ANTI-RACIST APPROACHES IN HEALTH CARE:

Community Health Workers as Catalysts for Change in Health Systems

Center *for the* Study *of* Social Policy
Ideas into Action

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ABOUT CSSP

CSSP is a national, non-profit policy organization that connects community action, public system reform, and policy change. We work to achieve a racially, economically, and socially just society in which all children and families thrive. To do this, we translate ideas into action, promote public policies grounded in equity, support strong and inclusive communities, and advocate with and for all children and families marginalized by public policies and institutional practices.

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Health is a basic human right, and yet, in this country, it is not one guaranteed to all. Systemic racism and a culture of white supremacy have created conditions within communities and in the health care system that actively threaten the physical and mental health of people of color, limit their access to health care, and make the health care they do access less responsive, less effective, and harmful.

Deeply entrenched systemic inequities and generations of discrimination and racism have resulted in policies and practices that segregate, marginalize, and exclude people of color from opportunities to be healthy. In the health care system, these inequities have led to limited access to health coverage and care and differences in the treatment and quality of care for children and families of color.

People of color are far more likely to be uninsured and, due to compounding effects of oppression, face greater threats to their health.[1] Our health care system systematically excludes children and families of color through prohibitively expensive care, eligibility restrictions on subsidized health insurance, and care that often is not attentive to their needs.[2] At times, health care providers threaten the health and well-being of families of color, reducing families' trust in the health care system as a whole.[3] People of color also experience racism and inequality on a daily basis regardless of their education or socioeconomic status, which contributes to chronic stress and wear on their physical and mental health.[4,5] These inequities drive a range of health disparities for Black people in particular, including higher rates of conditions such as diabetes, hypertension, and heart disease than other groups.[6,7]

Health is about much more than health care. It is about a sense of belonging, of community, and nurturing relationships, about access to transportation, child care, healthy foods, safe and stable housing, healthy environments, and opportunities for education and employment. We owe all children and families opportunities for good health. To do this, we have to support communities and create the conditions that promote and prioritize health for all.

This includes a health care system that provides the care essential to leading healthy lives. This means developing a comprehensive health insurance program and dismantling inequities and racism in care and in policies more intentionally. This means expanding and training a diverse, interdisciplinary health care workforce with diversity at all levels including leadership, to ensure people of color are reflected in the decision makers as well as the providers that care for families. This means ensuring that our system addresses the full-range of families' physical and emotional health needs by providing access to timely preventative care; integrating behavioral health into the model of care; addressing racism and factors outside of the medical care system that impact health by connecting families with housing, transportation, income supports,

access to food, and other basic needs; implementing medical training and competency that includes both an understanding of racism and approaches to addressing it at various levels; and establishing performance standards for health systems around systemic racism, anti-racism, and equity.[8] Designing and delivering programs and services in ways that are responsive to the needs of children and families of color by drawing on and valuing community health workers and others with lived experience and expertise in delivering care, is a key strategy for re-imagining health care.

In this brief, we highlight the importance of community health workers and their value as part of an anti-racist approach to supporting individuals, families, and communities most often marginalized and harmed by health care systems. We identify both opportunities and barriers to fully recognizing and integrating community health workers into health systems. Ensuring that community health workers are empowered to partner with and support families can move us closer to transforming our health system into one that prioritizes equity, provides the care children and families of color deserve, and advances health justice for all.

A BRIEF HISTORY OF COMMUNITY HEALTH WORKERS AS CATALYSTS FOR CHANGE

Community health workers have a long history as catalysts for change in traditional health care systems and can play a key role in efforts to advance anti-racist health systems. In the 1920s, community health workers—or barefoot doctors as they were known—began serving as primary health care providers in rural and under-resourced communities in China,[9] and in the 1950s, *promotoras* began providing health care and health resources to the poor across Latin America.[10] In the U.S., the first federal community health worker programs were established under the Economic Opportunity Act of 1964.[11] The oldest community health worker program in the U.S., started in the 1960s, continues today to serve Indian Country, in communities across Arizona, New Mexico, and Utah.[12]

At the heart of the community health worker approach is a recognition of the power that families and communities inherently hold over their own health and well-being. Rooted in traditional understandings of shared responsibility, self-reliance, and self-determination, Black and Indigenous communities have long centered community care as a form of anti-capitalist, anti-colonial resistance.[13,14] In 1965, the Delta Health Center—the first of two community health centers in the U.S.—was established in Mound Bayou, Mississippi. The health center approached health care as a tool for community development and empowerment. Local Black women who worked at the health center as nurse midwives, nurses, physicians, outreach workers, and other staff members, were also patients there, helping to design, deliver, and control their own health. As providers of their own health care, they determined what health care needs should be prioritized, ensuring that the health care system listened to and served them, their families, and their communities. These women created a health center that reflected the values of the Black community when it came to health and health care (and not that of the traditional White medical establishment), and responded to the wider problems (e.g., sanitation, housing, clothing, transportation, and food) confronted by the community.[15]

At the height of the Civil Rights Movement, the Black Panther Party established free community health clinics across the country, linking empowerment and community development, and recognizing local power in distributing comprehensive health care and services to meet the needs of Black people.[16,17] Similar home- and community-based clinics were established around the same time by The Young Lords Party, a Puerto Rican revolutionary group inspired both by the Black Panthers and by *sociedades mutualistas*, mutual aid societies supporting social services, including health care, for Mexican-American immigrants and Indigenous peoples across the Southwest.[18,19] Community health workers in fact have a long history of working in community-based organizations, and even today, most community health workers are employed outside of health care and within community-based organizations, although more are being integrated into health care settings.[20]

COMMUNITY HEALTH WORKERS AS PART OF AN ANTI-RACIST APPROACH TO HEALTH CARE

An essential part of the health workforce, community health workers are inclusive of community health advisors, lay health advocates, *promotoras*, outreach educators, community health representatives, peer health promoters, and peer health educators, among others.[21,22] In 2021, nearly 86,000 community health workers were employed nationally.[23] In this paper, we include the workforce mentioned above, but use a definition of community health workers that is slightly more expansive and includes roles such as doulas and family specialists.[24]

Research demonstrates the value of community health workers who can effectively connect families with public insurance programs, health care, housing supports, and other social or legal services. Community health workers have been shown to improve patients' use of prevention services, medication adherence, and chronic disease management and care for certain health conditions, including mental health, especially for underserved communities.[25,26,27] Among other findings, community health workers improve the use of prevention services among immigrant women and women with low incomes,[28] improve diabetes management for Black and Latinx adults,[29] and support Black women and women with low incomes in initiating breastfeeding.[30] Research also shows that community health workers play a critical role in addressing health disparities in children, including disparities in childhood asthma, which disproportionately impacts children of color and children in families with low incomes.[31] Community health worker programs are cost-effective, reporting an average savings of $2,245 per patient served.[32] These programs have demonstrated savings through decreased use of emergency departments, reduced hospitalizations, and fewer hospital readmissions.[33]

Community health workers support individuals and families as they navigate health and social services, helping identify and address racism and other structural and social determinants of health, and partner with families through strengths-based, relational care that empowers and respects families' knowledge and expertise. Here we outline the unique contributions of community health workers as part of an anti-racist approach to health care.

RACISM IN MEDICINE AND HEALTH CARE

The roots of racism in medicine run deep, dating back 2,500 years.[34] This history is described in detail in several works, including Byrd and Clayton's "An American Health Dilemma: A Medical History of African Americans and the Problem of Race: Beginnings to 1900," and its companion, "An American Health Dilemma: Race, Medicine, and Health Care in the United States 1900-2000." While we won't attempt to describe this history in detail here, we do want to highlight several important points.

Our health care system has a long and sordid history of marginalizing, exploiting, experimenting on, and harming Black people dating back to slavery.[35] By the 17th century, the foundations of racism in Western medicine were well-established with the British colonialization of North America.[36] The institution of slavery deeply affected the health care system in the colonies. Enslaved Africans received medical care only when it was deemed profitable and received care in substandard institutions and facilities. There were, in reality, no standards or requirements for providing health care for people who were enslaved. Theories and mythology of racial inferiority were taught in U.S. medical schools throughout the 18th, 19th, and into the first half of the 20th centuries.[37]

Our earliest hospitals, including the Philadelphia Almshouse, which was founded in 1732, discriminated against and medically abused Black patients.[38] During the 1830s, Samuel George Morton established the foundation of scientific racism with his claims that Black people have smaller skulls and brains. In the mid-1800s, the "father of modern gynecology" James Marion Sims experimented on enslaved Black women without the use of anesthesia. During the Civil War, Black soldiers were relegated to separate and poorly staffed wards if injured. The medical division of the Freedmen's Bureau, established in 1865, was the nation's first federal health program and intended to provide care to freed Black people but White ambivalence and fear that free and healthy Black people would upend the racial hierarchy meant that the Bureau did little to improve care for Black people.[39] Only 120 or so doctors were deployed across the South, and were then ignored when they requested personnel and equipment. The 40 hospitals that were built were quickly shuttered. Jim Crow Laws passed in the late 19th century continued segregated hospital practices; hospitals legally segregated waiting rooms and blood supplies, and entire hospital systems, as well as individual providers, were allowed to deny care to Black patients. As segregated Black hospitals were established in response, with fewer resources and fewer Black doctors, we saw continued inequities and unequal health care.[40] The legacy of segregation lives on as these once segregated hospitals continue today to face challenges, including financial hardship.[41,42]

In the early 1900s, government eugenics programs and forced sterilization laws led to Black women being sterilized in large numbers.[43] In 1910, the Flexner report, a catalyst for the closing of five of seven existing Black medical schools at that time, was published. Over a century later, funding remains a struggle for historically Black institutions. In 1932, the Tuskegee Study experimented on Black men who were told they were receiving medical care for Syphilis, but were never treated, even after treatment for Syphilis became readily available, 13 years into the 40-year study. In 1951, Henrietta Lacks sought treatment at Johns Hopkins Hospital for a tumor on her cervix; she died later that year. Cells from her tumor were harvested without her consent and have been used in biomedical research ever since. More recently, in 2016, a paper published in the Proceedings of the National Academy of Sciences found that White medical students and residents believe that there are biological differences between Black and White people, specifically, that Black people feel less pain. These students and residents exhibited a racial bias that impacted pain treatment recommendations.[44]

Until recently, most people of color were effectively excluded from medical education and training in our medical system, which has meant that people of color are rarely treated by those with the same ethnic or racial background who share their experiences in confronting racism on a daily basis. Today, although many states have expanded Medicaid, people of color are more likely to live in states that have not.[45] Black women and their babies sit at the epicenter of a maternal and infant mortality crisis, due in large part to centuries of systemic and institutional racism.[46,47] And the list goes on. These inequities only begin to tell the story of the history of racism in our health care system that continues to impact access to and quality of health care for Black people and contributes to persistent racial and ethnic health disparities.

COMMUNITY HEALTH WORKERS ARE CATALYSTS FOR CHANGE IN HEALTH CARE

Community health workers are trained to engage with families and communities in ways that are distinct from traditional medical training and practice. They are a different type of health provider, specifically recruited for their experiential expertise, connection to community, and ability to cultivate relationships. Community health workers come from the communities they serve and provide culturally-competent care.[48] Community health workers are relational in their approach, investing time with patients, learning about their needs, and working through both typical and atypical channels to address their needs.[49] Their approach includes an intentionality to ensuring patient needs are met (including those that extend beyond traditional medical care) that is not taught to other care workers. They also bring flexibility to care, adapting or pivoting in response to patients' needs, a value that is not often emphasized in traditional medical training.

As an example, doulas are positioned as disrupters of the medicalized birth experience. Drawing on midwifery models of care, doulas are non-clinical birth workers that provide physical, emotional, and educational support to birthing families prenatally, during labor, and postpartum which results in decreased use of pain medication and greater satisfaction with birthing experiences.[50,51] Doulas disrupt harmful medicalized approaches, such as unnecessary cesarean sections, and help to alleviate families' fears, center families' needs, and advocate on behalf of birthing people[i] in conversations with the medical team. In doing so, doulas recenter the birthing person within their own birthing experience and mitigate the potential for harm. Community-based doula programs serving birthing people of color have seen lower rates of cesarean delivery, which holds a higher risk of adverse birth outcomes, and higher exclusive breastfeeding rates, which are associated with improved parent and infant health and well-being.[52]

Importantly, community health workers operate while embedded within the very systems they are working to change. For example, community health representatives that work on Indigenous reservations are employed by the Indian Health Service (IHS), which is part of the colonial structure upholding systemic oppression of Indigenous peoples.[53,54] Also, given that IHS is vastly underfunded and, in many cases, the only source of health care for American Indian and Alaskan Native families, community health representatives fill in gaps, providing a critical and needed support for many Indigenous families by effectively connecting them to health care, human services, and community resources. In this way, they

[i] We recognize birthing people as women, transgender, and nonbinary individuals who experience pregnancy. We use this term intentionally to be inclusive and acknowledge the broadest group of people who might experience pregnancy. In our society, transgender and nonbinary people experience discrimination in pervasive ways and in all systems including health care. Our choice to use this gender-neutral term acknowledges that historically, we have punished women, transgender, and non-binary people for deviating from gender norms. Doing so is not intended to diminish the experiences of women or mothers, or the power and beauty of motherhood. It is not meant to minimize the systemic oppression that women, and specifically women of color, experience in everyday life and in health care. We recognize and believe it is important to also talk about the ways in which systemic oppression and gender discrimination impact women and mothers. The collective experiences of birthing people, and the intersectional identities and experiences of women, transgender, and nonbinary people are all important. We believe using this more inclusive language opens up space for us to recognize and more fully understand these identities and experiences.

DOULAS IN A POST-ROE WORLD

It's not possible to talk about the critical role of doulas without acknowledging the recent Supreme Court decision to strike down *Roe v. Wade* which has far reaching consequences for people who have historically been oppressed, marginalized, and surveilled by systems. For doulas who support birthing people, it raises many questions and concerns. In states with abortion bans, doulas may be fearful to support people, share what options they have and how they can access those options. They may be reluctant to help people who are experiencing a miscarriage or ectopic pregnancy or to send them to a hospital because, once there, they may not receive the care they need.

In states likely to protect abortions, "abortion doulas" who support people before, during, and after their abortions, are bracing for a significant ramp-up in demand for their services, preparing to increase access to both medical[55] and surgical abortions, as well as educational, legal, financial, and emotional support for people. Some initiatives, like the New York City-based Doula Project, which supports outcomes ranging from birth to miscarriage or the elected end of a pregnancy, are launching virtual programs to enable people to remotely receive doula care while self-managing abortions.[56] Those in states likely to implement new restrictions are finding ways to keep helping women end their pregnancies and looking at how they can support people who are going to have abortions to ensure services are safe, but it will be difficult work and likely take longer to help connect people with care.

effectively work within this federally created and imposed structure while simultaneously challenging the structure and power dynamics on the ground in their work with families.

A broad and deep body of research attests to the effectiveness of community health workers, provided they are resourced and valued in their positions within health systems. A recent international analysis of the research on community health workers described the knowledge of their effectiveness as "incontrovertible."[57] Essential to their effectiveness, however, is that they be resourced, trained, supported, and, most importantly, valued and recognized for their expertise within the practice and as part of the medical home team and as a voice and advocate for the people they serve.

Given the fundamentally distinct orientation of community health workers—who are more relational, grounded in community, and focused on addressing both the health and social needs of families—integrating them into the health care team and system can pose challenges. These challenges include tensions stemming from power dynamics between community health workers and health systems and providers. Often health systems or providers attempt to dictate how community health workers should serve families or constrain or limit the scope of work for community health workers rather than allowing them to do more "socially focused work."[58]

These power dynamics also manifest because community health workers themselves are often members of groups who have been systemically oppressed and underserved. The majority of community health workers are women of color.[59] Their intimate knowledge of the discrimination, racism, sexism, and harms their communities experience when seeking care comes from shared life experiences, often seeking care themselves and navigating the very systems they aim to disrupt.[60,61] In this way, community health workers are subjected to discrimination and bias both as patients and as members of clinical teams. These challenges highlight the importance of shifting health care culture and practice to meaningfully integrate community health workers into health teams and systems.[62]

Community health workers build trust with families. As noted earlier, health systems have a long history of racism and of atrocities perpetrated against communities of color, including medical racism, experimentation, and abuse. While most White people view those in the health system as trusted experts who provide needed health care, the same does not hold for many people of color. The lasting effects of historical trauma in medicine,[ii] combined with the persistence of bias and discrimination that communities of color face when interacting with the health care system are at the root of ongoing and justifiable mistrust of the health care system.[63] Community health workers can help build (or rebuild) trust with individuals and families who have been failed by systems in the past and who feel that systems are not designed to meet their needs by taking the time to listen to and learn from them and ensure that their needs are addressed.[64]

For community health workers working with patients for whom English is not their primary language, language proficiency becomes another critical part of their work, particularly as it relates to trust-building.[65] For patients with limited English proficiency, language barriers result in lower access to and quality of care, and also contribute to lower reported patient satisfaction and trust in their providers.[66,67] Forty-five percent of community health workers are bilingual,[68] helping families by providing language concordant care,[iii] and translating medical information and education.

Given their experience, knowledge, and relational approach to partnering with families, community health workers are able to gather critical information to address needs that may not have otherwise surfaced. In this way, they can promote improved timely use of medical services and better adherence with medical care providers' treatment instructions.[69]

Community health workers promote agency and support families as they lead. Community health workers both inform and support families, sharing valuable information, helping families gain skills as they navigate health and social services, and supporting them in proactively identifying their needs and effectively addressing them.[70] While the power dynamics in our health system typically position the individual as the recipient of care, with limited agency or voice allowed in interactions with providers, community health workers shift that dynamic. By centering families' needs and voices, and supporting families in identifying their own strengths, resources, and often solutions, community health workers create space for families to lead and to harness their power in determining their own health and well-being.[71,72] Community health workers support families as they engage in their own health care and drive change.[73,74]

Community health workers harness community power. Unlike other members of a traditional health care team, community health workers hold an inherent connection to their communities, allowing them to build and create change by harnessing community power.

[ii] Communities of color have been subjected to grossly unethical medical research practices resulting in mistrust of research institutions and the overall health care system. One example is the eugenic targeting and recruitment of poor Puerto Rican women in oral contraceptive research. In one study, the experimental nature of the medication was not disclosed to participants, resulting in the deaths of three women.
[iii] A clinical encounter where the health care provider and patient speak the same non-English language.

With their role on the health team and proximity to health systems, community health workers directly link health needs with the entities that affect them and become powerful advocates for community-determined action. In fact, community empowerment is often a stated commitment of community health worker efforts.[75,76] A summary of the National Community Health Advisor Study identified "building community capacity" as a core role of community health advisors, noting that they often lead or promote community-wide change efforts, in some instances, supporting communities as they actively set and reach a health promotion goal locally.[77] And evidence suggests community health workers are effective at increasing empowerment in communities.[78,79] Just as community health workers promote agency for individuals by supporting opportunities for self-advocacy, they also facilitate opportunities for community control over collective well-being.

Referenced earlier, the Community Health Representative Program in Indian Country employs approximately 1,700 community health representatives representing 264 Tribes.[80] Community health representatives serve as health promoters and a bridge between tribal members and the health care team. This program is community-directed and -centered. It embraces tribal self-determination, asking tribal leadership to select community health representatives and to define their scope of practice.[81,82] The majority of community health representative programs (95%) in Indian Country are led by their respective tribes.[iv] They design health interventions that incorporate community perspectives drawn from their unique relationships with individual community members, local health care providers, and tribal leadership—thus facilitating community control over well-being in sovereign communities that have historically been and continue to be subjugated.

Importantly, community health workers are also often housed in community-based organizations, such as the United American Indian Involvement, Inc. (UAII) in Los Angeles, CA, which serves American Indian and Alaskan Native families in Los Angeles County who do not reside on reservations of their affiliated tribes. During the pandemic, Los Angeles saw sharp increases in food insecurity, housing instability, slow job recovery, and the replacement of in-person health services with telehealth services. Witnessing the disproportionate toll of the pandemic on the local American Indian community, UAII mobilized its community health workers to support American Indian families and connect them with community resources and systems of care.[83]

[iv] In years past, oversight, training, and capacity building for Community Health Representatives was managed nationally by the Indian Health Service (IHS).

Community health workers diversify our health workforce. In 2019, Black, Latinx, and Indigenous people remained notably underrepresented in the health care workforce. Specifically, Black people represented 12.1% of the entire health workforce (across 10 health professions), ranging from 3.3% of physical therapists to 11.4% for respiratory therapists.[84] The majority of people of color in the health care workforce hold entry-level positions, which are often lower paying jobs with little opportunity for advancement.[85] Together, Black and Latinx people comprise over 30% of the U.S. population but make up less than 11% of all practicing physicians.[86] In particular, Black women are heavily concentrated in the lowest-wage and most hazardous jobs, including those that expose workers to biological agents such as viruses, heavy lifting of equipment and patients, and high-stress conditions such as long hours and night shift work.[87] Among community health workers, 45% are Hispanic/Latinx, 20% are Black, and 10% are American Indian/ Alaska Native.[88]

The many benefits of a racially and ethnically diverse health care workforce have all been well-documented, including greater patient satisfaction; increased trust between provider and patient; and improvements in health, access to care, relationships, and communication.[89,90] Community health workers improve families' experiences with health care and access to health services and community resources,[91,92] in part, by recognizing and mitigating discrimination in health care.[93] Recent research shows that experiences of discrimination in health care are common; 1 in 5 Americans report experiencing unfair treatment in the health system.[94] A 2020 survey by the Kaiser Family Foundation found that 7 in 10 Black adults reported race-based discrimination in health care happens at least somewhat often, and one in five have experienced it in the last year.[95] Black women, and in particular Black mothers, report experiencing even higher rates of discrimination in health care settings with 37% reporting unfair treatment in health care in the past year because of their race.[96]

Community health workers can help to improve practices within health care,[97] often taking a leadership role in helping to educate those with traditional power (e.g., doctors and health executives) about structural racism, root causes of inequities, and the experiences of people who face compounding stressors including racism, discrimination, and barriers to economic stability.[98,99] A health care workforce that is representative and reflective of the communities served can often ensure that families are heard, reduce families' cultural, linguistic, and systemic barriers, improve families' experiences in health care, and contribute to improved cultural-responsiveness, increasing understanding of cultural norms, values, and beliefs among other health providers.[100] We should diversify our health workforce at all levels, including physicians, nursing leaders and clinicians, and community health workers, to ensure people of color are reflected in the decision makers as well as the providers that care for families.

Community health workers focus on 'upstream' root causes of poor health. Recognizing that health related social needs (including but not limited to income, housing, food security, access to educational, work, and economic opportunities) drive close to 80%

of variation in health outcomes, health care is increasingly focused on addressing these needs. Community health workers and others in similar roles are often community leaders who work to alleviate structural inequities and improve community conditions that drive these health related social needs by effectively connecting and building trust with families underserved or harmed by existing practices, policies, and systems.[101]

As advocates for families and for systemic change, community health workers can support families in meeting a broad range of social needs outside of the health system, including connecting patients to transportation, housing, financial, and other community supports. Given their deep community roots and ability to build trust and relationships, they are able to forge stronger ties between the health system and community, and expand awareness of the range of services, supports, and opportunities available to families. In many programs, community health workers coordinate clients' relationships with multiple service systems. For example, community health workers maintain connection with clients who are at the highest risk of dropping out of a complicated system (sometimes solely because of multiple competing demands and family responsibilities), and who need extra social or logistical support.

Community health workers are critical to promoting healthy child development. While much of the research on community health workers has focused on adult populations and persons with special health care needs, the greatest potential for rectifying racial inequities and advancing population health lies with children. Children are the most diverse age group and the most likely to live in poor and medically-underserved communities where community health workers are needed. Effectively deploying community health workers is a critical strategy that can address the multiple challenges that undermine the health of our nation's youngest.

Community health workers can have a significant impact on lifelong health by supporting children and their families.[102] Research has shown that community health workers can improve a range of child health outcomes including: managing chronic conditions, reducing child morbidity and mortality, maternal and newborn health, immunization uptake, and helping families enroll in health insurance.[103] As an example, DULCE, an approach based in the pediatric care setting that addresses health related social needs, promotes the healthy development of infants, and provides support to their parents during the first six months of life, specialized community health workers (called family specialists) have been the key to the program's success with participating families receiving on-time well-child visits and immunizations more frequently and using emergency room care less than non-participating families.

THE CRITICAL ROLE OF COMMUNITY HEALTH WORKERS DURING THE PANDEMIC AND BEYOND

The COVID-19 pandemic brought into sharp relief the existing inequities in our systems, exacerbating barriers, creating new ones, and intensifying challenges with far-reaching implications for the health and well-being of communities of color. Due to longstanding historic and systemic inequities, people of color are more likely to experience stressors resulting from food insecurity, housing concerns, financial instability, and other hardships during the pandemic. Since the beginning of the pandemic, a growing body of research has consistently documented the disproportionate toll of the pandemic on people of color, including increased risk for exposure, as well as higher rates of infection, hospitalization, and death.[104] These stressors have contributed to declines in mental health, and were only compounded by concerns around lack of health coverage, cost of care, and barriers to needed care.[105] This is especially a concern for Black and Latinx parents who faced even greater financial instability and hardship during the pandemic.[106] Many families did not receive preventive visits and did not utilize health services for children.[107]

While the worst of the pandemic may soon be over, many of its effects linger. Even when it has passed, much can be learned from what the pandemic revealed about our systems, institutions, and policies. Reflecting on the pandemic, one thing is clear: Solutions to problems are best led by those in communities most impacted.

Not surprisingly, community health workers emerged early on as "essential" front-line workers in the public health response to the pandemic. When in-person office visits were restricted, community health workers were able to pivot quickly and connect with families virtually via video conference, phone, text, and email.[108,109] In many communities, community health workers took charge of contact tracing and follow-ups, particularly for individuals and families without working telephones. In Navajo Nation, community health representatives who have a long history of working with patients with limited access to health services were key in planning the broader pandemic response efforts. They were able to extend their traditional role to encompass long-term emergency response. They quickly identified the most underserved members of their community, reached those who were otherwise unreachable, and ensured that resources made it to the families that need them.[110] In Los Angeles, UAII's earlier mentioned community health workers mobilized quickly to deliver personal protective equipment, food baskets, take-home tests, sage for smudging,[111] and assisted with telehealth appointments, promoted vaccinations against COVID-19, and provided social and emotional support to the city's urban Indian population during mandated lock downs.

Community health workers were and continue to be a critical workforce for encouraging community members to seek the COVID-19 vaccine and stop the spread of the virus.[112] While a range of access barriers to vaccination exist, these barriers are further complicated for communities of color that have historically been marginalized or harmed by health systems, and also, disproportionately affected by disasters and public health emergencies, including

COVID-19.[113] Barriers to vaccination, including difficulty registering for online appointments, inflexible work hours, lack of transportation to and from vaccination sites (some far away), language barriers, and proof of eligibility requirements have posed disproportionate burdens on people of color.[114]

When the COVID-19 vaccine first became available, Black and Latinx people were less likely than their White counterparts to receive a vaccine. However, the data suggest that these disparities are narrowing over time with recent reports showing that the share of vaccinations reaching the Black population is similar to their share of the total population and has reversed for Latinx people.[115,116] Even so, there is a need for continued focus on addressing access barriers for those seeking to be vaccinated. Surveys by the Kaiser Family Foundation suggest that many Black Americans continue to face barriers to vaccination.[117,118] With booster shots now widely available, and eligibility for vaccines expanded to all individuals ages six months and older, our focus must remain on ensuring equity in the uptake of booster shots and in vaccinations for very young children.[119] While it may be too early to tell, some of the same barriers that led to disparities in vaccination rates earlier in the pandemic may again be contributing to disparities in booster rates.[120] What we do know is that community health workers have been pivotal to vaccination efforts, helping to improve access and reduce logistical barriers to vaccination, while also providing outreach and education.[121,122] They will continue to be critical to ongoing vaccination efforts.

COVID-19 AND THE PANDEMIC RESPONSE

Recognizing that community health workers are an essential part of our public health infrastructure and COVID-19 pandemic response, the federal government has made several key investments in this workforce. Importantly, in May 2021, the Department of Health and Human Services announced the availability of nearly $250 million across two funding opportunities to develop and support a community-based workforce to serve as trusted messengers sharing information about vaccines, increasing COVID-19 vaccine confidence, and addressing barriers to vaccination for individuals living in “vulnerable” and “medically underserved” communities.[123] The Centers for Disease Control and Prevention released another federal funding opportunity in July 2021, dedicating $330 million to support community health worker services, including programming, training, technical assistance, and evaluation, that address disparities in access to COVID-19 related care.[124,125] These funds can be used to support strategies tailored to populations and areas facing persistent racial, ethnic, and socioeconomic health inequities.

Several state Medicaid agencies have conducted COVID-19 vaccine outreach to their beneficiaries citing specific strategies including asking Medicaid Managed Care Organizations (MCOs) to adopt a community health worker model to assist individuals with disabilities, those experiencing homelessness, and other marginalized populations.[126] In this model, frontline workers, usually from the community, provide health education and connect individuals to services. In North Carolina, 400 community health workers were trained and deployed as part of its COVID-19 Vaccine Roadmap.[127]

As the pandemic winds down and we enter a new era in which we must adapt to the persistent presence of an endemic, community health workers will continue to be key in connecting children and families to vaccines and essential health and supportive services.

COMMUNITY HEALTH WORKERS IN ACTION

Our definition of community health workers is inclusive of a range of roles such as family specialists, community health representatives, and doulas. Here we highlight three examples of community health workers in action, all providing vital services and supports to children and families.

Developmental Understanding and Legal Collaboration for Everyone (DULCE). DULCE is an innovative evidence-based approach based in the pediatric care setting that proactively addresses health related social needs, promotes the healthy development of infants, and provides support to their parents during the first six months of life. DULCE currently operates in 13 sites, many of these in communities that are under-resourced and often marginalized by racist systems. DULCE leverages six core anti-racist strategies to advance equity and address the root causes of inequities including, ensuring that families are at the center, building trust through family specialists (specialized community health workers), and providing access to justice by connecting families to a legal expert.[128]

Data shows that participating families experienced improved access to supports that address health related social needs, received on-time well-child visits and immunizations more frequently, and used emergency room care less compared to control families.[129,130] DULCE family specialists are key to the program's success. They establish trust and build relationships with families given shared community, culture, language, and racial or ethnic backgrounds. The family specialist connects with families during and between routine visits, on average, connecting with families 11 times during the six-month approach. The high touch nature of the role provides the family specialist and, by extension, the health care team, with an understanding of the social and economic stressors facing families, positioning the pediatric medical home to effectively address families' needs.[131]

The Navajo Nation Community Health Representative Program. Established in 1968 and funded by IHS, the Navajo Nation Division of Health employs community health representatives who collaborate closely with health facilities to provide community-based care services to approximately 210,000 Navajo patients both on and around Navajo Nation.[132] As trained professionals and members of the community, community health representatives bridge medical and culturally-based care, providing clinical, social, and educational services. Community health representatives are integrated closely with local health systems, monitoring health, providing health education, and helping connect their patients with clinical and other health-related services, including insurance and transportation needs. The community health representative role extends further during home visits, especially for patients who experience disadvantage, helping with cooking and cleaning or providing aid during adverse weather events. In 2009, the COPE Program partnered with Brigham and Women's Hospital, Partners in Health, Navajo Area IHS, and the Community Health Representative Program to expand the role of community health representatives, providing training targeted specifically at combating health disparities for Diné people who bear disparately high rates of chronic conditions including diabetes, heart disease, and autoimmune disorders.[133] In the years following COPE's involvement, several studies have documented health improvements associated with community health representatives trained under COPE's curriculum.[134]

Harambee Village. Harambee Village in Madison, Wisconsin is a Black woman-founded and led community-based doula agency that provides a safe space for birthing people to have access to the support, compassion, and health care that they deserve. In operation since 2014, the agency provides consulting services, serves private doula clients, and also has an innovative community-based doula program that provides free or low-cost doula support services and programming for families that is funded through grants, in-kind work, service contracts, donations, and fundraising. Harambee Village Doulas provides contractual employment opportunities to local doulas, lactation professionals, students, community residents, parents, and others who are interested in working within the agency. Harambee Village was created as a hub for community doulas, particularly doulas of color. Through the annual doulas of color training initiative, Harambee has provided access to doula training for over 50 doulas in Wisconsin. The program offers mentorship, support and access to information and education for doulas locally and nationally. Additionally, a new in-house Harambee Village doula training and certification program began in 2021. This training is grounded in a reproductive justice framework and is designed to help potential doulas become expert labor support providers, utilizing various methods to build theoretical knowledge and practical skills.

COMMUNITY-BASED DOULAS

Community-based doulas are trained to support birthing people during pregnancy, childbirth, and in the postpartum period. Peer-to-peer support from doulas with similar lived experience, shared culture and language, and dedication to improving their clients' pregnancy and childbirth experience can make an enormous difference to birthing people and infants who are underserved, marginalized, and dealing with compounding stressors.[135] They have an especially promising track record of improving childbirth experiences and outcomes for their clients.[136,137,138]

PROMOTORES DE SALUD

Promotores are trusted individuals who empower their peers in Spanish speaking communities through education and connections to health and social resources. Employing promotores is an important strategy for reaching immigrant communities and promotes positive results within the communities they serve. Promotores use their insights and knowledge of cultural norms to provide relevant health information and education to support Latinx families as they navigate barriers in addressing complex issues and gaining access to resources such as affordable fresh and nutritious foods. For example, the health care application assistance provided through MHP Salud's Navigator Program helps to increase health coverage for children and families.[139]

RECOMMENDATIONS

Community health workers can improve families' experiences in health systems, providing responsive, family-centered care, and helping families navigate health and social services. The critical role of community health workers in promoting health and well-being for communities often marginalized or harmed by health systems, practices, and providers, demonstrates the need to expand the reach of community health worker programs.

State and federal policymakers, health systems, and practices can pursue the following recommendations to build a more robust and responsive community health worker workforce. While our first two set of recommendations are primarily focused on federal and state level policy levers to support the spread, scale, and sustainability of community health worker programs, the last three set of recommendations consider program-level policies and practices that support community health workers.

1 *Identify paths for sustainable financing of community health workers.*

Despite years of evidence of their effectiveness,[140,141] there are few funding mechanisms to ensure the sustainability of community health worker programs. Several federal programs support community health workers, but all are relatively small and together reach only a fraction of the children and families who could benefit. Community health workers are most often paid for by piecing together several sources of funding including time-limited short-term grants and philanthropic funds.[142] The lack of sustainable funding poses challenges for the community health worker workforce and limits the integration and sustainability of these programs into health systems.

Advocacy for sustainable financing for community health workers often focuses on Medicaid, with many community health worker programs targeting improving care for low-income communities and communities of color. Many policy mechanisms may be used to secure long-term funding for community health workers under Medicaid, though the process to obtain funding can be arduous. Pathways to funding community health workers through Medicaid include:

1. Using Medicaid state plan amendments (SPAs) to add community health worker services as a covered Medicaid benefit;
2. Using preventive services SPAs to fund specific community health worker services tied to prevention;
3. Including community health worker reimbursement in Section 1115 Medicaid waivers; and
4. Leveraging managed care contracts to require community health worker services or incentivize them through quality and value metrics.

These pathways each offer tradeoffs regarding the breadth of the community health worker benefit and the ability of the state's Medicaid program to target community health

worker services.[143] States should continue to use these strategies, and others, including Medicaid administrative funds and state and local general dollars, and explore opportunities in Medicaid Managed Care and Accountable Care Organizations, to expand the role of community health workers as part of integrated health teams.

As an example, California recently added full spectrum doula care as a new covered benefit for all pregnant and postpartum people to Medi-Cal, the state's Medicaid program. It will take effect in January 2023 and cost $10.8 million a year with the state paying $4.2 million and the remainder paid for by the federal government. The reimbursement rate for doula care was initially set at $450 per birth—one of the lowest in the nation. Many felt that it was so low, it wouldn't be worthwhile for doulas to accept Medi-Cal patients. Widespread criticism led Governor Gavin Newsom to increase the rate to $1,154 in a spending plan recently passed, far higher than in most other states. Advocates say that adding doulas to Medi-Cal's covered services could help lower maternal mortality rates, especially for Black mothers.[144]

The American Rescue Plan (ARP)[145] provided a critical one-time investment to strengthen the public health workforce, but more is needed. One clear opportunity is to create a state Medicaid option to support the community health worker workforce. A coalition of health organizations has issued a call to action[146] asking Congress and the Centers for Medicare & Medicaid Services (CMS) to develop solutions to support the funding of community health workers. These include calling on Congress to add community health worker services as an optional benefit in Medicaid, as well as an increased Federal Medical Assistance Percentage (FMAP) to incentivize states and territories to provide these services.

Congress should also expand Medicaid coverage to include prenatal, delivery, and postpartum services provided by doulas and midwives. Beyond Medicaid, efforts should focus on changes to state health systems and insurance coverage to ensure that doula services and midwifery care are available to all birthing people who seek more expansive choices in birthing options, irrespective of insurance or income level.[147] Sustainable financing should also support fair and equitable compensation of community health workers that acknowledges and supports them as a valued part of the health care workforce.

2 *Recognize and support the role that community health workers play in supporting young children and their families.*

While most children do not have specific medical diagnoses that require attention, they are growing and developing and their early life experiences play a major role in their life course development. While community health workers are needed for all populations, their biggest long-term impact is with children. This means recruiting, training, and supporting community health workers in partnering with families with young children.

A multi-disciplinary body of research, including from the family support, child welfare, and child development fields, shows the critical importance of strengthening protective factors

for children. The P.A.R.E.N.T.S. science (Protective factors, Adverse childhood experiences, Resiliency, Epigenetics, Neurobiology, and Social determinants of health) highlights the vital roles that relational health and nurturing play in health and healthy development.[148] The six-year Integrated Care for Kids (InCK) Marks Initiative funded by the Robert Wood Johnson Foundation concludes that the greatest opportunity to rectify racial inequities and advance population health lies in child health and in advancing relational health care.[149]

Recognizing the important role community health workers play in supporting young children and families, it is critical to advance family-centered health care and financing of this workforce as a core part of primary care for children. Consider the following actions:

- Recruit, train, and support community health workers to partner with young children and their families, with a focus on strengthening protective factors and supporting parent nurturing.
- Secure sustainable financing within Medicaid and the Children's Health Insurance Program (CHIP) for community health workers as an integral part of the medical home team.
- Provide further career development opportunities for community health workers who want to work in early childhood, child development, and related fields.

3 *Promote the growth of a vibrant community health worker workforce.*

Community health workers serve in a range of roles and possess a unique combination of qualities and attributes, some tangible and some not, like lived-experience and connections to community, empathy, adaptability and responsiveness, and a commitment to social justice. While the diversity in roles and qualities of community health workers is part of what makes them responsive and effective, it also presents challenges for setting standards.

Formal training of community health workers varies widely from on-the-job to community college certificate programs, and there is no national standardized curriculum for the community health worker role.[150] Certification is required for Medicaid reimbursement in select states, but it is not universally required. In an effort to build consensus to better support the full scope of community health worker practice and capacity, the Community Health Worker Core Consensus Project has developed a recommended list of 10 roles and 11 skills for community health workers and endorsed existing knowledge about qualities important for these roles.[151]

Standards, professional development, and certification pathways are needed that support a qualified community health worker workforce without increasing barriers to those with lower educational attainment, those for whom English is not their first language, and others who are the backbone of today's diverse community health worker workforce. Any standards that seek to define high quality community health workers should avoid over prioritizing education over skills, leadership quality, and connection to community.

Recruitment should be based on qualities including empathy and cultural connectedness, aptitude, and ability to engage families. Programs and practices should consider the following actions:

- Use community-based avenues to recruit and hire community health worker candidates.[152]
- Develop clear, inclusive job descriptions that emphasize qualities such as lived experience, connections to community, and relationship-building, rather than a focus on formal education.[153,154]
- Engage community health workers in the development of training and certification standards for the workforce.[155]
- Ensure that certification and training curriculum reinforce the strengths of the community health worker workforce, including building community capacity to identify and address racism and other structural and social determinants of health.[156]
- Consider and address any barriers to hiring, training, and certification, including language barriers for non-native English speakers, as well as fees, travel, and other obstacles.[157]
- Provide training on the job and pay for it.
- Provide opportunities for community health workers to serve as supervisors for other community health workers, to support, coach, and advocate for their peers.[v]
- Provide training, peer support and networking, mentoring and supervision, and professional advancement for community health workers, including pay raises commensurate with experience and career development opportunities, so these become sustainable occupations and careers.[158]
- Provide the training and support needed to ensure community health workers have the knowledge and skills to advance physical, cognitive, relational, and behavioral health, grounded in culturally-responsive, equity-driven, and anti-racist approaches.

4 *Establish policies and practices that value community health workers as part of the health care workforce.*

Community health workers and others in similar roles are trusted members of the community with expertise in supporting families and helping them navigate health and supportive services. Although community health workers play an important role in health systems, they are not equitably compensated or valued for the critical role they serve in health care delivery. Begin by making a commitment to ensuring community health workers are a valued and growing part of the workforce and recognized for the important role they serve in our child- and family-serving systems. Policies and practices should consider the following actions:

- Recognize community health workers as experts based on their understanding of the community's needs, culture, and norms, and involve them in program planning discussions to help inform community health worker program goals and principles.[159]

[v] Promote supervisors who are community health workers or who have a deep understanding of the community health worker role and can support, coach, and advocate for community health workers.

- Ensure community health workers are represented in decision-making, are recognized as key members in providing team-based care, and have the support they need within their organizations to advance changes and to identify and correct institutional or structural biases.
- Establish an emotionally just[vi] workplace focused on person-centered work practices and opportunities for self-care and attention to well-being for the community health worker workforce.
- Provide fair and equitable compensation for community health workers.
- Establish standards for adequate training, ongoing supervision, and opportunities for professional development.
- Support community health workers in bringing community needs and priorities into the health care system and create space for them to develop approaches to wellness and community empowerment, to design or codesign health promotion strategies or interventions.[160,161]
- Ensure that community health workers are empowered to participate in advocacy in the broader community, recognizing their critical role in identifying and addressing barriers to health and well-being and helping promote health equity and social well-being.[162]

5 *Ensure that community health workers are meaningfully integrated into the health care workforce.*

- Clearly define community health worker roles, while also providing community health workers flexibility and autonomy to determine how to carry out their work.[163]
- Ensure that health professionals working with community health workers have a solid understanding of and respect for this workforce, and how they contribute to health teams. This requires a foundational understanding of the history of community health workers, of the role of community health workers in community health, action, and empowerment, and also, of the ways in which community health workers support individuals and families, enhance care delivery and coordination, address non-medical needs that impact health, and improve patient's overall experiences with health care.[164]
- Consider changes in current care processes (e.g., facilitating clear communication by scheduling regular meetings and touch points between nurses, community health workers, and other members of the team) and in infrastructure (e.g., investing in health information technology that can capture data collected by community health workers) to ensure that community health workers are thoughtfully integrated into the clinic workflow.[165]
- Consider providing a professional home for community health workers in an agency or organization in the community but outside of the clinic, to ensure that community health workers have the training, support, and supervision they need, with supervisors who are from the community, and understand community-based work.[166]

[vi] The Icarus Project defines "emotional justice" as policies that protect the emotional well-being of our staff by centering anti-oppressive and trauma-informed practices in our workplace. More here: Vidal, Agustina. "8 Practices for a More Emotionally Just Organization." Rockwood Leadership Institute, November 3, 2016. Available at: https://rockwoodleadership.org/8-practices-emotionally-just-organization-guest-post/.

CONCLUSION

Our health care system is failing children and families of color. We owe it to all children and families to commit to combating systemic racism and white supremacy in health care and to creating conditions that guarantee equitable health for all. Health is however, about more than what we find within the four walls of a health clinic. To ensure that all children and families achieve good health, we have to find effective ways to address all of the underlying barriers to health and well-being, including racism and poverty.

Within health care, community health workers can be a catalyst for change, supporting individuals, families, and communities most often marginalized and harmed by health care systems. They can serve as a bridge between health systems and communities, building relationships between providers and patients, establishing trust with families, and advancing efforts to address inequities in health systems. Their advocacy on behalf of families and communities most marginalized by systems disrupts the status-quo and helps shift power back to families.

It is important to note, however, that despite the transformative potential of this workforce, creating a health system that promotes and prioritizes the health of all children and families will not be possible unless the system recognizes it has work to do, starting with: acknowledging the harms it has perpetrated through racist policies and practices that have systematically disadvantaged children and families of color; establishing policies and practices that work to undo and redress these harms; ensuring that the health workforce understands how racism and white supremacy have shaped health care, is prepared to address inequities, and can partner with community health workers in supporting families; recognizing and actively working to eliminate the entrenched power dynamics that lead families to feel powerless and limit the potential for community health workers within health systems; and committing to advancing policies and practices that support, empower, integrate, and promote the growth of a health care workforce that is reflective of and as dynamic as the communities they serve. These actions will help promote equity in our nation's health care system, bringing us closer to ensuring that children and families are afforded the right to health and can achieve the well-being they deserve.

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