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Commentary

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Democratizing care to care for democracy: community care workers and anti-racist public health

Raeghn Draper[1], **Eric Reinhart**[2,*]

[1]The CHAAD Project, Chicago, IL 60612, United States
[2]Department of Psychiatry and Behavioral Sciences, Northwestern University, Chicago, IL 60611, United States

*Corresponding author: Department of Psychiatry and Behavioral Sciences, Northwestern University, Chicago, IL 60611, United States. Email: s.ericreinhart@gmail.com

Abstract

The organization of care in the United States reflects a longstanding prioritization of medical interventions over broader social support systems. This has contributed to widening racial and class inequalities alongside poor health outcomes, weakened communities, and growing social isolation that has created fertile ground for rising authoritarianism. Following on Roy, Hamilton, and Chokshi (2024), who argue for the necessity of addressing the interconnected areas of capital, care, and culture to rebuild US public health, we outline how public investment in community care worker systems can address each of these areas by strengthening their synergistic overlaps and reframing the function of care in society. By recruiting residents of disinvested communities into career positions as publicly employed care workers in their own neighborhoods, such a program would implement a genuinely anti-racist model of public health. This approach is rooted in training and properly compensating members of disenfranchised communities to care for one another rather than perpetuating classist and racist models of care in which reliance on external actors is presumed necessary. By insisting on policies that support the essential interpersonal and political-economic functions of care as public infrastructure, care can obtain a collective ethical and spiritual significance beyond its material effects alone. Implementing community care programs designed to reanimate care in this way could not only dramatically improve health but also revitalize the twinned projects of American democracy and racial equality in a period during which both are under intensifying threat.

Key words: community care workers; public health; anti-racism; democracy; de-medicalization; social care; authoritarianism.

Introduction

Care is not only a fundamental determinant of health but also a critical component of the ethical community and meaning-making interactions upon which democracy depends. Yet, over the last half-century in the United States, care has been increasingly medicalized and professionalized, distancing it from the everyday relationships upon which it relies for its many social and political functions beyond physical health alone.[1,2] As a result, social care—encompassing the interpersonal, preventive, and nonmedical dimensions of care—has been systematically devalued and defunded in favor of high-cost, reactive medical interventions. This has contributed to poor health outcomes while also weakening communities, fueling social isolation and resentment, and undermining public trust. In our resulting era of profound inequality and nihilism in which authoritarian scapegoating of racial and gender minorities is now resurgent, the importance of renewing America's care systems cannot be overestimated.

The United States spends approximately 2 to 3 times more per capita on health care than other high-income nations but suffers from far inferior health outcomes characterized by large racial and class disparities.[3] Public health scholars have argued that more medical care alone, which is estimated to account for only 10%–20% of the factors determining human health in the United States,[4] cannot fix what ails us.[5] Instead, much more political attention and public investment must be directed towards nonmedical social care that is essential for preventing disease, lowering health care demand and costs, and enabling medical interventions to be effective.[6]

It is in this context that investments in community care workers have enormous potential to address interrelated health and economic needs. Amid declining trust in both government and medicine, community care worker programs could play a central role in reinvigorating democratic practices of inclusion and equality, meaningful interpersonal connections, and genuine community in a nation starving for each of these. To achieve these benefits requires synergizing the social, cultural, political-economic, and biological functions of caregiving—a task for which publicly funded community care programs are ideally suited.

At present, America's care systems are notable not only for how they exclude millions of people from receiving care but also for how they typically exclude lay caregivers—that is, those who do not have specialized degrees and are not members of the traditional licensed care professions (eg, nursing, medicine, psychology, and social work)—from providing it. This exclusion is enforced by multiple intersecting actors and processes, including federal and state policies, regulatory bodies, professional societies, and insurance company reimbursement rules. Although no single actor can be assigned sole responsibility for this reality, one important factor is physicians' control over billing in a fee-for-service system

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and lobbying campaigns to protect market share and revenue for various professional groups by opposing "scope creep" (ie, expanded scope of practice for non-physician and non-nursing caregivers). The exclusion of lay caregivers from caregiving is also inflected by a strong cultural pressure, fomented in part by our for-profit health care industry, towards the ever-growing medicalization of social suffering and an associated belief that only licensed health care professionals are capable of addressing it.[7]

When lay caregivers such as home health aides, community health workers, or peer mental health workers are included within current US systems, they are typically underpaid, underutilized, and exploited. We should respond to this fact by re-valuing such community care workers and ensuring them better working conditions and compensation to make their roles into long-term, dignified career positions. Many health leaders instead tolerate maintaining these essential roles as poverty jobs and take them for granted as such, often in part by emphasizing the importance of building career ladders for lay care workers to advance toward traditional professional roles, which are presumed to be more important, desirable, and valuable, as a substitute for providing proper support for community care work.

Such exclusions and exploitation enforced by top-down, market-driven, and excessively professionalized approaches to care exacerbate the demoralization of health care workers and suffering of patients.[8] Given the importance of care to not just the health of the body but also to that of the body politic, this ultimately undermines democracy and constitutes, as the historian of authoritarianism Timothy Snyder has put it, "an invitation to tyranny."[9] By contrast, a care infrastructure organized around community workers guided by principles of participatory and reciprocal care—supported by public jobs with living wages and labor protections—could provide a pivotal means of cultivating trust-building interactions with government and one's neighbors, countering growing economic inequality, and protecting against authoritarian drift.[10]

Participatory care

As the workforce for revitalized public health systems, community care workers would provide essential preventive care and everyday social support to their own neighbors in task-sharing coordination with licensed medical and mental health professionals. This includes home- and community-based care like peer mental health counseling; companionship with empathetic listening to counteract widespread isolation and associated sadness and anxiety; prenatal and postpartum support; health care and welfare navigation; vaccination and basic health screenings; home health support, including for medication procurement and adherence; preventative care for individuals with diabetes; assistance in acquiring groceries and preparing meals; etc—services that are essential for millions of US residents who are disabled, elderly, or live with serious mental illness, for example, but whose basic needs are routinely overlooked by health systems.

Community care worker systems have been shown to be highly effective at improving mental and physical health while substantially reducing health care costs. A large body of evidence for such programs has been generated in low- and middle-income nations,[11] but these approaches to care delivery are no less pertinent for the United States. A model program in Philadelphia, for example, within a single year of operation returned $2.47 in Medicaid savings for every dollar invested and reduced hospitalization days by 65%.[12,13] And amid the clear ongoing failure of the current biomedical approach to mental health that has largely ignored the social determinants of mental health and illness,[14-16] it is also notable that such models of preventive social care have been shown in numerous examples around the world to be more effective, efficient, and equitable than top-down biomedical approaches to mental health that constitute the failing American status quo today.[16-28]

Part of what makes community care worker programs so effective for improving health is what would also make them useful for galvanizing an inclusive democratic ethos and culture of care—namely, their bottom-up design.[29] This enables both more effective provision of care and the inclusion of historically excluded communities in the work of caregiving. The aim of such care systems is, in recognition of the value of both receiving and giving care, to ensure care for all by involving all by training and employing residents of communities with the greatest unmet social, economic, and medical needs to provide care to one another.

Participatory care models, based on the principle of accompaniment and its cultivation of ethical responsibility to one another, reject often-condescending preoccupations with caring for those whom our society has most harmed.[30,31] Such self-affirming humanitarian frameworks often reproduce the very inequalities they are ostensibly meant to address. By contrast, accompaniment-based care systems are instead about caring alongside one another and restoring to communities the resources required to care for themselves. They prioritize local knowledge and lived experience in program design and leadership, and the long-term gainful employment of residents of marginalized communities to care for their own neighbors. Built on principles of radical-democratic reciprocity and solidarity, they put into practice the ethical framework voiced by Aboriginal epistemologist Lilla Watson: "If you have come here to help me you are wasting your time, but if you have come because your liberation is bound up with mine, then let us work together."

Community care and anti-racist systems design

Reframing care as a participatory, reciprocal, and democratic project is essential to implementing an effective anti-racist model of public health. Although anti-racism is widely endorsed as both an ethical and epidemiological principle within public health, discussion of it is often restricted to measuring racial health disparities and then, at best, an ensuing consideration of how we might use existing systems to address them. Embedded assumptions that oppressed, racialized communities must necessarily depend upon the aid of traditional professionals, their class "betters," or "the talented tenth" to reverse their oppression often implicitly—or sometimes explicitly—denigrate the capacities and potential of oppressed communities. Such assumptions reproduce class and racial hierarchies, perpetuating the very inequalities, discrimination, and historical injustices that ostensibly anti-racist initiatives are meant to address.

As part of this process, the necessity of systems redesign that would reconstitute who provides care and how they might do so is often overlooked. This ignores an essential component of genuinely anti-racist public health: confronting and reversing

the erasure of already-existing abilities in dispossessed racialized communities by ensuring that residents are provided with the material resources required to provide effective care to one another. Backed by the forms of community this would support, each individual can be empowered to realize their own unique life potential.

By redesigning public health systems around community care workers who are provided with training, unionized public jobs, and dignified caregiving roles within their communities, such programs would be well positioned to address the interconnected areas of culture, care, and capital that are essential to rebuilding US public health.[32] First, they would support the strengthening of relationships and cultures of care in communities suffering from ruptured social fabric due to ongoing histories of racist oppression. Second, they would provide much-needed care services to members of these communities that feature a disproportionate number of those with disabilities and chronic illness. Third, they would infuse—via gainful public jobs—substantial financial capital into disinvested communities to address the economic determinants of health and opportunity. And, over time, such investments in preventative care would reduce needs for reactive, expensive medical care for which Medicare and Medicaid are often charged, offsetting the upfront investment required to build a robust community care infrastructure.

Putting the "public" back into public health

Despite its obvious benefits, a community care worker program of this kind is unlikely to emerge anytime soon at the federal level, where it would encounter substantial opposition from health care lobbies and where the neoliberal—and increasingly oligarchic—politics of austerity, punishment, and public abandonment exercise far more influence today than the politics of care.[33] This reality makes bold city-, county-, and state-level initiatives all the more important for incubating community care worker programs; demonstrating their effectiveness across health, social, and economic domains; refining their operations so as to maximize their benefits when implemented at larger scale; and providing future political campaigns with effective public health platforms and messaging tools.

Several academic groups and start-up companies have developed and successfully demonstrated pilot programs related to those described above with the goal of improving health outcomes and reducing health care costs. Public initiatives are fewer and further between in an American health landscape shaped by privatization and financial incentives that pervade both for-profit and nonprofit ventures. But, when considering community care worker programs from the perspective of their transformative economic and cultural potential and not only from the perspective of health care costs designed to optimize financial returns to health care payers, public funding and direct administration of community care worker programs appear far better suited to maximize their wide-ranging potential benefits and to bring them to scale. Furthermore, investment in the upfront cost of such programs that have high potential for multiplying returns, both financially and for the good of society, is an ideal use of public funds.

Chicago's Treatment Not Trauma campaign

A community-led initiative in Chicago, led by the Collaborative for Community Wellness, provides one such example of a local effort to build such a system as part of a public care infrastructure. As a coalition of patients, caregivers, mental health professionals, and over 80 community organizations, the collaborative has spent nearly a decade designing and building public support for a community care program, known as Treatment Not Trauma (TNT), meant to be housed within the Chicago Department of Public Health (CDPH).[34] Due to its common-sense appeal and widespread popularity, Mayor Brandon Johnson embraced TNT as central to the campaign that brought him to office in 2023. This gave him a mandate to invest in building an ambitious program for community care—a mandate that, as of yet, remains unfulfilled.

Treatment Not Trauma represents an integrated public health approach to violence prevention, shared safety, and individual and community wellness.[35] It consists of 3 interdependent parts. First, to relieve police of their current misplaced responsibility to function as de facto mental health crisis workers, it calls for CDPH to build out a citywide non-police mobile crisis-response system. Second, it entails reopening the network of 19 public mental health centers that Chicago operated until the 1990s—before all but 5 were subsequently closed as part of the city's defunding and privatization of public health under neoliberal reforms—to now function as crisis reception and stabilization centers as well as community hubs for everyday preventative outreach, neighborhood gatherings, and supportive services.

Third, recognizing that the most important part of addressing crises is to prevent them from ever arising, TNT revolves around hiring and training a large-scale community care worker corps composed of residents from Chicago's most disenfranchised neighborhoods. These care workers are to be trained and employed by CDPH in dignified, career positions (ie, with compensation, benefits, and protections parallel to those currently given to police officers) as peer-support workers working in task-sharing collaboration[36] with licensed mental health professionals in communities with the greatest unmet social, medical, and economic needs.

It is this last part—a bottom-up human infrastructure for community care funded as an essential public good rather than dependent on medical reimbursement—that is the central transformative element of TNT. It is also the piece that has being stripped from the policy by City Hall and the CDPH leadership, which has instead focused on building a non-police crisis-response program detached from a broader preventative community care model. Commitment to ambitious systems redesign and the budget fights it requires appears to be exceeded by the inertia of a severely disinvested public health department alongside a grossly overfunded, overburdened, and corrupt police department. Although the Chicago Police Department was subject to a 2019 federal consent decree mandating a series of reforms within 5 years to address systematic racism and corruption, more than 6 years later just 7% of the reforms required by the US Department of Justice have been implemented.[37,38] Its budget—the second-highest per capita among large American cities—has nonetheless continued to increase each year.[37,38]

Barring new state or federal grants adequate to fund construction of a community care worker infrastructure, implementing TNT as designed will require political confrontation to rebalance the city's budget—an electorally fraught task that, in light of the widespread power of police unions and correspondingly large proportion of local budgets allocated to reactive policing rather than preventative care, is far from unique

to Chicago. This underlines that the obstacles to rebuilding public health are not only presented by our profit-driven health care system but also by an American political tradition of criminalizing poverty, homelessness, and disability as a substitute for investing in supportive social care.[39,40]

To care for democracy

Community care worker programs represent the kind of revamped model of de-medicalized, relationship-based public health that the United States desperately needs.[6,29,41,42] They are also the kind of bold social programming required to foster trust in government and between neighbors during a historical period characterized by worsening social isolation, intensifying racism, growing inequality, and the profoundly fragile state of democracy.

By building systems to support people in caring for one another, we would also, in effect, be building systems with which to care for the future of democratic possibility. To do so, elected politicians and public health leaders must de-medicalize and democratize care while allocating the funding required to build public systems to support its everyday practice in our communities.

Supplementary material

Supplementary material is available at *Health Affairs Scholar* online.

Conflicts of interest

Please see ICMJE form(s) for author conflicts of interest. These have been provided as supplementary materials.

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