation of a resistant identity—one that positions us as central and treasured, not marginal; one that refuses the ways in which the world conspires to make us feel small. *Simply being* typically happens in the company of a close kinship network, like chosen family; in spaces that feel shielded from unsafety; with the resources of space and time (and sometimes money) available; where the outer world's stigma and stress are impotent; and where there is joy, pleasure, or even a sense of purpose.

> *I was getting rid of . . . things that were bringing me down, for sure. . . . I would say, yeah, [it was] a time when I was really focused on myself; making concrete steps towards my future. . . . I had mental and physical confidence. I had a swagger . . . not like, "I'm the shit!" but just, "I am me, and I'm comfortable with my skin." Some India Arie song or something. It was definitely a swagger: "Pssh. I'm ready to be me. I am me. Boom."—Marcus*[37]

Possibilities for thriving grow when people are invited to (1) recognize themselves as someone who is entitled to thrive, (2) imagine what their thriving can look like, and (3) receive affirmation and resources to support their vibrant, present *and* future dreaming and designing. It is immensely helpful to be able to do that with people who believe in one's thriving possibilities and who honor that each of us, regardless of age, stage, or position, is entitled to exert authority over our lives, needs, and futures.

As people center thriving, they begin to notice the parts of their lives that don't quite measure up, and make plans to change them. People also begin to name strategies and practices they can (and do) use to advance their thriving—from prioritizing their musicianship, to activism, to changing jobs, to changing partners, and so on.

> *Sometimes it's gonna take that courage to be okay with not being the same and not conforming or trying to change yourself.—Sonja*[38]

Finally, people being asked to consider the question of their thriving is powerful. Time and again, people say that they've never been invited to really think about it. What make this

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Because the systems that confound thriving are so strong, this work begins with a demand. We must believe that thriving is what we deserve, and we have to unapologetically imagine it into existence. The world we need doesn't yet exist.

exercise successful are conditions that allow for deep reflection. Moving through the BtTF© reshapes people's ideas about themselves, their present, and their future. It is an invitation to consider what constitutes life success—particularly as it is defined and understood by people who are asked to "not be" when offered access to the dominant frameworks for becoming in this world.

Pursuing the Bridge to Thriving is a both/and proposition. It acknowledges the need to pay attention to survival and healing, but urges us to balance that with dreaming in order to advance a visionary remaking of our relationships with one another and our world. Because the systems that confound thriving are so strong, this work begins with a demand. We must believe that thriving is what we deserve, and we have to unapologetically imagine it into existence. The world we need doesn't yet exist.

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The Bridge to Thriving is the space between survival/insufficiency and a state of vibrant wholeness. The pathway is not linear and it's not a one-time journey. Think of the Bridge to Thriving as portable—it can be applied to a variety of projects (building a school, building an office community, building oneself, etc.). It is, essentially, a way to remember what people need in order to flourish.

It is also important to remember that individuals or communities may construct their "bridges" differently. One person may require the time, resources, and space to play music regularly, while another may need to be truly understood by a caring friend. One community may need clean drinking water, while another may need a police oversight commission. Demands may be shared in some contexts and not in others. Ultimately, the bridge invites an analysis of what is needed for access, wholeness, and a life well-lived. Whatever the case, we can be sure that communities are experts regarding what they need to survive, and deserve to exist under conditions that allow them to pause, breathe, dream, and design toward what they need to thrive.

> *Honestly, I associate thriving a lot with . . . like un-structuring the structure that is society, and government, and all of these things. And thriving, creating abundance around me and for me and for other people. Abundance in that things are taken care of. And that you could be at peace. There is abundance. There's love and . . . loving connection.—Kat*[39]

As you undertake the work of designing toward thriving, you can ask questions like:

- What healing do I need to do in order to be a trustworthy partner in thriving?
- How do my efforts continuously seek, understand, honor, and amplify the deep wisdom of marginalized communities?
- How do my efforts provide opportunities for relief and pleasure? How do they create conditions that empower others to build lives rich with relief and pleasure?
- What kinds of "selves" are made available to me and the people I coexist with?
- What future possibilities can be imagined?
- How do I hold space for people (including myself) to *simply be*?
- What practices will make it possible for others to tell me what they truly need?
- How will I intervene against the reproduction of precarity and oppression? How am I complicit or active in its reproduction?

> *Thriving for me is being able to build up my family, my friends, myself, and our futures, and make sure there is a future to have.—Marcus*[40]

For the sake of ourselves and the seven generations to come, it's time we work to exceed survival[41]—to design a visionary, liberated, harmonious future and join together in starting its construction today. *The world we need lives in the imaginations and practices of the people our world fails to celebrate.* They are worldmakers and waymakers. They weave futures in zines and memes, songs and graffiti. They plot at kitchen tables. They march; they write; they sign; they refuse; they demand. *Let's catch up.*

NOTES

1. In Kia Darling-Hammond, "To simply be: Thriving as a black queer/same-gender-loving young adult" (PhD diss., Stanford University, 2018).
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HEALTH JUSTICE

Healing-Centered Leadership

A Path to Transformation

by Shawn A. Ginwright

> 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.

Editors' note: *This article was adapted from* The Four Pivots: Reimagining Justice, Reimagining Ourselves *by Shawn A. Ginwright (North Atlantic Books, 2022).*

The uncertainty in his voice was evident, even through Zoom. All the teachers in the meeting were frustrated by the lack of leadership and guidance regarding how they were supposed to teach and provide after-school programming in the midst of a pandemic. There just wasn't a blueprint for that.

Everyone could tell that the new Black superintendent was in over his head and didn't want anyone to know it, and was pretending that he had all the answers. The truth, of course, was that no one had the answers for how to support students and their families when schools had to close unexpectedly and for an unknown length of time. Some teachers expressed concern that the central office wasn't listening to their requests for guidance about how to teach virtually. A few teachers raised their voices in anger in response to the superintendent's inadequate comments, and others hurled insults at each other. The Zoom meeting was thick with tension, and nearly all thirty little square boxes neatly and clearly framed an angry face. The meeting itself, however, was anything but neat and clear.

YOU CAN'T SOLVE DEEP PROBLEMS WITH SHALLOW TOOLS

All leaders at some point come face to face with moments like this—when the answers we need don't come easily, and the solutions can't be found neatly

“BREATHING ON THE MOON (AFTER NAUDICA WILLIAMS)” BY AMIR KHADAR/WWW.AMIRKHADAR.COM. REPUBLISHED FROM *BLACK FREEDOM BEYOND BORDERS: MEMORIES OF ABOLITION DAY* (WAKANDA DREAM LAB, POLICYLINK, AND THE BIG WE, 2018, WITH PERMISSION)

When we focus on solving surface problems, it's like we are playing the game Whac-A-Mole, because it puts us in the position of having to respond to the next problem that shows up—and the next, and the next.

tucked away in leadership textbooks. For leaders of color, these leadership challenges are exacerbated by racism, intensified by inequality, and compounded by injustice. Inequality, in all its forms, doesn't only block opportunities; it also breeds distrust, skepticism, and fear. Researchers have studied this process among folks of color; they call it racial "weathering."[1] The term refers to the ways that poverty and social, political, and economic exclusion create stress and insecurity and, over time, like paint on a house, weather away our health and clarity. This is precisely what was occurring during that Zoom meeting. These educational leaders were trying desperately to solve deep problems with shallow tools. Sometimes, in our efforts to change systems and improve communities, we simply don't have the right tools to name and heal from the wounds inflicted by racism, sexism, and uncertainty in our work.

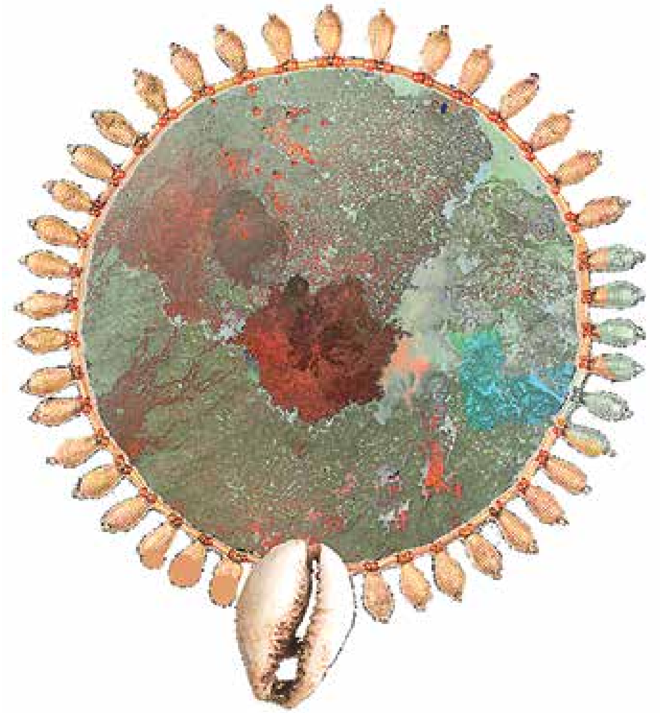
Somewhere along the way, however, we have bought into the myth that grinding harder, creating the perfect strategy, or having a deeper analysis of our problems is enough to solve them. Grinding harder, creating the perfect strategy, or having a deeper analysis of our problems doesn't get at the deeper, more fundamental issues that plague our organizations and movements for justice. *Trust*, *vision*, *wholeness*, *humane relationships*, and *hope* are the tools required for deep change in our work. Yet these spaces do not exist in our work as we now know it. As a result, this absence has been the Achilles' heel of our efforts to transform our organizations in a deeper way. Transformational change requires that we explore a few myths about social change.

FOUR MYTHS ABOUT SOCIAL CHANGE

Myth 1: Deep Change Can Be Achieved through Shallow Solutions

I've heard from policy-makers, educational leaders, social justice advocates, and community organizers that all that really matters in community change is that we remove the barriers to fairness. This is not to discount the efforts of folks who tirelessly work to reduce the structural impediments to equitable healthcare, employment, housing, jobs, and police accountability. These inequalities, to name just a few, are indeed barriers, and their removal is important in order to improve the quality of life for individuals and communities. Yet, we must recognize that deep change cannot be achieved through shallow solutions. Our solutions rarely address the root of the problems we are trying to solve. Fear, scarcity, division, distrust, isolation—all are at the root of many of our organizational and social problems. Rather than trying to heal fear, scarcity, division, distrust, and isolation—which is a very hard thing to do—we choose to address the symptoms of these fundamental problems. We address racist policies but never address the xenophobic fear that created them. We respond to gender inequality but leave in place the toxic masculinity that created it.

When we focus on solving surface problems, it's like we are playing the game Whac-A-Mole, because it puts us in the position of having to respond to the next problem that shows up—and the next, and the next. For example, I understand why our communities have advocated for policies requiring police officers to wear body cameras. However, body cameras are just a surface solution to a deeper issue. Body cameras don't train police in antiracist behavior, and they fail to address racial fear and anxiety officers hold about Black people. Body cameras don't require police officers to unpack



DETAIL OF "BREATHING ON THE MOON (AFTER NAUDICA WILLIAMS)" BY AMIR KHADAR (SEE P. 31)

Oftentimes, we view social change as "us versus them"—and it's hard not to. Our history and our lives remind us every day which groups we belong to and which groups we don't.

and reflect on their subconscious (and conscious) biases. Nor do they do away with the historic and current racism that lies at the root of policing in this country, which supports those biases. Deep change in policing and community safety will require us to rethink policing as we know it.

Myth 2: The More Power We Have, the More Change We Can Create

For years, I have worked with community organizations and young people, and have focused on building power. I learned that I had been thinking about power as a collective action attained by withholding labor, boycotting, or raising awareness about an issue in order to force some desired change. The one problem with this form of power building is that it doesn't address our collective trauma or our need for individual healing. Our definition of power is too narrowly defined and externally focused on activities that influence resources and policy. But power also comes from our capacity to heal our collective pain resulting from intergenerational trauma, present-day hopelessness, and persistent rage against injustice. This alternative form of power is an "inside job" that is cultivated when we speak our truth, fostered when we are vulnerable with one another, and strengthened when we take time to reflect on our relationships with others.

This myth about power is not one to be taken lightly. Consider how community organizing can lead to important structural policy-change wins yet is unable to account for the stress and emotional toll that it can have on individuals, families, and organizations. The power we gain from healing our relationships and restoring hope provides us with the deeper transformative changes we need.

Myth 3: We Can Strategize Solutions for Social Change

Most of us spend time creating really precise maps to vague and unclear destinations. The lie we tell ourselves is that if our strategies (or maps) are clear and precise, we can solve the problems of income inequality, climate change/environmental injustice, and structural racism. We focus on creating the perfect strategy (map), because we believe the myth that we can *strategize* solutions to achieve deep change. (By "strategizing solutions," I mean the mechanistic and technical application of data, information, and plans to solve intractable social problems.)

This myth showed up in my work with a division of a large city government that wanted me to support them in building equity into their systems and to design ways to train their workforce in healing-centered strategies. My team quickly learned that the city division viewed racial inequality and exposure to trauma in the city entirely through the lens of sophisticated population data: If X population has Y exposure to trauma, then the solution should involve higher doses of Z. They were searching for the perfect evidence-based strategy that they could plug into this equation. The issue (racial inequality and trauma exposure) was approached as a type of math problem, ignoring the nuances of human emotion and community resilience. Additionally, the levels of bureaucracy in the division had created a technical and mechanistic way of thinking about the issue: efficiency, order, redundancy, inputs, and outputs. The division's leaders were largely removed from the issue they wanted to solve, and they wanted my team to engineer a solution rather than work with the community to discover one.

Myth 4: "Us Versus Them" Is Concordant with Social Change

Oftentimes, we view social change as "us versus them"—and it's hard not to. Our history and our lives remind us every day which groups we belong to and which groups we don't. In fact, research shows that humans are wired for this. Anthropologists and primatologists have observed that "us versus them" exists in the natural world and has contributed to human survival.

But even though there is a natural human tendency to see the world as "us versus them," it's a myth when it comes to transformative social change. In fact, it's important to work against this tendency. "Us versus them" breeds "othering"—the process of labeling groups of people with negative attributes and then identifying with the positive attributes of one's own group. This process ultimately draws thick and hard boundaries around who is human and who is not. "Us versus them" thinking is precisely what created slavery, Jim Crow racism, the lynching of African Americans, the genocide

What does it take to heal a broken society? How do we begin to pivot toward values that build greater connection and meaning? The solutions to these challenges require a deeper shift in our values.

of Native Americans. "Us versus them" is a deeply colonized way of thinking—it is the root of the white supremacy that created the conditions for dehumanization globally.

Capitalist culture has cultivated this way of thinking, and it can be seen in our work every day. Take, for instance, how foundations often view nonprofit organizations as "grantees," a term that centers power and enshrines the privilege of the donor. "Us versus them" thinking has shaped the ways that foundations conceptualize how change occurs, how we interact with community partners, and how we choose who gets funded and who doesn't.

PIVOT TO HEALING-CENTERED LEADERSHIP

Our challenge is to let go of these myths and embrace a set of truths that can effectively guide our work and our lives. What does it take to heal a broken society? How do we begin to pivot toward values that build greater connection and meaning? The solutions to these challenges require a deeper shift in our values and in our ability to heal from the wounds of racism, sexism, and homophobia. This change will require a new form of leadership that is based in cultivating empathy, compassion, and connection. When we do this, we begin to heal ourselves and our communities. The bottom line is, when we let go of these myths, we begin to embrace a healing-centered form of leadership.

Our sector needs a fundamental shift in our values—a pivot in how we think, connect, act, and work. A pivot is a small change in direction from a single point where we are now. It means that through one small change in direction, over time we can get to where we want to be. A pivot is not a complete abandonment of what we know; rather, it braids together what we know with how we feel and who we wish to be. For example, in basketball, a pivot requires four interwoven and seamless steps. When a player has the ball, they pivot in order to advance the ball downcourt. This pivot requires that (1) they stop momentarily and reflect on what is happening; (2) they have awareness of the relationships of other players around them; (3) they maintain focus on the goal without distraction; and (4) they calmly and confidently flow into another direction. You don't see all of this, of course, because it happens in an instant. *That's* healing-centered leadership, and precisely what we need in times of deep uncertainty and trauma.

Healing-centered leadership acknowledges how we *all* have been harmed, and focuses on restoring relationships across differences. This means that healing-centered leaders practice empathy over blame, compassion over complacency, and curiosity over criticism. 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.

Specifically, healing-centered leadership is based on our ability to make four pivots. The first is a *pivot from lens to mirror*. Instead of viewing the world through a thick lens—that is, as analysts of social problems—we must view it as a mirror of ourselves. This involves the practice of self-reflection and exploration of who we are as individuals and how we contribute to the world we wish to create.

The second is a *pivot from transactional to transformative relationships*. Most of us have been trained to lead, teach, and work with others in highly technical ways. Transactional relationships are efficient, but insufficient for healing. Transformative relationships in our professional and personal lives cultivate deeper human connection through vulnerability, empathy, and listening.

The third is a *pivot from problem fixing to possibility creating*. Historical exclusion, scarcity mindset, and zero-sum thinking resulting from structural racism and inequality come with a psychic cost. Leaders often focus more on eliminating problems and not enough on creating possibilities.

The last is a *pivot from hustle to flow*—transforming our addiction to frenzy, which is one toxic result of our capitalist culture, into the calm awareness of how we create quality space and time for the things that matter most. We all know what it feels like to be addicted to frenzy. Our days are filled following the commands of our to-do lists. We are always busy, behind on pesky tasks, overcommitted, and in a rush to the next meeting or event. If we can admit it to ourselves, we know deep down that we get a great deal of satisfaction from this particular addiction. We say to ourselves, "If I'm busy, I'm important and I matter." However, like any addiction, this gratification obscures a core truth: that our addiction—in this case, to frenzy—gets in the way of our healing and well-being by keeping us forever focused on the "next thing."

OUR ONLY PATH FORWARD

We have an opportunity before us to transform and reimagine our work for social change. Our society sits directly between trauma and transformation—an old world and a new one. Our goal, as leaders who have dedicated our lives to improving our society, is to move boldly into a new world, leaving the trauma from the old world behind. But to do this, we will need new tools—new ways of thinking and relating to one another that heal us all.

Perhaps that is what the superintendent learned during that heated Zoom meeting with teachers and educational leaders. Without warning, he did something transformative. He lowered his head, closed his eyes, and paused in silence. He took a deep breath and exhaled—and when he raised his head, we could see that his eyes were watering, and we could feel that something important had shifted. He said, "The truth is . . . I don't know what to do! I'm sorry if I've been hiding that from you. The only thing I know for certain is that we have to work together as a team—no, no, not a team, but a *family*—in order to get to the other side of this." The superintendent's heartfelt confession created a shift for everyone almost immediately. Little red hearts began to pop up in those little square boxes, and the tone of the meeting became more humane—kind and contemplative. The meeting's mood transformed after that, as if his confession had cleared a path forward, removing the emotional clouds of confusion for everyone.

NOTE

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HEALTH JUSTICE

The Psychology of Place and the Critical Role It Plays in Individual and Community Health

by Dr. Mindy Thompson Fullilove

Editors' Note: *This article was excerpted from* Main Street: How a City's Heart Connects Us All *by Mindy Thompson Fullilove (New Village Press, 2020), with permission. It contains minor edits for publication here.*

When Main Streets disappear, the center is gone; people are thrown into a centrifugal crisis. When enough of the disparate centers are gone, whole regions are impaired. When enough regions are reeling, the nation becomes paralyzed. When enough nations are paralyzed, the world falls into profound crisis.

In 1979, I was selected by the American Psychiatric Association for a fellowship program that supported minority residents. Dr. Jeanne Spurlock and her team introduced us to a network of accomplished minority psychiatrists, financed our attendance at association meetings, and provided each of us with a stipend that we could use to create projects in our own training programs.

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Much of what I was learning in my residency had to do with the internal world of the patient. I didn't know what to do regarding racism and other forces I knew existed outside the individual's realm.

As a black resident in an all-white hospital, I found this experience liberating. Much of what I was learning in my residency had to do with the internal world of the patient. I didn't know what to do regarding racism and other forces I knew existed outside the individual's realm. The people I met through the fellowship—Charles Pinderhughes, Ezra Griffith, Bruce Ballard, Carl Bell, Altha Stewart, Joyce Kobayashi, Earline Houston, and many others—helped me to articulate the relationship between the internal and the external in people's lives and to manage the dilemma of seeing this complex picture when others in my program did not.

Many of those I met at APA offered useful advice, but one piece stands out. At the time of the 1982 convention in Toronto, I was writing a paper on the meanings of skin color in two short stories by Jessie Redmon Fauset, a major figure in the 1920s Harlem Renaissance. Fellow resident Ernest Kendrick challenged me. "Doctors don't think fiction is science. To reach a medical audience, you need to connect this literature to medicine. Why not use Engel's biopsychosocial model?"

HOW MR. GLOVER WAS SAVED BY HIS BOSS AND THEN ALMOST KILLED BY HIS DOCTORS

George Engel, a psychiatrist who helped surgeons and internists understand their patients' needs, had just published a paper demonstrating how his "biopsychosocial model" worked in the clinical setting. In contrast to the "biomedical model," which focused on what was going on inside the human body in a circumscribed biomedical sphere, the biopsychosocial model encompassed the sociology of illness.[1]

Engel told the story of Mr. Glover, a man who had had a heart attack. The biomedical way of telling the story would be something like this: This fifty-five-year-old well-nourished, well-developed white man with a previous history of myocardial infarction began experiencing chest pain at 10:00 a.m. and was brought to the emergency room by ambulance at 11:00 a.m. He was hospitalized in the intensive care unit, where he experienced cardiac arrest due to ventricular fibrillation. His heart was successfully restored to its normal rhythm. The rest of his hospital stay was uneventful, and he was discharged to follow up with his internist.

Event 1: Coronary Artery Occlusion

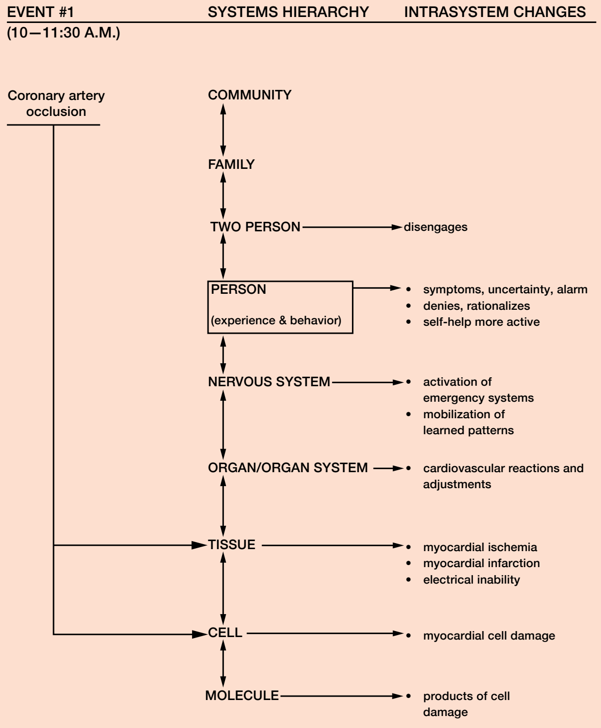

Figure 1: Mr. Glover's heart attack. This diagram, Event 1 in Engel's paper, shows the numerous levels of the biopsychosocial model, and indicates what was happening to the person and his internal systems at the opening of the episode of coronary artery occlusion. (From Engel, 1980, used with permission.)

Engel's approach to the story started at the same place, acknowledging that Mr. Glover had had a heart attack, a coronary artery occlusion, which affected the cell and tissue levels of the systems hierarchy, producing the symptom of pain that Mr. Glover experienced. (See Figure 1.)

But then Engel turned his attention to the hour between the onset of the heart attack and Mr. Glover's arrival at the hospital. At first, Mr. Glover hoped that the feelings of unease and pressure inside his chest were signs of indigestion. He avoided talking to anyone in his office. As the pain increased,

Engel made the point that the biomedical model, which considered only the factors that were interior to the person, missed crucial events at higher levels of scale, including the patient's experience of the event and the influence of other actors on the unfolding drama.

he realized that, if he were having a heart attack, he should get his affairs in order. Mr. Glover went off on that track, instead of going to the hospital.

What was it that got him on the right course? Mr. Glover's employer noticed his distress. She complimented him on his sense of responsibility, assured him that she and his coworkers would be able to manage because he'd done such a great job, and emphasized that his most urgent responsibility was to get well so that he could continue to be the fine family man and coworker she knew him to be. In the diagram for this event, Engel showed that while the processes inside Mr. Glover's body were continuing, important systems outside of his body were being mobilized. (See Figure 2.)

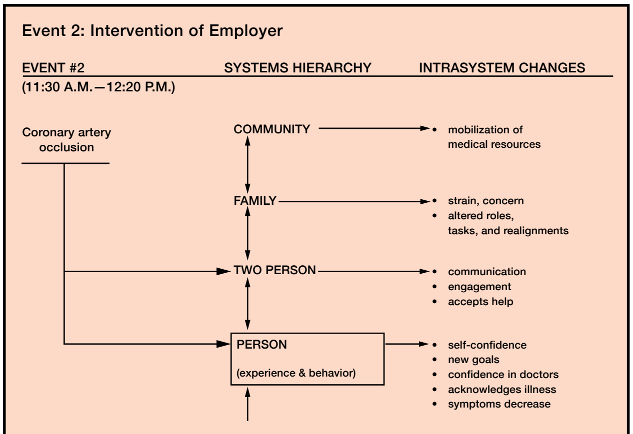

Figure 2: Not just his heart attack. This is a portion of Engel's Event 2, showing the ways in which the personal problem was affecting larger social systems—specifically, the two-person, family, and community systems. (From Engel, 1980, used with permission.)

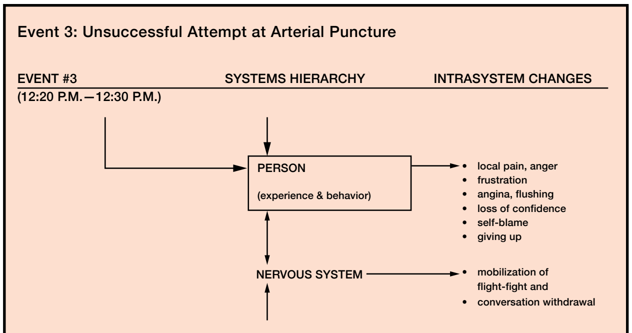

Figure 3: How the doctors caused a setback. This portion of Engel's Event 3 shows the ways in which the actions of the medical residents affected the physiology of the patient. Specifically, the failure to introduce the arterial line caused the patient many emotions, and mobilized the fight-or-flight. (From Engel, 1980, used with permission.)

Once he arrived at the hospital, Mr. Glover was admitted to the intensive care unit on a protocol for those with heart conditions. He relaxed and accepted that he had had a second heart attack. The cardiac team wanted to put a catheter in Mr. Glover's artery. The residents in charge of this task were not able to perform it. After several tries, they left to get help.

It was at that point that Mr. Glover had a near-fatal arrhythmia. Dr. Engel, in the diagram for this event, noted that at the person level, Mr. Glover experienced a wide range of emotions, including frustration, pain, anger, self-blame, and giving up, which mobilized responses of the nervous system, including the fight-or-flight reaction. The activated nervous system released a massive load of chemicals into the blood, which, Engel postulated, triggered the arrhythmia and cardiac arrest. Had the doctors taken the time to talk to Mr. Glover and learn the story of his dependence on authority, they wouldn't have left him alone after a failed arterial puncture. (See Figure 3.)

Happily, Mr. Glover was successfully resuscitated. The rest of his recovery was "uneventful," and he was discharged home. In taking us carefully through this assessment of Mr. Glover's experience, Engel made the point that the biomedical model, which considered only the factors that were interior to the person, missed crucial events at higher levels of scale, including the patient's experience of the event and the influence of other actors on the unfolding drama. When we have the full hierarchy of systems in front of us, we have a more accurate view of what is happening and better odds for saving the patient.

THE PSYCHOLOGY OF PLACE

It is this model that helped me link Fauset's fictional coming-of-age stories to the real-world problem of skin color.[2]

Engel's model proved to be a reliable companion as I plunged into the study of epidemics of AIDS, violence, and addiction that were sundering communities before my eyes.

I applied the model by systematically investigating each of its levels—person, family, community, and world—within the context of a past that was ultimately unknowable due to kidnapping and enslavement. I concluded, "The final integration of color in identity includes the known/unknown, chosen/rejected parts of self and society. In the consolidation of that identification it is the person who must grapple with truth, justice, honesty, and feelings for others. It is the person who at that moment becomes an adult."[3]

Engel's model proved to be a reliable companion as I plunged into the study of epidemics of AIDS, violence, and addiction that were sundering communities before my eyes. To get a handle on what was happening necessitated thinking constantly at many levels of scale.

This required a team of people and a window into the crises. I am reminded of the remarkable story of the documentation of digestion because a trapper named Alexis St. Martin had a gunshot wound that healed improperly, creating an opening to the stomach. Dr. William Beaumont recognized that this created an opportunity to peer into the workings of the stomach. This led to important discoveries about digestion and revolutionized the study of the human body.[4]

For me, the team and the window came together in 1990, when I was recruited to work at the HIV Center of Columbia University, located at the Columbia-Presbyterian Medical Center in New York City. While the Medical Center is a fortresslike building that dominates Washington Heights, the HIV Center arranged for my then husband, Bob Fullilove, and me to have offices at 513 West 166th Street, a large semi-abandoned building in the middle of a neighborhood that was traumatized by crack cocaine and all its related ills. To get to work, we walked down a sidewalk littered with crack vials, so prevalent there because one of the most important dealers in the area lived across the street. In that setting, walking to work was a constant source of inspiration.

We had other assets: We had a suite of offices that included a lounging area, and we had access to two conference rooms and a kitchen. We soon assembled the kind of multidisciplinary team that we needed to tackle the rapid-fire series of epidemics that were swirling around us. Calling ourselves the Community Research Group (CRG), we carried out studies of AIDS, crack addiction, violence, mental illness related to violence, and multidrug-resistant tuberculosis.

All of this was taking place in a context of social disintegration. Rodrick Wallace's 1988 paper, "A Synergism of Plagues," had been crucial to directing our work from the minute we received it.[5] We were even more fortunate that Rod worked at the New York State Psychiatric Institute, part of the Medical Center, and was a willing collaborator and mentor. He taught us how a 1970s New York City policy called "planned shrinkage" had destroyed inner-city neighborhoods, dispersing the residents and creating the conditions for the rapid dissemination of the AIDS virus.

One of the first projects we undertook was to ask our intern, David Swerdlick, to take photographs of Harlem and to search in the archive of the Schomburg Center for images of what it used to be like. The contrast he documented was shocking: The structure of the neighborhood had been destroyed and its vitality vitiated. I could not explain in scientific terms how the built environment and social system were connected. Using the biopsychosocial model as my guide, I began to search in geography, environmental psychology, anthropology, sociology, and history to find the answers.

The geographers taught me about "place," bounded areas that have social and psychological meaning, such as one's home. The environmental psychologists explained that there are essential connections between individuals and place, as well as among residents of a given place, and between and among residents of different places. These are connections of attachment, such as those described by John Bowlby and others, the strong and weak social bonds that Mark Granovetter has described, and the powerful influence of behavior settings, established through the work of Roger Barker and his colleagues. Anthropologists and sociologists parsed crucial incidents, looking for clues. Anthony F. C. Wallace examined mazeway disintegration by looking at an attack on an Iroquois village; Alexander Leighton documented community response to upheaval by following how the Japanese managed internment; and Kai Erikson

The process of urban renewal tore communities apart, destroying their accumulated social, cultural, political, and economic capital, as well as undermining their competitive position vis-à-vis neighborhoods that were not disturbed.

documented the aftermath of the disastrous flood at Buffalo Creek, West Virginia.[6]

From these scholars, I was able to piece together a set of propositions about the psychology of place.[7] I tested my hypotheses by looking at place in the stories of my family, which I shared in my book *House of Joshua: Meditations on Family and Place*.[8] The CRG team—Lesley Green Rennis, Jennifer Stevens Dickson, Lourdes Hernandez-Cordero Rodriguez, Caroline Parsons Moore, Molly Rose Kaufman, Bob, and I—was able to use the psychology of place in tracking epidemics, walking the streets, inventing interventions, and naming the chaos around us so that others might understand. We published over one hundred papers, several dissertations, and my second book on place, *Root Shock: How Tearing Up City Neighborhoods Hurts America, and What We Can Do About It.*[9]

Reading history was a major part of that work. The United States, despite arguing that its revolutionary fight was for "freedom," established itself as a slave nation, preserving and protecting the rights of slave owners, and counting enslaved people as only three-fifths of a person. African Americans and their white allies carried out a sustained struggle to abolish slavery and establish freedom and equality. However, gains in the Reconstruction era were largely lost as inclusive democratic institutions were replaced by the Jim Crow system, which was later copied by admirers in Nazi Germany to create fascism and in South Africa to create apartheid. The long civil rights struggle, which we can date from W. E. B. Du Bois and William Trotter's founding of the Niagara Movement in 1905, culminated in marked victories in the mid-1960s, with the signing of the Civil Rights Act, the Voting Rights Act, and the establishment of Medicaid, which desegregated hospitals.

A paradox of the post–civil rights era has been that the problems supposedly "fixed" by the movement have endured and even worsened. What emerged instead of an integrated nirvana was the "urban crisis," a polite way of saying "inner-city black poverty." Conservative politicians promulgated the idea that this was a failure of "personal responsibility," which took hold in the public's imagination but was patently false.[10]

The perspective of the psychology of place helps us track a different story, that of a series of forced displacements that had devastating effects on inner-city communities. Through that lens, we can appreciate the strength of segregated communities that managed to temper the ravages of racism through the Jim Crow era and build political power and many kinds of wealth. It was the power of these communities that was expressed in the civil rights movement. The example of the Montgomery bus boycott can illuminate this point. Rosa Parks's legendary act of civil disobedience took place on Thursday, December 1, 1955. By Monday morning, December 5, at 6:00 a.m., fifty thousand black people initiated a boycott of the buses. For more than a year, they walked, endured threats and attacks, faced layoffs, organized carpools, fed one another, conducted weekly rallies, and held firm until they won. Only a very well-integrated, powerful community—one with deep spiritual principles—could have accomplished such a feat.[11]

Against the backdrop of those impressive achievements, however, federal, state, and local governments had launched an attack on the collective power and wealth of African-American communities, which started with urban renewal, as carried out under the Housing Act of 1949.[12] Known among black people as "Negro removal," the Housing Act authorized cities to clear "blighted land," using the power of eminent domain, and sell the land at reduced cost to developers for "higher uses," like cultural centers, universities, and public housing. During the fourteen years of the urban renewal program, 993 cities participated, carrying out more than 2,500 projects. Of the one million people displaced, 63 percent were African Americans; the areas destroyed included substantial portions of such important black cultural centers as the Hill District in Pittsburgh and the Fillmore in San Francisco.

The Kerner Commission's study of civil disorder in 1967 included urban renewal in the list of factors that triggered the rebellions.[13] The process of urban renewal tore communities apart, destroying their accumulated social, cultural,

At the level of the neighborhood, the processes of urban renewal, deindustrialization, and planned shrinkage are centrifugal: They are pulling us apart from one another.

political, and economic capital, as well as undermining their competitive position vis-à-vis neighborhoods that were not disturbed.[14] This profoundly weakened affected neighborhoods; those harms were repeated in subsequent displacements due to planned shrinkage, mass incarceration, HOPE VI (which was directed at federal housing projects), the foreclosure crisis, and gentrification.[15]

The series of displacements from neighborhoods occurred contemporaneously with deindustrialization, which undermined the economic foundations of older American cities, leaving unskilled workers at a severe disadvantage.[16] This created the massive deindustrialization diaspora to the Sun Belt, destabilizing both sending and receiving cities. In the upheaval caused by serial displacement and deindustrialization, the epidemics of heroin and crack cocaine took off, violence soared, and AIDS became a serious threat to health. Asthma and obesity flourished. Trauma, as a result of these accumulating disasters, became a major source of psychiatric illness and contributor to ill health.

The economic and social dismemberment of African-American communities stole their wealth, their power, and their capacity to engage in problem solving. Returning to the biopsychosocial model, we can begin to name the processes that are happening at each level of scale. The vulnerability of the individual stripped of the protection of a known and loved place is greatly increased. The experiences of trauma, grief, and anger, as well as the stress of losing one's embedding community, have effects on the individual. These can lead to psychiatric illness, the use of drugs and other addictions, eating and autoimmune disorders, and infectious diseases.

At the level of the neighborhood, the processes of urban renewal, deindustrialization, and planned shrinkage are centrifugal: They are pulling us apart from one another. In my book *Root Shock*, I described the ways in which the centrifugal processes tear at people's places and their lives. I asked the question, "When the center fails, what will hold?"

The answer in the short term is that people take on the work of place in order to keep their lives together. They band together in groups defined by "strong ties," the ties of family, religion, and tribe.[17] Yet these ties partition society. In the aftermath of urban renewal and planned shrinkage, the reformation of society around strong ties fed antagonism and intergroup hostilities: The solution became part of the problem, triggering a reinforcing, exhausting, and dangerous downward spiral.

At the next level of scale, the effects of neighborhood destruction on the larger embedding society are very serious. This point is often overlooked, because, as I've described here, the neighborhoods that are destroyed are those of poor and minority people. The larger society is thought of as "white" and "middle-class," and therefore comprising people whose lives and fates are quite different and even insulated from the problems of the disadvantaged. The ecologists who mentored me, Ernest Thompson, Michel Cantal-Dupart, and Rodrick Wallace, taught me about the fallacy in this assumption of separation.

Rodrick Wallace, with his colleague and partner, Deborah Wallace, documented the ways in which the systematic destruction of minority inner-city communities had direct connections to the health of the larger society. They emphasized that concentration of people in ghettos did not mean that the harms inflicted on those communities would be contained within those spaces. *Concentration is not containment*, they emphasized. In fact, they identified what they called the "paradox of Apartheid," the finding that segregation actually tightened connections between communities thought to be divided by race and class.[18]

In light of this serious history, which poses a substantial threat to the whole country, Rod made one of the most important advances in our field of social psychiatry: He described the workings of collective consciousness in our segregated society. Drawing on a large body of literature in many fields of study, Rod articulated the workings of "distributed cognition," the ways in which people think together, across time and space. He built on this work by examining the threats to collective consciousness posed by rigid, Manichean systems of racial segregation. I collaborated with him on a book entitled *Collective Consciousness and Its Discontents*. In that book, we pulled together the fields of distributed cognition and social history. We wrote:

I became deeply aware that rebuilding was about fixing the injuries to place as well as mending the social fractures.

> [A] neighborhood [has the ability] to perceive patterns of threat or opportunity, to compare those perceived patterns with an internal, shared, picture of the world, and to choose one or a few collective actions from a much larger repertory of those possible and to carry them out . . . This phenomenon is, however, constrained, not just by shared culture, but by the path-dependent historic development of the community itself. Recent work demonstrates that "planned shrinkage," "urban renewal," or other disruptions of weak ties akin to ethnic cleansing, can place neighborhoods onto decades-long irreversible developmental, perhaps evolutionary, trajectories of social disintegration, which short-circuit effective community cognition. This is, indeed, a fundamental political purpose of such programs.[19]

NOT SPARED HISTORY

While CRG was learning history, we were not immune to the processes we were describing. CRG was not a group that got major grant funds for big, long-term studies. Instead, we survived on small grants and contracts that allowed us to track processes unfolding all around us. The recession dried up our usual sources, and the team had to disperse. Gentrification hit Washington Heights, and we were evicted from our home at 513 in 2008.

This turned our attention to problems of rebuilding: Where were we to go? Like others displaced by gentrification, we had to go somewhere. At first, this seemed like a catastrophe, but we realized it was an opportunity to follow the path other displaced people were taking. Visits to Orange, New Jersey, my hometown, soon led to our joining local leaders to found the "free people's university" of Orange. Eventually, we reestablished our research group under the name Cities Research Group of the University of Orange. Our experience rebuilding taught us a lot and helped me integrate the many lessons I'd learned through the careful tutelage of the renowned French urbanist Michel Cantal-Dupart, known universally as Cantal. I became deeply aware that rebuilding was about fixing the injuries to place as well as mending the social fractures.

In *Urban Alchemy: Restoring Joy in America's Sorted-Out Cities*, I presented nine elements of urban restoration I'd seen Cantal and others use in the rebuilding process: *Keep the whole city in mind*, *Find what you're FOR*, *Make a mark*, *Unpuzzle the fractured space*, *Unslum the neighborhoods*, *Create meaningful places*, *Strengthen the region*, *Show solidarity with all life*, and *Celebrate your accomplishments*. These elements guide us toward the work that needs to be done, slowly and carefully, building on the existing assets of our cities.[20]

MAIN STREET IN THE MIX

While working on that book, I went to downtown Englewood, New Jersey, to get some coffee at Starbucks. I was sitting by the picture window, looking at the crowds passing by, and was struck by the liveliness of the scene. I, like most people, thought of Main Street as dead; but that day, I realized our Main Street was not dead at all. I started to think of all the functional Main Streets I knew and loved, civic, commercial and social centers that had been part of my life since childhood. Then I thought, if Main Streets are alive, what role are they playing in making our common life?

I started with the plan that over the coming year I would visit Main Streets in one hundred cities. It took longer and was harder than I thought it would be to discern the contribution of Main Streets to our collective mental health. From visits to Main Streets in 178 cities in fourteen countries, I have learned that these civic and commercial centers are designed and built to provide a centripetal—gathering—force for a community. Our survival is built on people's coming together, and our social nature has evolved to reinforce gathering with pleasure. We have a built-in "Joy of Being In," which explains the powerful "Fear of Missing Out." When we go to Main Street, we take in fashion, culture, and sociability. We shop, mail letters, get library books, and have coffee. Or we loiter, whether on a bench or in a Starbucks window. Sometimes we take our laptops to be in the flow and in the know while ostensibly working. This makes us happy. It is a Machine for Living.

I also learned that this Machine for Living can be adapted to help us solve the horrific problems we face now: climate

While Main Streets are not dead everywhere, many are. It took me a while to see this. Perceiving what is not there is tricky: It is the task of seeing the black hole.

change, racism, militarism, and concentration of wealth, among them. One of my favorite Main Street spots is the Thomas Edison National Historical Site in West Orange, New Jersey—Edison's "Factory of Invention." It turns out that Edison needed a lot of people to get from idea to patented product. And he needed materials, spaces to experiment, ways to document the process, a library, and a couch for naps. The Factory of Invention is the remarkable space in which these things were meticulously organized as a place of distributed cognition.

Because of his recognition that this was the way people can innovate, Edison received 2,332 patents. While respect for his fertile imagination is universal, few of us know of the system that supported it. At the heart of that system was not a single great man, but, rather, a very large team that could think together, a working group with a massive collective consciousness, informed by science, mechanics, art, and imagination. It should not be a surprise that Edison's Factory of Invention had a movie studio and a chemistry lab. This ability for humans to think in a collective manner is an extraordinary evolutionary advantage. Emphasis on collective: Had Edison not been hobbled by such antisocial character defects as anti-Semitism and belligerence with competitors, he might have died with four thousand patents.

When I first visited the Factory of Invention, I understood immediately that we at CRG had had such a factory at 513, where we could track epidemics and explain their social roots. Our factory, I would say, encompassed the whole neighborhood, which we scoured in our search for comprehension. We also had the luxury of a suite of offices that included places to share, to chat, to do the collective work of comprehension, what Rod would come to call "collective consciousness." We could sit in the lounge or a conference room and pool our knowledge, tossing ideas around until we came to an understanding that fit all the facts.

One of my tasks in the wake of our displacement has been to rebuild CRG's factory of invention. But I've also realized that the challenges and resources of Main Street offer groups large and small their own "factories of invention." In the course of my study of Main Streets I've encountered many of these organizations. I am deeply impressed by what they have accomplished and what they might do next. Main Streets offer a unique combination of assets that can help us name and solve our problems.

But this potential tool is not in good shape. While Main Streets are not dead everywhere, many are. It took me a while to see this. Perceiving what is not there is tricky: It is the task of seeing the black hole. When Main Streets disappear, the center is gone; people are thrown into a centrifugal crisis. When enough of the disparate centers are gone, whole regions are impaired. When enough regions are reeling, the nation becomes paralyzed. When enough nations are paralyzed, the world falls into profound crisis.

And this is the situation in which we find ourselves currently: a dark situation with too little connection to make problem solving possible. Mounting crisis may force us to work together, but increasing anxiety may feed anger and hatred faster than solidarity. In our terrified apartness, we could fall into the worst possible outcomes of the current crises of climate change, species extinction, and international warfare.

Greta Thunberg, a teenage leader in the fight to face climate change, called on us all to shift to "cathedral thinking." As she said to the European Parliament:

> It is still not too late to act. It will take a far-reaching vision, it will take courage, it will take fierce, fierce determination to act now, to lay the foundations where we may not know all the details about how to shape the ceiling. In other words it will take cathedral thinking. I ask you to please wake up and make changes required possible. To do your best is no longer good enough. We must all do the seemingly impossible.[21]

I contend that *cathedral thinking* is another term for Factory of Invention. We can create on Main Street the spaces and sentiments for collective problem solving, so that we might transform these magnificent Machines for Living into the Factories of Invention that can see us through.

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HEALTH JUSTICE

System Shock

Nonlocal Grassroots Response to COVID-19 at Ground Zero, Wuhan

by Yuan (Daniel) Cheng,
Xiaoyun Wang, and
Xueshan Zhang

China's policies and regulations vis-à-vis the nonprofit sector meant that very limited grassroots action took place during COVID-19's first stages, and most came from those social organizations heavily managed and coordinated by local government . . . or by citizen self-help groups. These local GONGO chapters and local nonprofit organizations indeed played an instrumental role in Wuhan's response to the crisis. But it was a collection of nonlocal nonprofit organizations and volunteer groups, with little professional experience in disaster relief and insufficient resources and local networks, that in the end emerged and managed to deliver aid.

"DRAPOU VODOU EXPLORATION" BY AMIR KHADAR/WWW.AMIRKHADAR.COM

On January 23, 2020, two days before the Chinese New Year of the Rat (the new start in the twelve-year cycle of the Chinese zodiac), the central government of China announced the lockdown of Wuhan—the capital of Hubei Province, a city with over eleven million people—due to the outbreak of COVID-19. It was an unprecedented crisis that neither the government nor the society had ever encountered. COVID-19 patients flocked to hospitals and soon discovered that there was a dearth of available beds. Essential community services were cut off, leaving vulnerable populations—the elderly, pregnant women, people with chronic diseases—desperately seeking support. The shortage of medical supplies was so serious that medical workers had to bypass the government and send out individual pleas for donations.[1] Indeed, the government's responses to COVID-19 in the first few weeks were inadequate; the emergency plan developed by the government to deal with "normal" disasters was simply insufficient for such a sweeping crisis.

When COVID-19 hit Wuhan, a city with no prior experiences of a pandemic, the whole society went into system shock.[2] Wuhan being the global ground zero for COVID-19, citizens did not know how dangerous and widespread the virus would turn out to be. The Chinese government was still collecting information in order to coordinate public health resources. Businesses were dealing with the beginning impacts of a looming economic shutdown. Nonprofits were trying to figure out how they could help—a tough order, given that they could not operate their normal disaster relief efforts on the ground. For two to three weeks after the emergency lockdown, things in Wuhan were chaotic. Heartrending stories broke on Chinese social media about frontline medical workers lacking medical supplies and unattended family members dying due to lack of care. Before February 21, 2020, when all the Fangcang shelter hospitals (hospitals built for COVID-19 patients) came into use, the situation was desperate.[3]

Given how severe and unprecedented the COVID-19 pandemic was and the increasingly restrictive institutional environment facing grassroots nonprofits in China, it is not surprising that grassroots nonprofits faced many challenges during the initial stage of the pandemic in Wuhan.[4] The Ministry of Civil Affairs in the State Council authorized just a few government-organized nongovernmental organizations (GONGOs) to receive and distribute donations and medical supplies; nonlocal nonprofits were not allowed to enter or send volunteers to Hubei Province.[5] Some local GONGO chapters' exclusive access to raising public donations, coupled with lack of capacity, resulted in scandal when they failed to effectively distribute medical supplies raised from the general public.[6]

China's policies and regulations vis-à-vis the nonprofit sector meant that very limited grassroots action took place during COVID-19's first stages, and most came from those social organizations heavily managed and coordinated by local government (for example, residential committees) or by citizen

In China . . .

Formal nonprofit organizations are organizations legally registered at the Ministry/Bureau of Civil Affairs and that operate as independent legal entities.

Informal nonprofit organizations are not independent legal entities, and include neighborhood associations registered via street-level bureaucracy and unregistered grassroots organizations.

Government-organized nongovernmental organizations (GONGOs) are nonprofit organizations initiated by government and quasi-governmental agencies (for example, Communist Youth League of China and Women's Federation). Most GONGOs are formal nonprofit organizations. The Red Cross Society of China and its local branches are an exception; they operate as an independent system and do not need to register at the Ministry/Bureau of Civil Affairs.

Grassroots organizations are nonprofit organizations that have neither official government ties nor the backing of wealthy individuals and/or large corporations. Grassroots organizations can be either formal or informal. Unregistered grassroots organizations do not have official government approval, but in most cases the government does not impose sanctions on such organizations unless they are perceived to be a potential political threat.

As it did all over the world, in Wuhan COVID-19 systematically worsened the conditions of already marginalized groups.

self-help groups. These local GONGO chapters and local nonprofit organizations indeed played an instrumental role in Wuhan's response to the crisis.[7] But it was a collection of nonlocal nonprofit organizations and volunteer groups, with little professional experience in disaster relief and insufficient resources and local networks, that in the end emerged and managed to deliver aid not only to Wuhan but also surrounding regions.[8] Despite the regulatory and information barriers, these groups managed to send masks and ventilators to hospitals in desperate need, and also to address medical needs not directly connected to the pandemic, such as supplying medication to people with other diseases who were falling by the wayside due to the national focus on COVID-19.

How was it that these nonlocal grassroots nonprofit organizations were able to effectively deliver aid? Two critical, connected differences are at the very foundation of this organizational tier, which has its roots in close community work. First, the grassroots nonprofits that stepped up during the initial outbreak were able to emerge as key contributors during the pandemic as a result of their close relationship with their clients and partners—which supports their creative leveraging of new technology platforms and their practice of constantly adjusting strategic priorities based on critical needs at the moment, as well as their capacity to fulfill those needs. The success of these organizations, which lack government affiliation and big funding, is driven by their deep understanding of the changing needs of the communities they serve and their ability to mobilize quickly and effectively with whatever resources are at hand in the moment. This gave them a key advantage over organizations with superior financial and political resources.

The second critical difference has to do with ethos. Compared to the scale of resources that the Chinese government had at its disposal, the resources the grassroots organizations were able to mobilize during the pandemic were trivial. But it was left to these organizations to fill the gaps in care for already marginalized groups that became further marginalized during the COVID-19 outbreak. People with rare and chronic diseases, pregnant women experiencing complications, the economically disadvantaged, the elderly, people with disabilities, and even people simply living outside of the immediate Wuhan metro area did not have access to the same level of administrative and medical resources devoted to Wuhan and COVID-19. As it did all over the world, in Wuhan COVID-19 systematically worsened the conditions of already marginalized groups.[9] Without grassroots organizations committed to whole community care, many in these groups would not have survived.

Below are some examples that showcase how nonlocal grassroots nonprofit organizations were able to respond quickly and effectively during the early stages of the COVID-19 crisis,[10] complementing our existing knowledge about the critical roles local, community-based organizations played in different stages of pandemic control in China.[11] They offer important implications for a world ill-prepared for global crises.

MEETING CRITICAL NEEDS WHILE RAPIDLY ADJUSTING STRATEGIC PRIORITIES

In a time of unprecedented crisis, nonprofit organizations must decide whether to act immediately or wait to see what/who will emerge in response, and then move in to fill any gaps. When COVID-19 broke out in Wuhan, most organizational staff members were at home, because the Chinese New Year was imminent. Therefore, when news of the pandemic broke, it was impossible to run through the normal administrative procedures regarding what should be the level of organizational involvement. Moreover, getting involved in the early stages of a crisis presents significant risks for such organizations. Would there be financial and legal risks that only come to light later on for those organizations? Could local volunteers come to harm? As the city of Wuhan had gone straight into lockdown and the general public had limited information about what was actually going on inside the city, those nonlocal grassroots organizations had many more reasons to stay put until more information was forthcoming, rather than actively engaging with the crisis. However, a number of these organizations went into action, and were effective in addressing the moment's critical needs by rapidly adjusting their strategic priorities based on their mission, expertise, and how other organizations were involved.

No single organization or individual holds the solution to the problems when a whole city faces an unprecedented pandemic and lockdown.

Beijing Chunmiao Charity Foundation, a foundation that focuses on providing professional social services for children and families in need, did not have much experience in responding to a public health crisis.[12] But when the pandemic hit, the foundation quickly realized that its public fundraising know-how could serve other nonprofit organizations. It pivoted to become a fundraising platform for civil organizations providing direct services and aid to Wuhan.[13] During the initial stage of the COVID-19 breakout, one of the most critical challenges that faced many organizations was a mismatch in timing between fundraising and the purchase of key supplies, as the pricing of such supplies was volatile. Often, by the time funds had been raised for a key item, the price had already increased. Chunmiao leadership described how, to solve this problem, the foundation established a funding pool of one million renminbi (RMB) to facilitate the synchronous purchase of key supplies. It then raised funds to cover the costs. According to Chunmiao, during its initial response to COVID-19 in Wuhan, the foundation raised more than eighty million RMB, and it became one of the most essential funders and backbone organizations for other nonprofits during the pandemic.

The Beijing Ginkgo Foundation, a private foundation famous for its fellowship program supporting social entrepreneurs and leaders of grassroots nonprofits, played an important role in supporting its fellows and partner organizations during the pandemic.[14] Ginkgo understood that, compared to other major private foundations and the government, the amount of funding it could provide for COVID-19 responses would be minimal and would not generate the social impact Ginkgo desired. Instead of following the practices of other foundations or fundraising platforms, it identified three areas as its core grantmaking strategy: (1) establishing the Ginkgo Instant Action Fund to support the administrative expenses of nonprofit organizations;[15] (2) building supportive networks among Ginkgo fellows to better coordinate their efforts for COVID-19 response; and (3) carrying out an action-research program to help nonprofits systematically document and reflect on their responses during the crisis. By quickly understanding the need for frontline nonprofit organizations and adjusting its strategic priorities, the Ginkgo Foundation was able to leverage its financial and human capital for a larger social impact during the crisis.

Shanghai Hand in Hand Life Care Developing Center, one of the first nonprofit organizations in China to specialize in hospice care and psychological counseling, quickly became involved in sending key medical supplies to Wuhan when the city locked down.[16] Due to its strong connections to volunteers and donors both overseas and in China, it achieved an impressive record of raising funds and medical supplies for hospitals in Wuhan. However, as more organizations became involved in such work, particularly government organizations, Hand in Hand became aware that sending medical supplies to hospitals was no longer a critical gap it needed to fill. What became apparent was that there was a big void in the psychological counseling for Wuhan citizens dealing with the unexpected death or quarantine of family members. Hand in Hand leveraged the network it had built in the initial stage of its response, as well as its expertise in hospice care, to speedily design psychological counseling programs for patients and their families. The pandemic surfaced a need for people's deeper understanding of life and death, and Hand in Hand is currently exploring ways to integrate life education into its traditional hospice care program, after the pandemic.

SCALING UP EXISTING ORGANIZATIONAL NETWORKS THROUGH CROSS-SECTORAL COLLABORATION

No single organization or individual holds the solution to the problems when a whole city faces an unprecedented pandemic and lockdown. Implementation of all the strategies needed requires a network of organizations across sectors. Thus, grassroots nonprofit organizations must quickly develop reliable cross-sectoral partnerships with individuals and organizations that previously they may not have worked closely with. Such a wide network connecting suppliers, donors, hospitals, patients, and the government cannot be built overnight. Organizations must leverage their existing networks and quickly scale them up by identifying and working with key partners who can help them connect to their current and emerging clients and potential resource suppliers.

> ***Nonprofit organizations have historically been key contributors when disaster hits a community. Their ability to pivot as needed comes from the agility it takes to survive in not-always-secure financial and, in the case of China, political environments.***

The Beijing Illness Challenge Foundation (ICF), an organization serving patients with rare diseases, proved to be an exemplar in building partnerships and scaling its existing organizational networks.[17] After the Wuhan lockdown, ICF received requests from patients with rare diseases in Wuhan and Hubei Province who were running out of drugs and having difficulties getting treatment and prescriptions. ICF was determined to help these patients, but it recognized that it did not have sufficient channels to purchase and deliver the drugs. ICF decided to collaborate with the China Alliance of Rare Diseases (CHARD)—a GONGO affiliated with the National Health Committee, which had comprehensive information on and access to hospitals, drugstores, pharmaceutical companies, and medical associations. The collaboration with CHARD ensured the supply of medicines. In addition to CHARD, ICF partnered with patient support groups for each rare disease to verify the information and needs of patients. In total, through CHARD and patient-support groups, ICF connected with over thirty pharmaceutical companies and drugstores and served patients with thirty-four rare diseases. ICF became the hub of the collaborative network during the lockdown period of Wuhan as a result of its reputation for providing high-quality services to patients with rare diseases, and the network it built with CHARD and patient support groups. With these key partners, ICF was able to speedily scale up its existing network with hospitals and patients who needed its services and pharmaceutical companies that could provide the medications. ICF filled a significant overlooked gap in services that faced patients with rare diseases when the whole country became unilaterally focused on COVID-19.

BUILDING A SOCIAL-MEDIA-FACILITATED DECENTRALIZED INFORMATION-FLOW SYSTEM

During a major crisis like COVID-19, information can become chaotic and volatile. During the first two weeks after the lockdown in Wuhan, not even the government had all the information it needed about what hospitals would require to service a pandemic. This made it challenging to coordinate donations and the logistics of medical supplies even when organizations were successful in obtaining those resources. The traditional information-flow systems based on hierarchical control no longer functioned, as no individual or organization could verify and cope with the ever-changing information. With the use of social media by these nonlocal nonprofit organizations, a social-media-facilitated decentralized information-flow system emerged. This innovation coordinated the instant feedback between the needs of the hospitals and the supply from donors and volunteers.

ACE Youth, a nonprofit organization dedicated to building communications platforms for youth development, became involved in obtaining face masks and sending them to local hospitals.[18] Instead of controlling the information flow between the donors and local hospitals, ACE Youth (via WeChat, a Chinese social media platform) brought together the doctors and hospitals needing face masks and donors who were interested in supporting them. Doctors were able to send messages directly to the WeChat group regarding their needs, and donors could reply and then send the requested masks. The doctors then confirmed the arrival of the masks via photo. ACE Youth set the ground rules for how the WeChat group operated, and encouraged the donors and doctors to be directly in touch with one another via the platform and to post updates of the process. By directly linking the donors and doctors on a platform where all users actively monitored the program status, ACE Youth was able to organize timely support to local hospitals and doctors.

■

Nonprofit organizations have historically been key contributors when disaster hits a community. Their ability to pivot as needed comes from the agility it takes to survive in not-always-secure financial and, in the case of China, political environments. This agility proved to be a critical aspect of Wuhan's recovery from the pandemic's first wave, when the government was stymied for a time while figuring out how to mobilize its resources. The crisis pushed grassroots nonprofits, particularly those that were nonlocal, to make multiple adjustments and to innovate in order to rise to the needs

As mega-disasters like the COVID-19 crisis become a new normal for our times, our governments need to recognize and leverage the unique values these groups can create.

of the people in Wuhan and surrounding areas. It also stimulated wider participation of nonprofit organizations and volunteer groups that didn't necessarily have much experience in disaster relief.

Down the line, we will need to assess the consequences for these grassroots nonprofit organizations that stepped up without government backing during the initial outbreak of COVID-19. Will the system in China reward or punish their engagement? In their reflection reports, quite a few nonprofit leaders stated that the worst barriers they encountered during and after their response were not in fact the information and access problems as discussed in this article, but rather the endless paperwork they had to prepare for subsequent auditing requirements, which lowered morale and wasted valuable time. But for funders that decided to go beyond those normal procedures in order to more effectively fund the COVID-19 responders—for example, the Beijing Chunmiao Charity Foundation—it took enormous effort to keep their excellent performance rating. The financial reporting and auditing requirements during and after the initial pandemic relief cost some organizations a large amount of staff time and created burdens for grassroots organizations with tight administrative budgets. More importantly, it created a risk-averse incentive structure for both funders and frontline grassroots nonprofits wanting to engage quickly in pandemic relief efforts right when the social demand was greatest. A grantor–grantee relationship is needed that facilitates flexibility and prioritizes the expertise and voice of those who truly understand their client communities rather than solely the accountability requirements and control from the funders. If we do not learn from these critical lessons that emerged from the COVID-19 crisis, we will continue to struggle when other crises hit.

It may be too soon to tell whether these innovative responses by nonlocal grassroots nonprofits prove to be a short-term phenomenon or if they will have long-term implications for the state–society relationship in China. That is beyond the scope of this article, and only time will tell. However, what has become clear in this systematic analysis of nonlocal grassroots nonprofits' responses to the pandemic is the value of a relatively independent and autonomous nonprofit sector. The success of the sector should be judged not only by the financial or medical resources they were able to mobilize, but also for whom and how they were able to mobilize them. These grassroots nonprofits created a full array of public values during the pandemic, including broad citizen participation and support for marginalized populations. As mega-disasters like the COVID-19 crisis become a new normal for our times, our governments need to recognize and leverage the unique values these groups can create, instead of treating them exclusively as a means to achieving (or a tool for) governmental goals and purposes.

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Healthcare as a Public Service

Redesigning U.S. Healthcare with Health and Equity at the Center

by Dana Brown

As the healthcare "system" of the world's wealthiest country is teetering, if not close to collapse, the pressing need for transformative solutions is obvious. Scaling publicly owned healthcare to serve all would be just that—a way to take healthcare from a source of private profit, mass suffering, and financial ruin, and make it a public good.

What might healthcare look like if the profit motive were removed from the provision of care altogether? If healthcare were designed as a public service, what possibilities would exist for health equity, health system resilience, and reduced costs? The multiple crises of our current healthcare sector, laid bare by COVID-19, should move us to ask deeper questions about how our investments into the healthcare sector should be employed to maximize the health and well-being of our people and economy.

There are, sadly, few bright spots in a system that has allowed more than one in five hundred Americans to die due to COVID-19.[1] Many readers may be surprised to learn that one of the few highlights in healthcare performance during the pandemic comes not from the nation's richest hospital systems or biggest names in medicine but from the poorly understood and often maligned Veterans Health Administration (VHA).

"COMFORT" BY AMIR KHADAR/WWW.AMIRKHADAR.COM

The COVID-19 pandemic has brutally exposed the weaknesses of the nation’s fragmented, inequitable, and extraordinarily expensive healthcare system.

The VHA—the country’s only fully public, integrated healthcare system—has a lot to tell us about how a national healthcare service for the United States might operate, and not just for its performance amid COVID-19. Indeed, combined with other public healthcare institutions, it could prove to be a critical institution to achieving health justice.

While the new is often fetishized, sometimes the most effective and feasible models are not new; they just need dusting off so that we can see them for what they are. Healthcare as a public service is one such model, and the VHA could help jump-start a revival of this model today.

U.S. HEALTHCARE IN CRISIS

The COVID-19 pandemic has brutally exposed the weaknesses of the nation’s fragmented, inequitable, and extraordinarily expensive healthcare system. In the early days of the pandemic, as revenue from elective procedures cratered, many health systems furloughed staff, cut their hours, or reduced pay, even as demand for emergency care due to COVID-19 exploded. Many hospitals resorted to rationing care, and some shuttered altogether. Increasingly, we are witnessing the collapse of U.S. healthcare, as multiple crises—including lack of rural hospitals, shortages of physicians, and overpriced treatments—collide.[2]

Hard though it may be to believe, today healthcare consumes almost one fifth of the entire U.S. economy. This is far more than most other advanced economies, even as health outcomes fail to match this extraordinary expenditure.[3] Life expectancy in the United States has been declining for years, and existing health inequities have only been exacerbated by the pandemic. To do better requires changing how the nation finances, administers, and allocates healthcare resources.

The VHA’s pandemic experience provides some valuable lessons. When COVID-19 hit, the VHA, rather than contracting, expanded to meet needs. It opened its doors to accept hundreds of nonveteran patients and sent staff to assist in non-VA hospitals and nursing homes. By September 2021, it had provided nearly a million pieces of personal protective equipment to non-VA facilities and sent personnel to more than fifty states and territories to assist local authorities and health systems.[4]

The department moved swiftly to protect its workers and patients, restricting nonessential visitors at facilities, screening returning soldiers, and offering telehealth options nationwide for both medical and mental health services. It also used its novel tele-ICU (intensive care unit) program to help alleviate the pressure on overtaxed ICUs. VA-run nursing homes fared so well that the VA was asked to take over some state-level Veterans Homes from the private, for-profit companies experiencing crises.[5]

In this time of extraordinary challenges for the healthcare sector, what can this tale of two health systems teach us?

HEALTHCARE AS A PUBLIC SERVICE

The VHA operates like a Beveridge-style health system. Beveridge, for the uninitiated, refers to the British economist William Henry Beveridge, author of the famed Beveridge Report during World War II that set the foundations for what would in the United Kingdom become that nation’s enormously popular National Health System.[6]

In such a system, both the payer and provider are public: Funding for the VHA, for example, is appropriated by Congress; VHA personnel are salaried public employees; and the hospitals, clinics, and equipment used to serve patients are publicly owned. Like the United Kingdom, Spain, New Zealand, Cuba, Hong Kong, and much of Scandinavia employ this model for virtually their entire healthcare sector.[7] Rather than seeking to maximize profit and allocate resources based on ability to pay, these systems run like public services.

Without the constraints of market imperatives, Beveridge-style systems are free to adopt public-interest missions. For example, the VHA’s principal mission is to care for the nation's veterans, while one of the missions (called its "Fourth Mission") of its parent agency, the Veterans Administration (VA), is to improve the nation's emergency preparedness and serve as a backup to the rest of the healthcare sector during emergencies.

While many of these healthcare systems have suffered times of severe underfunding and privatization attempts, their popularity with both patients and healthcare workers has generally endured over time. Even Brexiteers recognized the potency of the U.K.'s National Health Service (NHS) as a totemic expression of British values when they pledged that leaving the European Union would mean an extra £350 million a week for the NHS—a pledge that was emblazoned on the side of their campaign bus.

There are likewise valid criticisms of the VHA. It has certainly not always been managed in the best interest of its patients or staff.[8] Persisting geographic variations in the availability and accessibility of some of its services disadvantage some groups of veterans over others.[9] Chronic underfunding coupled with increasing demands by Congress and the executive branch have contributed to critical staffing shortages and unmet goals to modernize its infrastructure.[10] But despite these challenges, the VHA has delivered impressive improvements in recent decades and—most important—health outcomes consistently equal to or better than those in the private sector.[11]

The public nature of the VHA does not, by default, make it the perfect health system. But because it is free of the imperatives of profit seeking, the VHA can create space for other imperatives—for example, centering patients' needs, training and retaining a highly skilled and effective healthcare workforce, and advancing the science of medicine. Also, as a single integrated system, the VHA can manage its shared assets across multiple sites and move both staff and supplies from one geographic location to another more easily than private-sector competitors. This ability to steward resources for the collective good is particularly useful in times of emergency or unexpected strain—such as a supply chain failure—on the healthcare sector.

> **Building a Beveridge-style health system for all based on the VHA—a kind of "VA for all"—would transform the economics of U.S. healthcare.**

PUBLIC HEALTHCARE, AMERICAN-STYLE

Building a Beveridge-style health system for all based on the VHA—a kind of "VA for all"—would transform the economics of U.S. healthcare by removing extractive profit seeking from health insurance, the provision of care, and the procurement of medical supplies. It would also drastically reduce political capture by the healthcare industry, thus removing one of the key obstacles to such long-sought reforms as Medicare for All and enabling the government to negotiate drug prices with pharmaceutical companies.

How could a "VA for all"–style system benefit payers, providers, and patients alike?

First, scaling the VHA would increase the efficiency of healthcare spending through strictly evidence-based care, reduced duplication in testing and procedures, and far lower prescription prices. Moreover, the VHA model relies on a foundation of comprehensive primary and preventative care services. These "first dollar" investments reduce demand for more costly care later. For example, a 2018 study of dual-eligible veterans showed that veterans who relied on the VA for their healthcare saw fewer emergency department visits and hospitalizations than those using private-sector care.[12]

Together, these features would make establishing universal health insurance coverage—a key goal of Medicare for All—less costly. Although the VHA serves patients who are, on average, older and sicker than the overall population, it achieves better results at a lower average per-patient cost than Medicare.

A VA Commission on Care study found that if 60 percent of VHA patients were to start seeking care in the private sector, costs to the VA for their care would quadruple.[13] Rather than privatizing veterans' care, the real cost savings for the country lies in bringing more patients under the care of the VHA, particularly as the overall patient population in the United

If cash-strapped hospitals have no incentive to stay open, where do the patients seek care? Where do the jobs go?

States is on average younger and healthier than the average current VHA patient.[14]

Second, patients would experience better and more equitable outcomes from the kinds of integrated services provided by the VHA. The VHA's "whole health" model starts with primary care teams that include a physician, a nurse serving as the care manager, a clinical associate, and an administrative clerk. Based on the individual needs of each veteran, and in consultation with them, other providers such as mental health professionals, pharmacists, and social workers may be added to that team to ensure all aspects of the patients' health and well-being are understood, addressed, and monitored. This type of coordinated and individualized care is unavailable to most patients in the private sector, despite the importance of care coordination in reducing misdiagnoses and improving patient safety and outcomes.[15]

Multiple studies show this is working in practice. A 2018 Dartmouth College study compared performance between VHA hospitals and private hospitals across the country and found that in fourteen out of fifteen metrics, the VHA care fared "significantly better" than private hospitals.[16] A 2010 systematic review of all studies from 1990 to 2009 comparing the quality of medical and other nonsurgical care in VA and non-VA settings found that studies "almost always demonstrated that the VA performed *better* than non-VA comparison groups" (emphasis added).[17]

Lastly, workers would benefit from a fully public healthcare system like a VA for All. The public sector has long done a better job of employing women and people of color than the private sector.

Already, the VHA's workforce is salaried and almost entirely unionized. For nonclinical staff, VHA jobs offer more stability and better benefits than many private sector healthcare administration jobs, which tend to be based on at-will contracts. And clinical staff can focus on patient care, since they do not have to build a practice, recruit patients, or bill multiple insurers. Research and training opportunities abound for staff inside the VHA. Because the institution plays such a large role in training the U.S. healthcare workforce, it has explicit career ladders; and, as it engages in significant amounts of in-house research, clinical staff can also easily engage in ongoing research and both further their own careers and their scientific field.

TOWARD A VA FOR ALL

Currently, around nine hundred hospitals across every state outside the VA system are on the verge of shutting down due to financial losses.[18] Even before the pandemic, the United States had fewer hospital beds per one thousand residents than many other high-income countries.[19] If cash-strapped hospitals have no incentive to stay open, where do the patients seek care? Where do the jobs go? And how is the broader local and regional economy expected to recover? Some will undoubtedly be purchased by large health systems, consolidating their economic and political power. But many will close—leaving critical gaps in access to care.

We could empower the VHA to acquire and administer many of these hospitals. These acquisitions would not only ensure that communities can access affordable, high-quality healthcare but also help to preserve local community economies.

The VHA could also be tasked to work with Federally Qualified Health Centers (FQHCs), which provide comprehensive primary care to low-income and medically underserved populations and receive support from across the political spectrum. Both could be scaled in a public–public partnership to achieve access to quality primary, secondary, and tertiary healthcare services for all, regardless of income or geography.

Like VHA patients, the FQHC patients experience more chronic health conditions than the overall U.S. population. Yet the health outcomes of FQHCs rival those of the private sector.[20] Numerous studies suggest that FQHCs are associated with lower total per-patient costs to Medicare and Medicaid, as well as economic benefits to the local communities in which they operate, through job creation and purchasing.[21] Moreover, primary care is associated with more equitable health outcomes than specialty care.[22] Thus, expanding the network of FQHCs and linking them to other public healthcare infrastructure like that provided by the VHA could both advance health equity goals and contribute to overall health system savings.

Additionally, FQHCs offer a model for democratized governance of healthcare services and responsiveness to local community needs due to their "consumer board" structure. By federal mandate, 51 percent of each board must come from the patient population served by the health center in terms of demographics, and "of the nonpatient health center board members, no more than one-half may derive more than 10% of their annual income from the health care industry."[23]

TRANSFORMATION, NOT REFORMATION

As the healthcare "system" of the world's wealthiest country is teetering, if not close to collapse, the pressing need for transformative solutions is obvious. Scaling publicly owned healthcare to serve all would be just that—a way to take healthcare from a source of private profit, mass suffering, and financial ruin, and make it a public good.

Leveraging healthcare investments to actually improve the health and well-being of our people, our communities, and our economy is eminently possible. The models for how to do it already exist. Building on the successes of the VHA and FQHCs offers a path to delivering better healthcare at lower cost, with greater stability for our healthcare workforce.

■

As patients and healthcare workers know, sometimes the body can heal itself—but only if nutrients it takes in are feeding the body's essential organs rather than a cancer or pernicious bacteria. Sometimes a tumor must be excised—and tissue must be irradiated—to stop a malignant growth. But with the proper support and care, a body can transform itself, develop new habits and abilities, and return to a state of health and well-being.

Likewise, the U.S. healthcare system needs major surgery before it can heal. The malignancy of profit seeking must be cut out, so that life-giving resources may flow where they are most needed. Only then can the dream of healthcare as a human right be truly realized.

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Person First, Disability Second

The Road to Full Inclusion

by Nicole Zerillo

Shared language around the experience of disability is a starting point for having increased choices in the world. It also helps ensure people with disabilities are respected for who they are as people. Practice and policy must shift to become person-centered.

Disability is a core justice issue, but people with disabilities are often an afterthought where social justice is concerned. Unless you have a disability or a relationship with a person who has a disability, the barriers to full inclusion may not be immediately visible; but inherent bias and a lack of engagement of people with disabilities have led to separate, segregated service models that continue to isolate people with disabilities from the community and their typical peers. The "invisibility" of people with intellectual and developmental disabilities (IDD) to typical citizens has long been a marker for potential abuse and neglect.[1]

Disability cuts across all segments of society. Even though an estimated sixty-one million American adults have a disability and about seven million Americans have intellectual and developmental disabilities (IDD), the challenges faced by people with disabilities remain largely hidden from view, and systems of support are often lacking.[2] Opportunity exists to build neurodiversity and disability into justice conversations.[3] A recent study showed that 90 percent of companies had diversity priorities, but only 4 percent factored in disability.[4] Certainly, the conversation about diversity, equity, and inclusion (DEI) is not a new one in the nonprofit sector. Increased consideration for "accessibility" is gaining traction as DEIA (diversity, equity, inclusion, and accessibility) reflects issues of ableism and sanism.[5] It also signals greater attention and investment from nonprofit and other leaders.

"MAMA'S HANDS" BY AMIR KHADAR/WWW.AMIRKHADAR.COM

The structural exclusion and underfunding of disability programs create troubling outcomes that appear at each life stage for people with disabilities.

Broadly speaking, equity and inclusion initiatives have increased in prominence in the nonprofit sector in the wake of the movement against anti-Black racism, thanks to the activist efforts of the Movement for Black Lives (M4BL) and Black Lives Matter keeping antiracist work front and center. According to Nonprofit HR's *2021 Nonprofit Diversity Practices* report, Black Lives Matter "responses" inspired 63 percent of 675 North American organizations to make "adjustments to prioritize/reprioritize diversity objectives, programs and/or initiatives."[6] Of the surveyed organizations, 28 percent also reported that they planned to increase or had increased their diversity budget.[7] However, only 6 percent had provided "ability-centered training."[8]

The structural exclusion and underfunding of disability programs create troubling outcomes that appear at each life stage for people with disabilities.[9] Special education funding through the Individuals with Disabilities Education Act (IDEA) has not progressed alongside existing needs.[10] In 2020, Congress funded only 13.2 percent of its 40 percent contribution—leaving states and local districts on the hook for $24 billion in costs.[11] Like so much in the disability sector, service funding varies across individual states and becomes an annual advocacy charge to maintain or even meet the status quo.[12]

PUTTING THE PERSON FIRST

A justice lens begins with putting the person first when referring to the experience of disability: *a person with* developmental disabilities; *a person who* resides in a group home. It's about acknowledging the experience of disability *for a person* rather than using a diagnosis to define a person's personality, interests, or goals. When possible, consider not referring to the disability at all and just tell the story. Language goes to deeper issues that tie to visibility and the systemic exclusion of people with a disability. Some people live independently, in supportive apartments, in group homes, or with their families. How people with disabilities process and engage with the world is as varied as the human experience itself.

Society's general unwillingness to engage people with disabilities—as individual people rather than as some abstract public policy area—has a "devastating effect" on an ongoing basis, according to a study out of the United Kingdom from 2018, showing that the perception gap of disability prejudice has more than tripled since 2000.[13] Negative perceptions of people with disabilities persist "from the seemingly benign to overt discrimination." Displaying "commonly held" attitudes, the study showed 75 percent of respondents perceiving people with disabilities "some or most of the time. . . needing to be cared for," and 13 percent "hardly ever or never think(ing) of (people with disabilities) as the same as everyone else." Negative perceptions of people with disabilities shifted according to the quality of relationships with those who had disabilities—and were likened to "long-term contact" with other diverse populations. The disability charity Scope shared these results from a 2017 British Social Attitudes survey of "a nationally representative sample of around 3,000 people," focused in part on the experience of living in the United Kingdom.[14]

Increased attention to the dominance of ableism and sanism is needed at a time when disparities that impact vulnerable populations continue to surface. For children with disabilities, the use of electric shock devices is still legal in several states, despite being deemed torture by the United Nations.[15] In the past year, the Food and Drug Administration sought to ban such use, but was overturned by the United States Court of Appeals for the District of Columbia Circuit.[16] Just as the Centers for Disease Control and Prevention declared racism "an epidemic impacting public health,"[17] children of color remain underdiagnosed with autism and developmental disabilities.[18]

DISABILITY DISCRIMINATION

COVID-19 has spotlighted bioethical questions and the gaps in equitable treatment. Adults with disabilities who are as young as eighteen live in nursing homes or institutions due to a lack of home- or community-based alternatives in their state.[19] During the pandemic, this setting exacerbated issues, ranging from higher infection rates to unequal access to vaccines to a lack of timely guidance on virus monitoring or social distancing.[20] In such settings, deaths

Segregation, casual prejudice, and isolation continue to separate people with disabilities from full community inclusion and the opportunity to lead the lives they choose.

have been underreported.[21] Disability discrimination also appeared in reported incidences of ventilator-use limits, triage biases, and denial of care.[22]

Outside of pandemic realities and despite more than thirty years of the Americans with Disabilities Act of 1990 and its antidiscrimination mandate, people with disabilities remain one of the most vulnerable groups in the United States.[23] They are more likely to be unemployed, victims of crimes, and live in poverty.[24] Thirty-eight percent of state and federal prisoners have at least one disability, according to a 2016 Bureau of Justice Statistics report. Of those disabilities, the most common is a cognitive disability (23 percent).[25]

Segregation, casual prejudice, and isolation continue to separate people with disabilities from full community inclusion and the opportunity to lead the lives they choose.[26] Funding for services that assist people with disabilities to more fully participate in the community remains inadequate. Disability advocates campaigned for the Better Care Better Jobs Act—currently under review by the Senate Finance Committee—because it increased Medicaid funding for home and community–based services (HCBS),[27] among other key investments, such as the direct care workforce.[28]

Community integration was advanced by the U.S. Supreme Court in *Olmstead v. L.C.* (1999), known as the *Brown v. Board of Education* of the disability rights movement.[29] Rejecting segregation and wide-spread institutionalization, the *Olmstead* ruling held that people with disabilities had the civil right to live in the community with state-funded supports[30]—albeit with approval from treatment professionals who determined that they met specific criteria. Under Title II of the Americans With Disabilities Act, such community-based services must be provided when medical professionals find it "appropriate," and the person to be supported chooses such an option and "can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."[31] Yet the flexibility of *Olmstead* enables states to, at a "reasonable pace," maintain ongoing waiting lists to "transition" people into the community; integration efforts continue to evolve via Medicaid access and funding.[32] *Olmstead* violations occur on an ongoing basis and are addressed by the U.S. Department of Justice (DOJ) and Department of Health and Human Services' Office of Civil Rights (OCR).[33] According to a 2019 report from the Medicaid and CHIP Payment and Access Commission (MACPAC), there were over fifty "integration matters" addressed by the DOJ in twenty-six states and D.C. from 2009 to 2016. The OCR "intervened," "often with DOJ," in more than "80 cases of Medicaid beneficiaries in institutional or segregated settings as well as for persons at-risk of institutionalization or loss of community-based services."[34]

POLICY PERILS

Medicaid also funds direct care for people with disabilities. The professionals undertaking this work are known in the industry as direct support professionals (DSPs). The DSP role and term are not well-known outside of the disability sector. It's a profession requiring talent and care of the most intimate parts of a person's life. This lack of recognition unfortunately corresponds with "an average annual turnover rate of 45 percent" and "an average pay of $10.72 per hour"[35]—which, according to Nicole Jorwic, senior executive officer, state advocacy, and senior director, public policy, at The Arc—was a statistic from before COVID-19; since the pandemic, turnover probably even increased.[36]

"We are requiring people to be impoverished in order to access these services, and then on the flip side of that the workforce is not making a living wage," said Jorwic.[37]

These positions are primarily held by women of color.[38] The Arc—as part of the Care Can't Wait coalition, which includes the National Women's Law Center and TIME'S UP Foundation—is advancing an agenda with requests including "the investment of $400 billion in Medicaid home and community-based services."[39]

The Better Care Better Jobs Act brings to life the American Jobs Plan proposal for $400 billion in funding for home- and community-based services. Though not all of that money will support the DSP workforce, such an investment will begin the important work of improving supports for more than 3.2 million Americans, including senior citizens and people

Socially enforced invisibility, isolation, and social barriers divide people with disabilities from their peers and endanger them.

with disabilities, to lead lives of increased independence and inclusion.[40]

For Jorwic, like many advocates, full integration in society remains a critical focus. Disability was part of the fabric of Jorwic's life, from being a student in the "first included classroom in her school district" to being a sibling advocate for her brother, Chris. "There's a huge deficit in understanding in the general public of the disability experience . . . (and) of the history of the disability rights movement," said Jorwic. "We need to make people comfortable with using language around disability and incorporating people with disabilities and their stories into things that aren't necessarily about disability specifically."[41]

This lack of understanding and shared language, according to Jorwic, also impacts policy-makers through inconsistent language provided by constituents when sending legislative requests and in data collection. For example, DSPs do not currently have a standard occupational code, which impacts workforce statistics.[42] Data are also lacking around "the places where people with disabilities were living during the pandemic," according to Jorwic.[43]

"A lot of support for people with disabilities is funded through Medicaid, which is a federal program run by states. It's called different things in different places. This leads to confusion for families and for media . . . (and) state and federal government when it comes to data collection," said Jorwic.[44] In Illinois, community-based residences are called community integrated living arrangements (CILAs). New York, instead, has individualized residential alternatives (IRAs). Unsurprisingly, "because of that variation, we don't have a lot of national data when it comes to settings ultimately or during COVID specifically for people with disabilities."[45]

Socially enforced invisibility, isolation, and social barriers divide people with disabilities from their peers and endanger them. The divide begins almost imperceptibly in early childhood, when students with disabilities are placed on a separate track from their peers. This impacts the quality of education these students receive, which is also affected by race and class.

Bernard Baker, president of Self Advocates Becoming Empowered (SABE), a national nonprofit, remembers the challenges of being in a chair and special education classrooms at a time when to be included in typical classrooms meant having to be carried up and down flights of stairs. After decades of advocacy across a number of states, Baker believes that normalizing the experience of disability is a value of compassion and community that should begin in childhood.

"[People] are afraid to ask you what happened, and they'll sit there and stare at you. When I went to high school, a lot of people . . . were afraid to talk to me," said Baker. "What I want people to understand is that we're people first. Disability comes second."[46]

Hezzy Smith, director of advocacy initiatives at the Harvard Law School Project on Disability, agrees. Smith is a sibling advocate, has volunteered at Special Olympics, and sees his support of the disability sector as "always . . . just a part of life." In addition to increasing meaningful self-advocate roles at provider agencies, Smith says that "people with intellectual and developmental disabilities need to be hired by those state and federal organizations to be quality control specialists."[47]

Increased inclusion would lead to "a win-win, because the policy-makers, administrators, and auditors would have an array of people who could bring potential flags to their attention," as well as "provide jobs to the people with intellectual and developmental disabilities to whom they're paying lots of taxpayer dollars to just provide services," said Smith.[48]

For Smith, "Without it even being altruistic, it would make good business sense in a lot of these cases to get people with intellectual disabilities on boards, employ them as consultants, and use their expertise to enhance whatever you're offering."[49]

As a self-advocate, Baker, a father who dreams of opening up his own transportation company and has taught people who recently developed disabilities to ride the bus, is interested in more than a seat at the table. He wants to ensure that his voice is not only heard but also valued. For people uncertain about how to speak about the experience of disabilities, Baker proposes that they "invite people with disabilities to come in and talk to their employers."[50]

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Shared language around the experience of disability is a starting point for having increased choices in the world. It also helps ensure people with disabilities are respected for who they are as people. Practice and policy must shift to become person-centered. For individuals, signing up for advocacy alerts or following disability rights organizations online can help keep them informed about federal and state legislation, where lawmakers may need to see constituent support for disability issues. Organizations can join this call to action by developing training and evaluating gaps in their operations and culture. It's a matter of placing value on different abilities and experiences.

In order for deep change to take place, Baker insists that people with disabilities need a seat at the table. "People with disabilities need to be included in all segments of the government. And we don't need to be included in the middle, when people are planning stuff for us; we need to be included from the beginning. When you leave out people with disabilities and put them in the middle, then we're lost—because we're trying to fill in something that somebody else started."[51]

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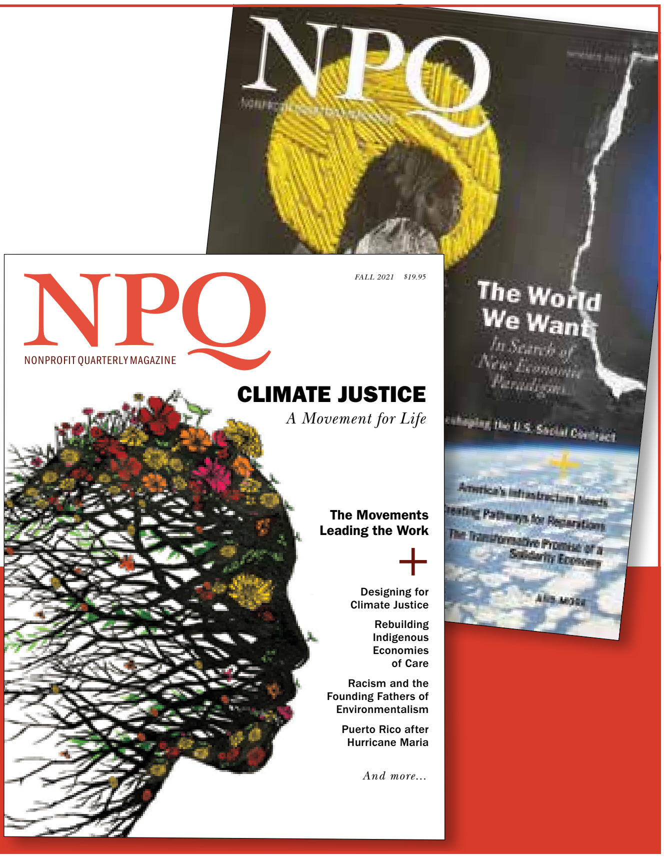

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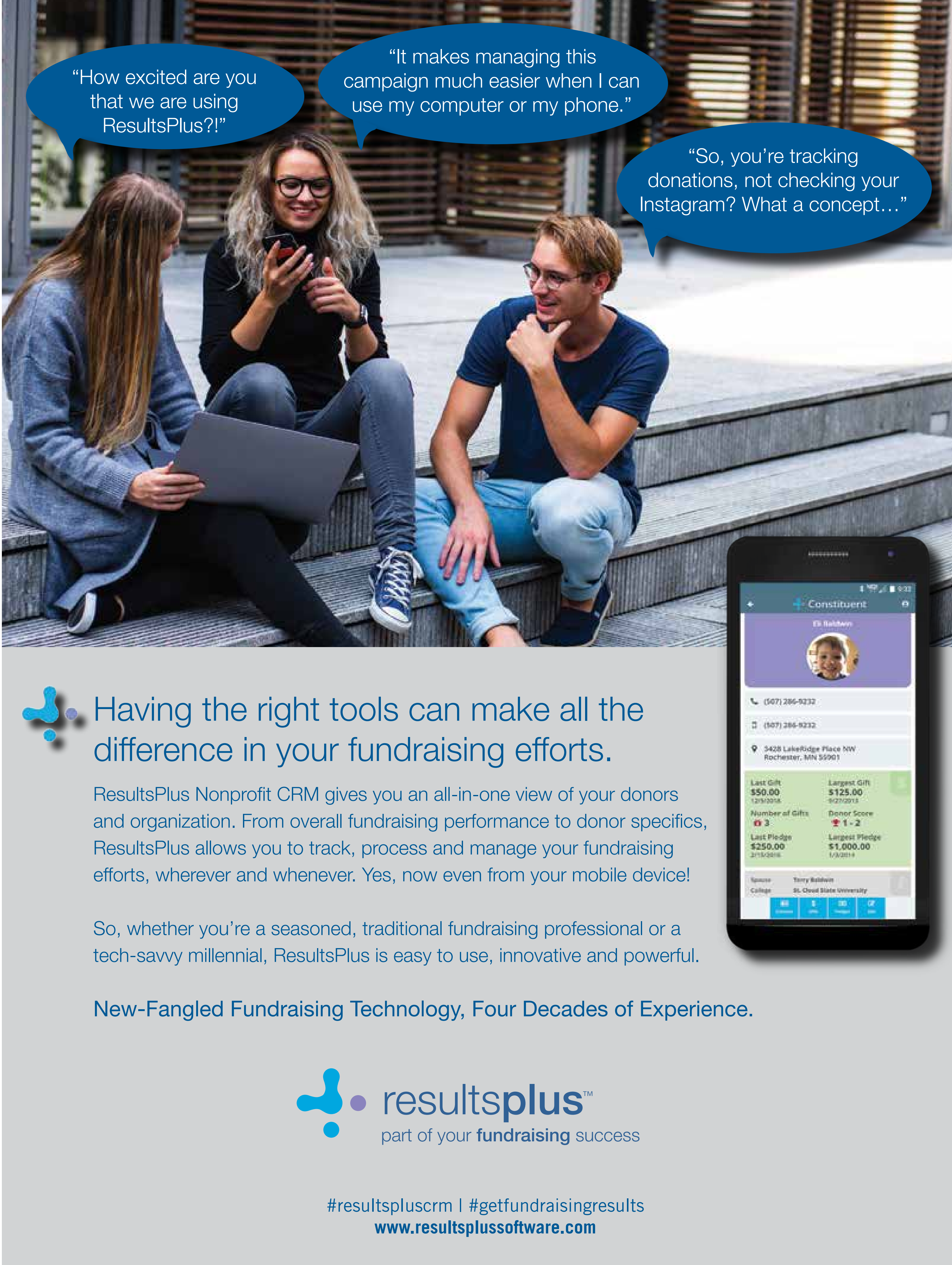

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HEALTH JUSTICE

Healing a Sick System

From Big Pharma to Our Pharma

by Dana Brown

✿

Creating a robust public pharmaceutical sector can help break Big Pharma's monopoly on the nation's medicine supply and shift the balance of power, offering a systemic solution to exorbitant prices, recurring shortages, and declining innovation.

Imagine a world in which insulin and PrEP—the revolutionary one-a-day preventative HIV pill—were available to all who needed them at prices they could easily afford. Imagine that the effective Lyme disease vaccine once available was still on the market, and that new drugs consistently provided new clinical benefits, not just new prices.

In this world, there would be no artificial scarcity of COVID-19 vaccines, therapeutics, or tests needlessly prolonging the pandemic and upping the body count. Pharmaceutical manufacturing plants would be considered critical infrastructure, and retail pharmacies would be run for the benefit of their workers and local communities.

That world is eminently possible, and it could be built from a foundation of democratic, public ownership in the pharmaceutical sector. In fact, from Massachusetts, in the United States, to India, Thailand, and Great Britain, regions and whole countries have turned to public ownership in the sector to combat high prices, drug shortages, and political interference by multinational corporations, or to strengthen local economies and focus biomedical innovation on socially important goals.[1] Historically, much of the world—including the United States—relies on public sector labs for the development of vaccines.

"OUR STORIES OUR VISIONS SERIES #13" BY AMIR KHADAR/WWW.AMIRKHADAR.COM

PUBLIC OWNERSHIP OF PHARMACEUTICAL COMPANIES CAN BE A VEHICLE FOR THE DESIGNS WE NEED TO PRODUCE SUPERIOR OUTCOMES.

But today, drug production is dominated by large, for-profit companies—“Big Pharma”—whose political power and market share allow them to dictate terms to patients, payers, and entire swaths of the globe. Big Pharma does whatever it takes to maintain its power: suing governments,[2] buying off competitors,[3] and keeping life-saving medications off markets if not given total freedom to set prices.[4] Despite comprising the most profitable large companies on the Standard and Poor’s 500,[5] Big Pharma has delivered recurring shortages, increasing regulatory capture, rising post-market safety issues, and a decline in clinically meaningful innovation in recent decades.[6] As highly financialized corporations, they favor downsizing, outsourcing, and paying out extraordinary dividends to shareholders (often accounting for more than 100 percent of profits) over reinvesting in the business of making medicines.[7]

These trends are harmful to our health, our economy, and our democracy, and they disproportionately impact the least powerful groups in our society, including immigrants, people of color, LGBTI people, and people with disabilities. They are also the natural outcomes of an industry oriented around the singular goal of maximizing profit. To get different outcomes, we need a different design.

A PUBLIC PHARMA

Public ownership of pharmaceutical companies can be a vehicle for the designs we need to produce superior outcomes. Because they are not beholden to market imperatives, publicly owned pharmaceuticals are free from the constraints of profit maximization and rent seeking. Instead, they can define their bottom line on the basis of their contributions to public health, scientific advancement, and local economic benefit. With such goals, they would find it in their interest to reinvest earnings for socially productive purposes, such as researching new therapies, improving existing ones, and making essential medicines broadly available and affordable.

“Public pharma” institutions may exist at any or all points in the supply chain. Since 1960, Cuba’s entire pharmaceutical sector has been public. It produces both low-cost generics and first-in-class therapies, manufactures a majority share of the domestic supply of medicine, provides thousands of good jobs, and contributes significantly to the national economy.[8] Known for its innovations, like the world’s first lung cancer and meningitis B vaccines, Cuba’s public pharmaceutical industry also engages in active technology transfer with numerous low- and middle-income countries, diminishing reliance on Big Pharma to meet healthcare needs.[9]

Several other countries employ public ownership in one or more nodes of the supply chain to meet local public health goals, support the economy, and assure sufficient supply of essential medicines. Sweden’s public APL is the largest specialty drug manufacturer in Europe.[10] South Korea provides public contract manufacturing facilities to support small and medium biopharmaceutical enterprises as part of its industrial strategy.[11]

Properly designed publicly owned pharmaceuticals can have significant positive social benefits. Assuring that high-quality medications are available and affordable for all means that more people can stay active in their communities, remain in the workforce, pursue educational opportunities, and contribute to the local economy. Publicly owned pharmaceuticals can also foster resilient supply chains by building in surge capacity for emergencies in ways that actors in competitive markets do not.

SHIFTING THE BALANCE OF POWER

Establishing a publicly owned full-cycle pharmaceutical research and development (R&D) institute in the United States would be the most impactful public intervention in the sector. Because R&D is associated with the ability to claim and monetize intellectual property rights (IPR) on the new medicines that result, it is the point of greatest extraction and distortion in the current system. Industry-friendly regulations

PUBLIC OWNERSHIP OF PHARMACEUTICAL R&D CAN ALSO ASSURE THAT THE MEDICATIONS MOST ESSENTIAL TO PUBLIC HEALTH ARE PRIORITIZED FOR DEVELOPMENT—A SHARP CONTRAST TO BIG PHARMA COMPANIES THAT PRIORITIZE THE MOST PROFITABLE MEDICATIONS.

and IPR not only allow companies to charge whatever they please for the drugs they produce (regardless of clinical efficacy or production cost) but also slow down innovation, provide incentives to develop some drugs but not others, and keep competing products off the market—often for well beyond the original twenty years granted for any single patent.[12]

Companies also charge exorbitant prices to a public that has essentially already paid for its products through decades of publicly funded research, tax breaks, subsidies, and government purchasing through Medicare, Medicaid, and the Veterans Administration. Funding from a single public lab, the National Institutes of Health (NIH), already accounts for more than half of the R&D spend reported by major pharmaceutical companies each year.[13] In one striking example, this funding was linked at some level to the development of every single one of the 210 novel drugs approved for the U.S. market between 2010 and 2016.[14] Directing more of these funds into a public, not-for-profit institute would increase the efficiency of these investments.

Public ownership of pharmaceutical R&D can also assure that the medications most essential to public health are prioritized for development—a sharp contrast to Big Pharma companies that prioritize the most profitable medications, often copies of existing products, or "me-too drugs." These drugs not only offer little if any clinical benefit over existing drugs on the market, but their centrality to drugmakers' profit margins can even lead to what is called "negative innovation," with drugs coming to market that are "affirmatively harmful to patients."[15] Authors of a recent article in *Nature Biotechnology* highlight a cancer drug sold at a dose that provokes severe side effects because safer doses would not have earned the company the coveted patent it sought.[16]

While these duplicative and sometimes harmful drugs *are* being developed by the industry, many medications critical to health are *not*. Drugs like antibiotics and therapies for central nervous system diseases are chronically neglected by Big Pharma due to their low profit potential. Publicly owned labs can be explicitly tasked to prioritize R&D in these areas (as they already are in Brazil and Cuba) because it is valuable to the national healthcare system. A focus on therapies "overlooked" by the market would contribute to more equitable biomedical innovation, since diseases that predominantly affect less privileged groups (e.g., sickle cell anemia, multidrug-resistant tuberculosis, and many tropical diseases) are often eschewed by the market because the affected patient population is seen as too small or too poor to constitute a lucrative market.

A PUBLIC PHARMACEUTICAL R&D INSTITUTE

As an article I coauthored in 2020 details, a natural place to house a public pharmaceutical R&D institute would be at the National Institutes of Health, effectively closing the loop on the majority of existing public investment in pharmaceutical innovation.[17] There, the institute would also benefit from "close collaboration with existing institutes and their increasing involvement in early-phase clinical trials."[18] Nothing prohibits states or regions from also investing in public pharmaceutical R&D; but building on existing federal public investment in biomedical research and leveraging research already occurring at the NIH is likely the most direct route to achieving public return on public investment in the sector at scale.

Freed from market constraints, the institute could embrace explicit mandates to develop a safe, adequate, and accessible supply of essential medicines for the public; adhere to the highest standards of clinical trial and data transparency; and manage the intellectual property resulting from its discoveries in the public interest.

OVER TIME, A NETWORK OF STATE, LOCAL, AND REGIONAL PUBLIC PHARMACEUTICAL MANUFACTURERS, RETAILERS, AND DRUG DEVELOPERS COULD GROW TO DISPLACE EXTRACTIVE FOR-PROFIT COMPANIES AND RECLAIM MEDICINE AS A PUBLIC GOOD.

Initial R&D priorities could include products neglected by the market, medications to combat emerging pathogens, and promising areas of science that could lead to breakthrough technologies. Priorities could be updated over time in a similar process already used by the NIH to determine internal research priorities that balance "the opportunities presented by the best science, public health needs, and the unique ability of NIH to address challenges in human health that would otherwise go unmet."[19]

The institute's clinical trial and data transparency practices would help speed innovation by reducing duplication and waste.[20] Additionally, it would put pressure on private sector pharmaceuticals to manage their data more transparently—something advocates have long demanded—which, in turn, would further scientific advancement, ensure patient safety, and promote fairer pricing.

Regarding intellectual property rights on its innovations, the institute could be directed to maintain its patents in a pool subject to a "copyleft"-type license,[21] but to seek no trade secrets or data protections, as these forms of IPR present significant impediments to scientific collaboration and slow down innovation.[22] Managed in this way, new publicly developed medications would be broadly available and could be priced to ensure equitable access. Brazil provides a compelling example in which a network of its public labs and retail pharmacies were leveraged to help establish the country's Popular Pharmacies program, which provides low-income patients with over one hundred medications used to treat the most prevalent diseases for free or at deeply reduced prices.[23]

A PATH FORWARD

To be sure, a federal public pharmaceutical R&D institute in the United States would face many challenges. Political pressure from Big Pharma could easily undercut attempts to adequately fund the institute and constrain its mandate. Start-up costs would be significant, while achieving lower drug prices and innovation would take time. As short-termism dominates American politics, the institute could suffer a backlash in its early years before it is able to produce many easily recognizable returns. (This is not merely a theoretical concern; a similar pattern was evident in the initial U.S. public response to the Affordable Care Act.) For these reasons, it might be strategic to start with a limited mandate focused on developing drugs neglected or abandoned by the industry for their lack of profitability. If Big Pharma's bottom line is not threatened, the institute might enjoy broader political and financial support, enabling a successful start.

Notwithstanding the promise of public R&D at scale, experiments in public manufacturing, wholesale, or distribution may be easier to set in motion first. In fact, some of the groundwork for such initiatives has already been laid. In 2018, Senator Elizabeth Warren (D-MA) and Representative Jan Schakowsky (D-IL) introduced a bill for federal public drug manufacturing for the first time.[24] In 2020, California passed legislation that created a public generic drug label and established a pathway for future public manufacturing.[25] Since then, other states have introduced public drug manufacturing bills, largely at the behest of type 1 diabetes patient advocates aiming to break the insulin cartel's stronghold on the medicine that keeps them alive (which, ironically, was developed in a public lab in Canada a century ago).[26]

While one state-owned pharmaceutical manufacturer or retailer alone will not transform the economics of the industry, it could provide a powerful model and inspire others to experiment with interventions that prioritize residents' health. Over time, a network of state, local, and regional public pharmaceutical manufacturers, retailers, and drug developers could grow to displace extractive for-profit companies and reclaim medicine as a public good.

■

In recent years, much attention has rightly been focused on achieving swift and equitable access to COVID-19 vaccines and treatments globally. Strategies advanced include sharing intellectual property rights, engaging in active tech transfer, and helping scale manufacturing efforts worldwide. These steps can and should be taken. But most of these efforts do not address the root causes of artificial scarcity and high prices in the drug market. Ultimately, the main structural impediment to broad access to medicines must be addressed: the system of profit-based drug production.

Creating a robust public pharmaceutical sector can help break Big Pharma's monopoly on the nation's medicine supply and shift the balance of power, offering a systemic solution to exorbitant prices, recurring shortages, and declining innovation. As a leading funder of pharmaceutical R&D globally, the U.S. public sector is uniquely positioned to contribute to a new global paradigm of medicine provision as a public good. It would be a big step away from Big Pharma toward Our Pharma.

NOTES

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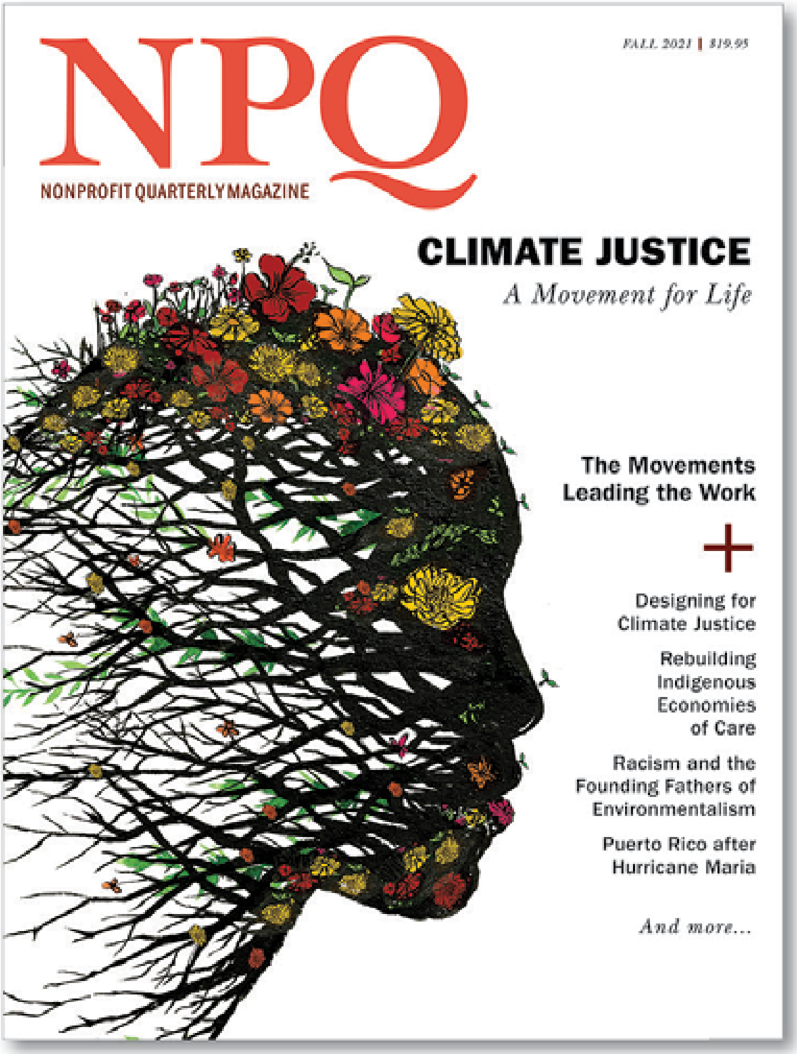

HEALTH JUSTICE

First Aides

Indigenous Stories to Reclaim and Reframe Our Highest Health to Each Other and Mother Earth

by Solana Rose Booth

Emotional and spiritual health directly affect our mental and physical health, so health justice needs to be inclusive of all our parts and our relationships to all of Mother Earth's inhabitants. This includes Mother's Breath. These plant medicines and power invoke in us the connections we already have inside us to other inhabitants, to the star people, to our ancestors and our grandchildren's grandchildren.

"OUR STORIES OUR VISIONS SERIES #15" BY AMIR KHADAR/WWW.AMIRKHADAR.COM

Allow me to invite you to radically accept that we as a human family and Mother Earth have been in an unhealthy relationship, and that this relationship in turn is causing us to have an unhealthy relationship within ourselves and with one another. Regardless of which happened first, we are all in tough times—we are in "the thick of it" (a term used to refer to a tough time during a plant ceremony with entheogenic, or psychoactive, plant medicine). This story is a testament to humanity and Mother Earth. This story is what we are all asking for—what humans are asking for and also what Mother Earth is asking for.

Indigenous people are the original sentinels of Mother Earth. This means that we have an intimate, informed, and practice/evidence-based connection to her. It is knowing that we are both made of the same elements—mostly water. Here is a first story of how deeply connected we are to Mother Earth as a human family, and how we can reframe the dysfunction happening among all of us right now.

Today, we are thick in the cycle of healing, and it feels more like a cycle of suffering. The COVID-19 pandemic has reminded Indigenous peoples that we are all not just survivors of genocide and sour truths but also are surviving radical physical, mental, emotional, and spiritual labors of migrations. While we have desires and will to connect both to our ancestors and our grandchildren's grandchildren (who are yet to be born), we are also in an opportune position *right now* to heal, reconcile, and sustain our health. There are many medicine people with wisdom who have passed on, and there are people who are tapping into their highest selves these days to help us keep going forward toward *our* highest selves.

The story of "The Eagle and the Star People" came to me May 27, 2021. Earlier that week, I had helped to rescue an eagle. Later that week, the eagle, whose name came to me as Zelda, shared many knowings of her travels, of her mate, of her eaglets, and of the nests she had made throughout her journeying across Turtle Island. Zelda shared examples of her song and of tools she'd used to share her songs. She was strong, and took up a lot of space; she was regal, and demonstrated by her posture primal ways of being a bird of prey—the one who flies the highest of all the winged creatures. The night she went to her new house (she passed away), I held her, and she showed me more relationships she'd sown, and how she had sustained her nest. The story came to me as a memory later that evening, and I quickly shared it with a sister and brother as it downloaded into my mind and I embodied its essence. It was as if Zelda were whispering more and more parts of the story while I was sharing. It is one of the longest Creation stories I have known.

The star people were gathering and sharing their stories, and they sensed and they noticed that the human family weren't looking up at them as much. They noticed that soon the human family did not notice them at all.

THE EAGLE AND THE STAR PEOPLE

Before colonial contact, Indigenous peoples relied on Creation stories to heal our hearts and grow our minds and human development to maximize our potential for love, creation, and relationships with each other and Mother Earth, including her other inhabitants, our individual human technologies, and more. First narratives are the oldest healing modality, and existed long before newspapers and other written texts, before radio and TV, before diseases, and before hospitals, prisons, and other institutions.

This story I am going to share with you is to remind you of a time when people *sensed*—they didn't speak with their mouths.

This story comes from a time of not having certain amenities and not having certain conditions that we're living in today. It was a time when the star people and the human family had a special kind of relationship. If we asked them, the star people would say that this time was about *sensing*, *noticing*, and *speaking to*—and it was about *light*. The human family would say that it was a time when they could see in the dark—the dark times: the cold becoming warm, sharing stories, and trusting each other, all of Mother Earth's inhabitants. The humans would also speak of their relationship to Father Sun, but that is a different story.

In this story, "The Eagle and the Star People," the human family would gather into groups and tell stories to each other. And the star people told stories to each other, too, as they gathered in groups. And they had an order to the way they told their stories. The star people noticed much happening in the daytime, so they would gather into their groups every night and share what they sensed and noticed. The people down below would sense the star people noticing them, and they would look up and notice the star people clustering into their groups, their constellations.

The people would sense the stories the stars shared, and interpreted the stories as advice on what they should or could be doing. It's as if the people looked up at the stars to get a framework or template and ideas as to what they needed to be harvesting, or how they needed to be foraging, or where they needed to move camp, or what was coming for the people.

The star people also sensed and then noticed why the human family were doing what they did and how they modified themselves according to the stars' stories. Star people noticed the human family begin to mimic them by gathering into groups and families or tribes to share their stories among each other.

Pretty soon, the star people decided to pay extra attention to the human family and their stories, and one day they made an extra effort to sense and emotionally feel what the people down below were doing. It was interesting, because that same day, the human family decided to pay extra attention to each other. They noticed strong emotions, and they decided to pay extra attention to Mother Earth—so they didn't look up as much when the night came.

The star people were gathering and sharing their stories, and they sensed and they noticed that the human family weren't looking up at them as much. They noticed that soon the human family did not notice them at all. At night, the stars shared their stories, and went on about their nights of shining and days of not shining, and they created their plans of movement and which stars were going to gather into what groups and share their stories for the human family down below.

Night after night, they noticed that the human family continued not looking up as much anymore. The star people decided to watch them and figure out what was going on, and sensed the humans' attention to their own advancing technologies.

Soon, the humans didn't look up, and would only look at Mother Earth sometimes. The stars noticed that the humans had begun to not look at each other, and that they had stopped sharing their stories. Humans focused most of their time on the technologies that they created, and on sharing those with each other—and pretty soon, the star people also stopped gathering into their groups.

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Humans were starting to become sick—not sick from disease or other physical ailments, but sick in a way of lacking authenticity, of not being able to sense truth, of not noticing that their relationships were failing.

The stars weren't showing as much light anymore at nighttime. Humans were so busy looking down at their technologies, and then looking down on each other, that pretty soon they didn't talk to each other anymore, either. Humans kept to themselves, and pretty soon, night after night, it began to get darker and darker, because the star people weren't lighting up anymore. They had no stories to share, so there was no longer any reason to light with each other, and they began to dim.

Nights became darker and darker, the human family below kept creating as many things as they could, and they decided to create their own tools so that they wouldn't need the stars' light anymore. Humans had their own "synthetic" light now; they didn't have to look up anymore to see where they were going or what they were going to be doing, so they just kept moving about their lives.

As it became darker above, it got darker below. The darker nights quickly became a problem for all the other relatives of Mother Earth, including Eagle, who sits at the top of the trees and notices what goes on in the sky and what goes on down below. Eagle is a wise one, who's able to fly atop Mother Earth's atmosphere, notices everything during the daylight, and senses people and many others of Mother Earth's inhabitants. Eagle could have been a messenger to the star people, helping them to interpret the human family and their needs. Eagle has very good vision, so Eagle could see people's behavior from far, far away, and could sense that the star people were still out at night, even though they were no longer gathering and sharing stories.

Since Eagle was around during the times when the star people shared their stories and lit up the night sky, Eagle knew those stories of care, collaboration, and other human behaviors. Eagle began to do some research, and to soar and find other relatives. Among the plant relatives, Eagle met Mother's Breath (psilocybin), who told Eagle about when the people used to come and harvest the plants.

Eagle also stayed awake after day's end and talked to the keepers of the night, like Owl, Killer Whale/Blackfish, Mosquito, and more. Eagle and the night keepers and plants were talking a lot of wisdom, they were exchanging stories. Eagle helped them to tell their own Creation stories from as far back as when the star people would first gather for the humans.

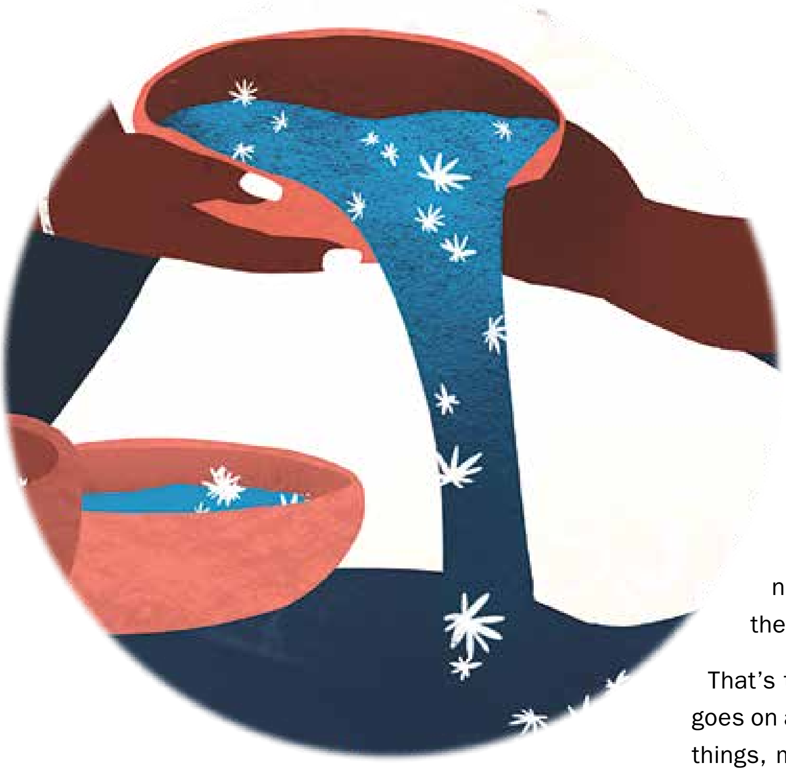
Eagle remembered long ago, and recalled Cedar Tree's genesis. Cedar Tree began to talk about generosity, and how she shared her moisture with the other trees—and she helped Eagle with Eagle's own Creation narrative. Cedar Tree began to talk about the Salmon stories, about when Salmon comes back home to spawn, and all the stories Salmon has of the people fishing them, of Killer Whale/Blackfish, and other mammals fishing for Salmon way out in the middle of the sea.

Cedar Tree told stories from the sea, from the plant people, from Mother's Breath, from other winged creatures—and pretty soon, someone else was scratching at Cedar Tree. It was Bear, who had their own stories of the humans, and who shared more "remember when?" stories. These were stories from a time of chaos, like what was happening now, with no star stories at night.

Eagle, Owl, Cedar Tree, Bear, and Mother's Breath sensed the River and Stone stories also—and the hydromorphology of the rivers and the mountains were shared with them.

Everyone except humans were in these stories. Humans weren't connected to the stars, to Eagle, Owl, plants, Cedar Tree, Mother's Breath, Salmon, rivers, and mountains, even though humans were physically walking around. Humans were starting to become sick—not sick from disease or other physical ailments, but sick in a way of lacking authenticity, of not being able to sense truth, of not noticing that their relationships were failing. I'm not sure exactly how sick they got, but pretty soon they were no longer conducting themselves as tribal or familial creatures—meaning no more singing, gathering, sharing, foraging or harvesting, or honoring their relatives. Owl, Eagle, Bear, plants, Cedar Tree, Stone, and River felt that humans were disconnected or that there was something amiss in those relationships with them.

After a short time, Eagle stopped the stories of chaos about the humans and the stars that were being shared among the relatives. Eagle interrupted all these stories, and stopped the cycle of pain. Eagle said, "Originally, humans



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noticed, or sensed, as the stars sensed and noticed. Let's get the people to look up again and notice—just notice."

Eagle, Owl, and other winged creatures decided to gather and sing as strongly as they could high above the human family just as the night was coming—when typically you might see the first star shine, around that special time of transition, when night and day are one, and all the relatives are ready for change, for the dark to fall, or for the light to go. The winged relatives shared all these stories high above the people, causing some of them to look up. Stars sensed humans looking up at them, and soon, with the help of all the other relatives—with the plant people, Mother's Breath, Cedar Tree (from whom humans gathered for their clothes and tools), river people (stones, freshwater, cleansing areas)—got really busy at that time too, and decided to spread that message to the humans to look up. Salmon also talked to the humans, since they knew humans were hungry and had to eat. "Look up" is the message the humans received from eating Salmon.

Soon, humans and star people began to seek and be curious about noticing and sharing stories, and what we might call a *reconciliation* happened. Humans and stars began sharing stories of light, sharing stories of being in the dark, remembering stories of being able to see in the dark. Finally, all the humans and all the other inhabitants began looking up to the sky at night, while stars gathered into their constellations, groups sharing their stories, sharing their light, showing their direction.

Things have changed quite a bit since then; but what hasn't changed since the stars came back, since Eagle sensed, noticed, then remembered and spread that message, is that humans still look up to the star people even when it's cloudy. People still look up to that light in the dark even when it's raining. People still look up and notice constellations and groups of stars sharing their stories.

That's the end of the story for now. This Creation story goes on and on, and can last for days, as it explains many things, many dynamic relationships, and other interconnected Creation stories.

That darkest of times demonstrates a true collaboration among the star people and the human people, and the winged relatives, Eagle, Salmon, river people, plant people and Mother's Breath, and others. Repairs and reconciliations among different relationships have happened since then, and one thing that's steady and consistent is that people still look up and that the stars are still noticing us, as well.

There are many way to interpret this story—many reflections. That moment when humans started looking up again holds an interpretation: There must have been stiffness, aches in the back of the neck and elsewhere in the body. Human bodies have needs too, supported by how we forage for plant medicines, go fishing or hunting or gathering, connect emotionally and spiritually with plants, rivers, Salmon, with the eagles when we notice them flying above us. The comfort of knowing that the eagles that we notice are the descendants of the eagles that our ancestors noticed as well, the wisdom in sensing and noticing the first stories, and the love in all those relationships among our relatives—and seeking the love and light inside of people, and noticing the cries for help, the cries for connection, the cries for reconciliation.

Another interpretation is how when you're feeding a baby (bottle or breast), oxytocin floods your body, and you feel like you want to go to sleep. Feeding a baby brings feelings

It's time for us to look up together, provide sustainable services to one another. And we can't talk our way to healing—we must sense it and notice it and feel it.

of calmness and peace inside. The desire to connect, care for, and nurture causes oxytocin to flow. When you're eating and your baby wants you to hold them, it's because the baby knows about the oxytocin effect and how they'll get more nourishment because oxytocin is present. The baby wants to sustain their own life, which means your health matters most. This is reflected in Salmon giving the messages of "look up, look up, look up" and "notice" and "care" as they swim and listen to the river—it's the benefits of looking up, and it's also the benefits of eating this Salmon.

Another reflection from this story (and there are many more) is how, as Indigenous peoples, we are losing so many to suicide, disease, and addiction—and how, recently, the remains of thousands of Native children have been found on the grounds of former boarding schools in Canada. This reflects the story's dark time, when human and star stories were not being shared, there was no connection to Mother Earth's inhabitants or each other (there was only a focus on the self), and there was endemic sickness. The pandemic of self-medicating and young people dying and causing harm to themselves and each other are today's *not-looking-up-anymore*. Whether harm happens on purpose or by accident is irrelevant, because the truth is, they were causing it to happen. Harm is on humans whether they are looking down at their devices or self-medicating or committing suicide—and it comes from not being in good relationship with the plant people or Eagle or prayer or whatever else they are neglecting.

That part of the story carries a lot of pain and reminds me of the possibilities we can begin to seek again. Now is the time for us to share, listen, integrate, reclaim, and reframe our stories. It's time for us to look up together, provide sustainable services to one another. And we can't talk our way to healing—we must sense it and notice it and feel it. Being able to care during this pandemic and civil unrest among all of Mother Earth's inhabitants is an act of radical compassion as well as an example of *somatic spoilage*.[1] Wisdom of the helper is reflected in the story when Eagle shows insight and provides reframing of the stories for the stars and the humans to reclaim their relationship. There is always someone demonstrating love, care, and authenticity during times of crisis, which interrupts trauma or becomes a catalyst for transformation for humans. When this happens, we are invited to look inside and do the reflection or partner with the relative. This happens in the story many times, when it describes how we can't go into special places of our hearts and minds by ourselves. It took the stars grouping together into constellations for the people to see the stories and directions. And stars had to be telling a story in order to gather into groups in order to become constellations—just as the people down below needed to group together in order to look up in order to share their stories for wellness.

It is the same for humans now: we need a witness, we need a partner—whether it's a colleague, a friend, a sister or brother, an uncle, an auntie, a grandparent, nephew, niece, child, plant. We need somebody in order to go into that story inside of us. We need someone to go into that moment with us in order for us to get there. As humans, we can't go into certain parts of our heart for redemption or into our body for reconciliation, for forgiveness, for grief or sorrow, for love. We just can't go into certain parts on our own: we need another being with us on those travels.

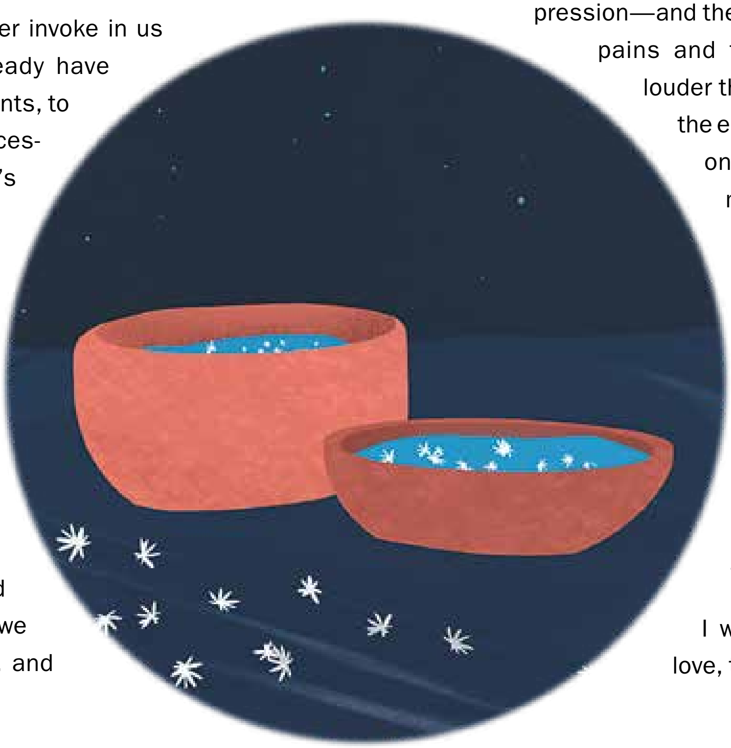
Trauma clusters into constellations in our bodies as the stars cluster in the sky. If we don't deal with it, then heal, then integrate our stories, we cannot "light up" again. When we begin to sense more, notice, and then share more of our human stories—of navigating our healing journeys of emotional, spiritual, physical, and mental abundance-seeking—then we can look outside to our other relatives, to Mother Earth's inhabitants, including plant medicines. Mother's Breath is craving visibility, trust, and vulnerability, but humans can't give what we don't have. All the examples we need of order among chaos exist outside of ourselves, demonstrated by Mother Earth and our other relatives. There is a lot of discipline and a lot of trust and a lot of obedience to our natural protocols reflected there. And as the original sentinels of Mother Earth, Indigenous peoples understand the natural laws best. We have an unmatched, beautiful relationship with ourselves, each other, Mother Earth, and her Breath (plant peoples).

I invite you to consider parts of this story shared to be true. And I invite you to reconcile with yourself and with Mother Earth as a partner in a relationship again, as it once was.

I invite you to consider parts of this story shared to be true. And I invite you to reconcile with yourself and with Mother Earth as a partner in a relationship again, as it once was. For Mother Earth, and for ourselves, this relationship is about preservation. It's about partnership. It's an invitation, a call to action. It's about reclaiming and reframing our stories.

Emotional and spiritual health directly affect our mental and physical health, so health justice needs to be inclusive of all our parts and our relationships to all of Mother Earth's inhabitants. This includes Mother's Breath. These plant medicines and power invoke in us the connections we already have inside us to other inhabitants, to the star people, to our ancestors and our grandchildren's grandchildren. In Mother's Breath medicine, tucked-away stories of implicit memories from familial territories, including relationships of trauma and truths for love and connection, are revealed. Entheogenic plants crave for us to trust, be vulnerable, and give them visibility, just as we crave healing, belonging, and the progression of whole-health justice. I've talked a lot about this regarding social justice activism and protest, because as important as it is to not be silenced and to speak out against un-rights, we cannot via protest heal the traumas and existential disconnection without looking at the roots of our pains. Whole healing cannot take place without individual and collective recalibration and recovery from trauma. Our pregnant people have been delivering Indigenous babies while in fear that our babies will be taken from us or not make it past the age of four months. Many things, like this, don't get talked about, which causes suppression—and the more we suppress these pains and traumas and hurts, the louder the silencing becomes and the easier it becomes to silence oneself. Since humans are mostly composed of the element of water—just like Mother Earth—this lack of movement causes dis-ease. In terms of correlation and causation, one's health is dramatically impacted by neglecting the emotional and spiritual self.

I write this from depths of love, trust, and radical humility.



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NOTE

1. "Somatic spoilage" is a reframing and recalibrating of "empathy erosion" to articulate that people cannot, in fact, erode their empathy. Rather, they create and further hold *somatic spoilage* in their bodies, which is at the root of racism, sexualizing or objectifying peoples, and so forth.

SOLANA ROSE BOOTH, Tsymsyan, Mohawk, Nooksack, lives in the State of Washington, USA, where, among her many skills and responsibilities, she is a storyteller, filmmaker, Lineage Medicine keeper, and community leader promoting, cultivating, and integrating Mother Earth and ancestral teachings employing Indigenous healing modalities.

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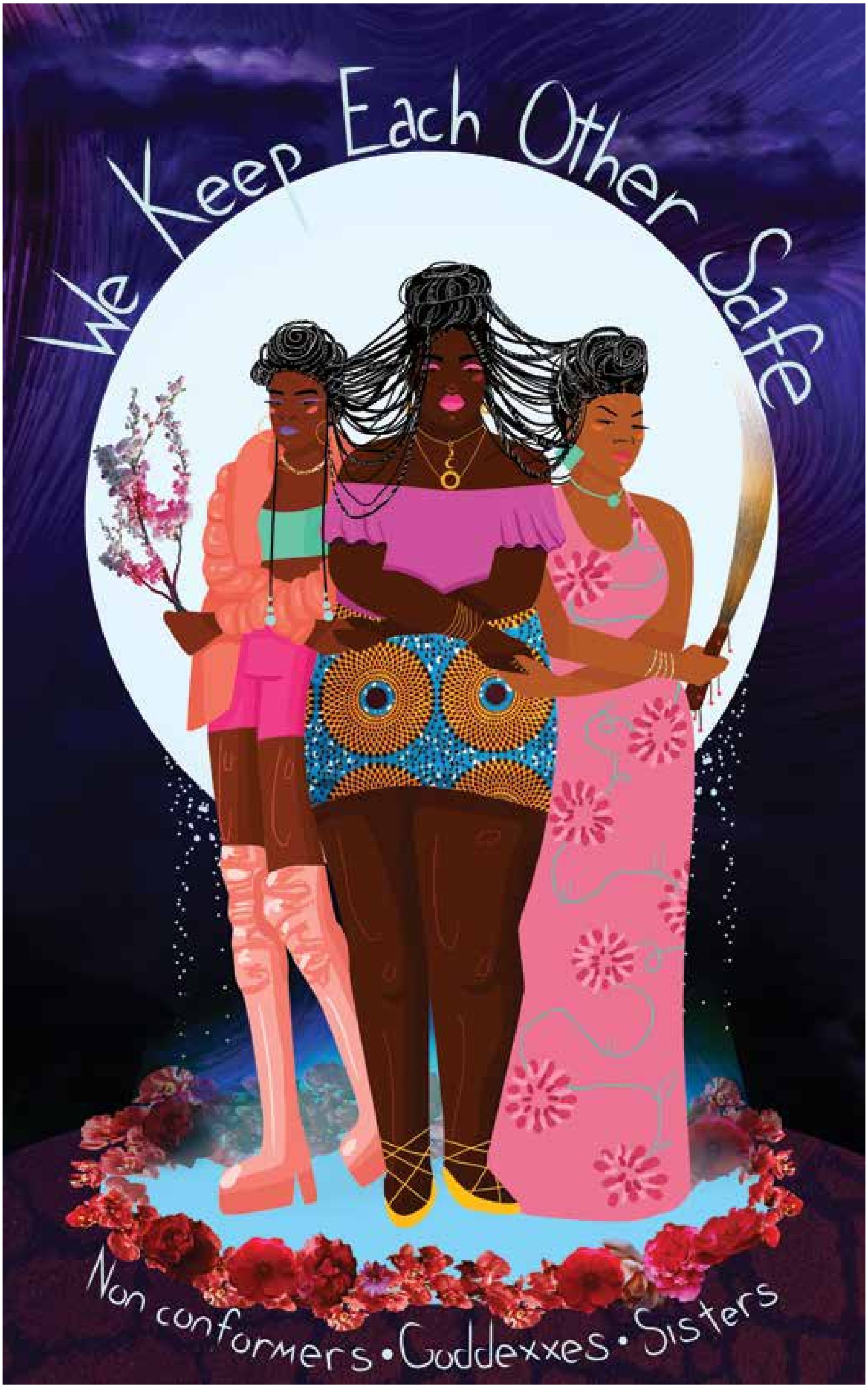

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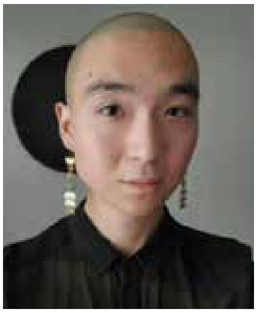

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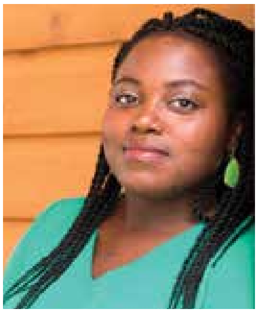

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