



Community Voices: Recommendations to State Policymakers for Advancing Health Equity

The nation's ongoing fight against COVID-19 demonstrates the importance of community-driven policies and programs to protect the public's health: Vaccine campaigns are more successful when trusted community-based organizations provide care, design outreach campaigns and provide focused messages.^{1,2} As policymakers across the U.S. move to address additional health inequities, community-based voices should be central in setting the policy agenda.

To that end, Families USA interviewed leaders from 50 state- and community-based nonprofit organizations in the winter of 2021-2022. Almost all interviewees were people of color or worked in an organization led by people of color. Informed by their voices, this paper attempts to answer the following questions:

- » *What are the top equity issues impacting communities of color in America?*
- » *What are possible solutions to address those issues within health policy?*

Seven key themes emerged from our interviews with leaders of community-based organizations that highlight the areas of greatest community need and where policymakers should focus their work:

- 1. Equip community organizations to work for equity.**
- 2. Mobilize to fight racism and bias.**
- 3. Address disparities through research and measurement.**
- 4. Provide equitable access to coverage.**
- 5. Provide equitable access to care.**
- 6. Implement and expand culturally competent behavioral health care.**
- 7. End inequities generated by health systems that have ramifications beyond health.**

This paper is organized around these seven themes and describes our findings. It also summarizes the recent health equity policy literature regarding each of these themes together with a review of our interviews. We conclude the paper by distilling our findings into policy recommendations relevant for state policymakers.

Methodology

Our findings represent themes heard from community leaders within organizations that are either embedded in or reflective of communities of color in the District of Columbia and the following 20 states: Alaska, Arizona, California (both in the Los Angeles area and statewide), Colorado, Connecticut, Georgia, Illinois, Kentucky, Maryland, Michigan, Mississippi, Nebraska, New Jersey, New York, Ohio, Oklahoma, Oregon, Tennessee, Texas and Washington. Two interviewees represented tribes, and three represented national organizations with state chapters.

We developed a structured interview tool that included questions about the organizations themselves, the people the organizations served, how the organizations have changed over time, the health issues that most impact the organizations' communities and the top equity issues (including and beyond health) affecting their communities. We then asked about possible policy solutions at the federal, state and health system levels. Families USA interviewed 41 leaders directly through one-on-one interviews and informal focus groups, and contracted with HIT Strategies for professionally led dyadic and triadic interviews with an additional nine interview participants. Following the interview process, we synthesized the responses to identify common themes.

We also reviewed stakeholder-authored literature to determine what priorities leading equity-focused national and state organizations set in 2021 and 2022. We reviewed blogs and articles from leading organizations that serve the interests of people of color; findings from community surveys conducted by UnidosUS, the Asian & Pacific Islander American Health Forum and the National Urban League in partnership with the Alliance of National Psychological Associations for Racial and Ethnic Equity; academic journal articles; national research compiled by health care foundations; and findings of several states' recent health equity task forces.

Findings: Key themes from interviews and literature review

In conducting this research, Families USA sought to draw out perspectives from people on the front lines at the community level in order to better understand the key issues facing communities of color today. We also sought to identify possible solutions where health policy might be used to ameliorate equity-related challenges and issues. Our findings revealed themes that span several issues, with some specific to health and health coverage and others more broadly categorized under racial injustice and discrimination. The common themes — and the areas that are ripe for policy development — fall into the following areas of community need.

1. Equip community organizations to work for equity

The growing movement for racial equity, the alarming impacts of COVID-19 on communities of color and the acute problems experienced by immigrants who have fled unsafe countries prompted many community organizations to expand their focus on health equity in recent years. Some leaders we interviewed said their community-based organizations increased their focus on community and civic engagement, seeing opportunities for the people they serve to help bring about change. Some prioritized intersections between the justice system and health. Many advocacy organizations, especially during the pandemic, increased partnerships with direct service organizations to provide a combination of food relief, vaccine outreach, health advocacy and assistance navigating economic benefits and services.

Other researchers also have documented the growing visibility of long-standing inequities during the pandemic. Communities of color have keenly experienced losses of income in the last two years and rising food and housing insecurity, which contribute to poor health.³ Temporary relief measures like cash payments, the child tax credit and food assistance modestly lessened pain in the first half of 2021, but significant disparities remained, and problems may worsen again in 2022 as pandemic aid ends.⁴ Further, increased violence, including police violence, hate crimes, domestic violence and gun violence, have disproportionately affected low-income communities of color, bringing trauma, grief, injuries and death.⁵

Interviewees noted the importance of community engagement and voice in addressing these intersecting problems. One participant noted:

People writing the policy are so far removed from the needs of those facing inequity. The poorest people should be designing the programs — that might be real health equity. ... Accessibility is a serious issue at multiple levels: People live in dangerous and downtrodden neighborhoods, and they can't easily leave to get services. With low or poor literacy, it is hard to spread the word. A working mom doesn't have health insurance. She also can't get to a food bank because it closes before she can get there, and she doesn't have a way to get food back on a bus.

Community-based organizations play crucial roles in getting resources directly into the hands of the people who need them and building trust. These organizations are vital in developing and implementing initiatives, including vaccine outreach, food distribution, addiction recovery support, housing and the creation of safe shelters from climate change events.⁶ These essential advocates need resources to continue and expand their work.⁷

2. Mobilize to fight racism and bias

The racial reckoning that followed the murder of George Floyd, the massive health disparities exposed by the coronavirus pandemic and the ugly history of racism in health care all push health equity to the forefront of issues that national and local movements must address.⁸ This is evident from literature from the past year and was a major theme of our interviews. Racial disparities in health care originate from racist structures. They emerge, for example, from a sordid history of racist beliefs that certain people do not experience the same pain or are innately prone to illness⁹; and from a history of racist myths that certain ethnic groups were responsible for the spread of diseases.¹⁰

After facing endless years of discrimination, many people of color now live in the places most harmed by climate change, pollution and disasters, and in communities disproportionately experiencing stressors ranging from food and housing insecurity to community violence. Although their living and working conditions cause and exacerbate illness, they lack timely treatment and culturally competent care. People of color make up a large share of the “essential workforce” but most do not have the same opportunities as white people to become health care professionals.

There is an urgent need for change to address the devastating history and continuing impacts of racism. As an article in *The New England Journal of Medicine* notes, “[S]tructural racism has been challenged, perhaps most successfully, by mass social movements.”¹¹ There is much left to correct both from the aftermath of enslavement and the national history of oppression of many ethnicities.

Community leaders we interviewed noted our obligations to tribes among the examples of justice left undone. In the 1950s, Congress aimed to terminate federal obligations to American Indian tribes and relocate people from reservations to urban areas. Though this policy eventually ended, the United States has still not allocated enough resources to tribes to address the shortage of service providers, fix health facilities in urgent need of repair or tackle issues of drinking water and broadband access. The government also does not fully respect tribal rights to land or the importance of cultural practices such as ceremony for healing. An interviewee who provides advocacy and outreach noted:

These are communities who have been told that you have made this sacrifice to the country and in return the federal government will supply you with all your health care needs. But we have seen shortages of service providers across the Indian Health Service and tribal and urban Indian Health organizations that have left people without timely care.

Nearly everyone we interviewed named racism and bias by health care providers and health systems as a top health issue impacting their communities.

Perhaps a lesser known example, pointed out by our participants, concerns the U.S. obligations under the Compacts of Free Association (COFA) between the Federated States of Micronesia, the Republic of the Marshall Islands, the Republic of Palau and the United States. The United States conducted nuclear testing in the Marshall Islands from 1945 to 1958, with widespread health impacts. In exchange for military occupancy of their islands, an extension of the territorial trusteeship agreement between the United States and the United Nations guaranteed the Federated States of Micronesia, the Republic of Marshall Islands and the Republic of Palau would receive financial assistance and medical care, such as through Medicaid. However, in 1994, COFA migrants' Medicaid rights were taken away. After 25 years, Congress finally restored the right to Medicaid in December 2020. Now that Medicaid is again available to COFA migrants, outreach, enrollment and education about the U.S. health care system are major tasks that require translation and interpretation to the languages spoken and understood by COFA migrants.¹² In fact, as two interviewees reported, ***COFA migrants require staff dedicated to serving their communities, not just a language line that provides translations over the phone.***

Nearly everyone we interviewed named racism and bias by health care providers and health systems as a top health issue impacting their communities. We interviewed one peer worker, a refugee who provides behavioral health and emotional support to a refugee community, who commented that the problem in this country is not just structural racism but the regular experiences of ***“structural anti-Blackness.”***

“A lot of people who do the health care work have anti-Blackness built into them. It’s the culture. We live in a culture that is heavily anti-Black, so you get those messages. And so, in how they interact with clients and how they do the service provision, it comes through.”

Interviewees talked about, a lack of trust between providers and patients, implicit bias and lack of cultural competence and cultural congruency, and they described providers not listening to patients or dismissing experiences of the unhoused population. One respondent noted that Blacks and other people of color are disproportionately affected by HIV, but the stigma they and the LGBTQ+ community face interferes with prevention and treatment. Another respondent noted disparities in the care that dialysis patients receive in ZIP code areas where people of color predominantly reside.

Literature supports the findings from our interviews that to combat racism and bias in health professions and institutions, the health care workforce must be diversified.

Pregnancy-related deaths disproportionately affect people of color, and respondents described the insensitivity and outright abuse perpetrated by some providers to their patients, including “obstetric violence” — that is, performing procedures on patients without their consent. Across much of the country, people of color lack access to birthing providers who look like them, including doulas and lactation support providers. A number of state advocates are working on policy initiatives to address these problems and remove barriers to licensure for Black prenatal care and postnatal care workers.

Literature supports the findings from our interviews that to combat racism and bias in health professions and institutions, the health care workforce must be diversified. Health care workers of color are concentrated in lower-level direct care occupations¹³ and greatly underrepresented in both primary and specialty care professions.¹⁴ Having a provider of the same race improves provider-patient communication and care. For instance, it increases survival rates of newborns.¹⁵ Over time, federal and state investments in workforce training, scholarships and loan forgiveness programs could help diversify the health professional workforce.¹⁶

Already, community-based doulas, peer support service providers, and other traditional and community health workers who come from the communities they serve are playing a central role in achieving equity in communities where they have been able to operate. They have proven vital in delivering care and providing contact tracing and outreach during the COVID-pandemic, and they have provided psychosocial supports for many years. These essential community health workers need sustainable funding.¹⁷

3. Address disparities through research and measurement

Medical organizations are just beginning to realize that certain diseases affect people of color. For instance, for years, multiple sclerosis had been thought of as a disease affecting white women because clinical research excluded Black people. Now that researchers understand that Black people are also affected, organizations are working to educate both doctors and patients so they will not overlook disease symptoms in Black women.

Interview respondents named a range of specific medical issues that disproportionately affect people of color, with infant and maternal mortality at the top of that list. Others noted work they were doing for people with conditions that are relatively common in the communities they serve, like diabetes, hypertension, cancer and HIV.

Many respondents noted the need for health care performance data stratified by race, ethnicity and language to better understand disease prevalence, monitor quality and identify program and

policy improvements. As one respondent said, ***“Even just a few qualitative questions would help lawmakers understand the disparate outcomes.”*** Respondents also noted concerns about populations missed in overly broad stratifications. For instance, the broad category of Asian Americans and Pacific Islanders misses the problems experienced by Native Hawaiians and Micronesian Islanders. Most data sets do not include a category for people from the Middle East and North Africa (MENA), so Arab Americans, Afghan refugees and others are classified as white, which does not capture the barriers they face to access care.

A number of studies, including studies conducted during the COVID-19 pandemic, document the need for stratified data that divides diagnoses, interventions and outcomes by race, ethnicity and language. Similarly, many organizations are calling for data on the impact of health issues on LGBTQ+ populations.¹⁸ Health agencies and health systems use disaggregated data to target resources and to monitor the effectiveness of interventions for COVID-19 as well as for other health conditions (that is, preventable mortality rates, late-stage diagnoses, receipt of preventive care, hospital admissions for ambulatory care sensitive conditions and cost-related barriers to care). More states and agencies should use such data.¹⁹ However, while the six racial and ethnic groupings commonly used in national data are helpful,* they still ignore subpopulations and therefore perpetuate injustices. For instance, Native Hawaiians and Pacific Islanders are grouped together in national data, but further breakdowns from some states show shockingly high COVID-19 death rates among 18- to 64-year-old Fijians, Tongans and Samoans (subgroups of Native Hawaiians and Pacific Islanders) that are hidden in aggregated data.²⁰ Health agencies should further disaggregate data to examine health disparities among people from the Middle East and North Africa, subgroups of Asian Americans and various linguistic minorities.²¹

4. Provide equitable access to coverage

A top priority for equity advocates is expanding Medicaid in the states that have not yet taken up the Affordable Care Act’s Medicaid expansion. People of color disproportionately experience coverage gaps in these states and do not have access to care.²² About 1.3 million people of color would gain coverage if the remaining states expanded Medicaid.²³ Without coverage, many people lack access to health care or often face massive medical debt when they do obtain care. Community-based advocates desperately want their state lawmakers to expand Medicaid coverage but are skeptical that will occur. Various interviewees said:

“Federal legislation needs to mandate health coverage expansion because if it is optional, our state is not going to do it.”

“If there is an inch of flexibility in a bill, my state is never going to take it up.” “It is unfair for some states to have access to care, [while] others do not.”

* The six common groupings are: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, Hispanic or Latino, and white.

Another key priority of community-based advocates is to ensure immigrants have access to comprehensive coverage.²⁴ For example, immigrants who were brought to the U.S. as children and who qualify for the Deferred Action for Childhood Arrivals program can get work permits as adults, but they do not qualify for Medicaid or for coverage through the marketplace. Many other lawfully residing children and pregnant people are currently barred from Medicaid coverage for five years. Two states (California and Illinois) have started state-funded coverage programs for children and older adults regardless of immigration status, but in most other states, undocumented people cannot obtain public coverage and must rely on sparse safety net health care services. Many are essential workers who cannot work from home and have experienced disproportionate rates of COVID-19.²⁵ Initiatives are moving in a number of states to provide coverage to at least some immigrants, and community-based organizations are at the forefront pushing for that coverage.

People covered by Medicaid during the COVID-19 public health emergency have maintained stable coverage without going through an eligibility redetermination. However, when the public health emergency ends, community-based organizations fear that many people will lose coverage — even though they remain qualified for Medicaid — due to documentation requirements, paperwork burdens and other administrative barriers, like having to provide income information. Others moved during the pandemic, and their state Medicaid agency does not have the correct address. For people with limited proficiency in English, it is also difficult to fill out the complex forms without assistance. One interview participant described these barriers:

It takes hours to get through an application. ... We have been dealing with a lot of returned mail. No one has a good way to update their addresses. They lose coverage because the state does not know how to contact them.

Workers with job-based health insurance are also concerned about possible cuts in their health care benefits that would result in higher premiums and coinsurance, including for low-wage workers who are people of color. ***“Unions are the best anti-poverty tool,”*** one respondent said, noting that her union is fighting against such benefit cuts.

5. Provide equitable access to care

Interview respondents noted major problems with access to health care, though the specific obstacles varied by community. Hospital closures have left many rural counties without hospital and emergency department care. Some communities are “pharmacy deserts,” and a growing number are “contraceptive deserts.” Some communities have no dentists. It can be hard to find a doctor who can meet specific needs, such as for transgender care. Abortion restrictions, enacted in Texas and Mississippi, also fell hard on people of color who lack access to essential reproductive health services.²⁶ Transportation to health care appointments and for other services is an issue in urban as well as rural communities. Across the country, there is a general shortage of providers who will accept Medicaid.

Literature similarly documents that getting to health services, and being able to use them, involves overcoming significant and worsening hurdles in many communities of color. Hospital closures over the past few years have particularly strained low-income city neighborhoods and rural communities, leaving some of the communities of color that were hardest hit by COVID-19 without timely access to care.²⁷ Although many people welcomed the use of internet health care visits to gain access to less intensive care, the digital divide made such virtual visits impossible for many, pointing to ongoing needs to reimburse for audio-only visits as well.²⁸

Advocates in some states noted long waiting lists for people with developmental disabilities trying to access Medicaid home- and community-based services that are often limited under state waivers. Two interviewees who advocate for people with developmental disabilities discussed these waits.

“They’ve been waiting almost a decade.”

“The biggest thing that impacts families is the difficulty of taking care of a child with special health needs. Often one parent won’t be able to work, and a single parent [caring for such a child] has to rely on government assistance.”

Immigrants and refugees face barriers in obtaining even the public health care to which they are entitled regardless of status. Fears that they would be considered a “public charge” and not be able to qualify for permanent residency, or that they would be deported, have deterred their access. Some have foregone free COVID-19 testing because they did not want to show IDs or proof of residency. Some refugees who are legally entitled to full access to Medicaid asked to be disenrolled due to fears that they would be deported. Further, though federal funding helped the public get immediate care for COVID-19, federal resources have not been provided to help uninsured people with long COVID.

An interview participant who works at a community clinic that has about 12,000 patients with diabetes and serves a large immigrant population reported,

“The last administration caused a lot of stress and many [immigrants] do not want to visit the clinic or apply for public benefits.”

Further, the clinic did not at first receive the supplies it needed to care for its patients initially.

“We only received ten tests and 100 vaccines at the beginning of the rollout. Our positivity rate was at 25-40%, way higher than the county. Why did we receive materials last?”

Language access and cultural competency are major barriers to care, particularly for people from linguistic minorities. The clinic cited above serves people from the Mayan diaspora who speak K'iche, Kakchiquel, Kanjobal, and Mam. Many Mayas have emigrated due to ethnocide during the Guatemalan Civil War, and subsequent violence, environmental decay and economic destabilization. They speak over 20 different languages.²⁹ COFA communities speak eight languages, none of which are translated by the federal government in online health care materials. People from various cultures report difficulties communicating with providers without trained interpreters, and cultural competency barriers, especially when a male doctor is treating a female patient, can limit access to care. About 6 million Asian Americans have limited English proficiency, and 16 million people speak Spanish as their main language. Outreach experience during the pandemic showed the importance of providing culturally appropriate materials in people's primary language.³⁰

Peer workers sometimes help to bridge communication gaps. One peer worker who serves refugees said the focus on preventive care in the U.S. is “anathema in the populations that we work with.” The respondent explained that their cultures orient with health care differently than other populations in the United States:

If you have a problem, you get the doctor to fix it rather than you have to work with your doctor. ... A lot of the clients that I've worked with have had complex medical issues, and that's really related also to their trauma, but their ability to understand what they can do about those complex medical issues in terms of diet, exercise, lifestyle changes is really quite complicated. And so that's why we feel like we need this communal approach where we're able to actually provide wellness support services for our community members.

6. Implement and expand culturally centered behavioral health care

The treatment and services provided for behavioral health — already undertreated and worsened by trauma — have long been inequitable, and the grief and isolation people suffered as a result of the pandemic brought community behavioral health needs to the forefront. An interviewee who works with tribes said,

“People lost loved ones who seemed healthy days before. Loved ones were ill and passed without anyone being there to comfort them.”

The pandemic laid bare behavioral health disparities. Communities of color experienced high levels of mental health distress and a significant increase in drug overdose fatalities, but had limited access to behavioral health care.³¹ Needs assessments that took place in communities of color in 2020-2021 showed that 24% of Native Americans have seriously considered suicide over the course of a month; nearly 40% of Asian Americans need help accessing mental health care; and about 40% of Blacks, Native Americans and Asian Americans had depression and/or anxiety symptoms.³²

The whole country has a shortage of behavioral health care providers, exacerbated in Medicaid because of low provider reimbursement rates. There are even fewer providers who are people of color, who are culturally competent or who specialize in serving children. Interviewees working in twelve different states brought up these shortages. For instance, one noted,

“Kids have no access to inpatient mental health care because these facilities aren’t equipped to handle these kids, and they are coming out worse than how they went in.”

Another said,

“Mental health is a huge issue. It always has been for people of color and it was made worse by the pandemic. It looks like our state legislature is looking into children’s mental health programs, but we need to make sure we are talking about all populations.”

Some states are working to increase diversity in the behavioral health workforce and have noted that working alliances between patients and clinicians are stronger when they are of the same ethnic background.³³ Additionally, some tribes and community-based organizations are urging state Medicaid programs and public health departments to fund traditional healing practices, which center on community healing and recognize historical trauma.³⁴ Some other important areas in need of improvement include the incorporation of language and cultural competency criteria into mental health care provider recruitment, reimbursement of traditional health workers and peer support workers, grants to tribes, and the employment of community-defined, evidence-based approaches to behavioral health care.³⁵

7. End inequities generated by health systems that have ramifications beyond health

We asked interview respondents what issues beyond health and health care most impacted their communities, and how families in the communities would describe their top three struggles. Respondents named the following issues most often:

- » Housing issues, including shortages of affordable housing, homelessness, housing insecurity, overcrowding, lead paint in homes and vacant housing that makes neighborhoods unsafe.
- » Economic insecurity and injustice, including poverty, lack of access to higher-paying jobs or social mobility, lack of paid leave,³⁶ and medical debt.
- » Food insecurity.
- » Structural discrimination and racial stigma (further exacerbated by a lack of diversity in executive positions).

- » Environmental and climate issues, including higher levels of air pollution, a lack of water purity, and the lack of opportunities for low-income communities to use renewable resources.

The following issues were also mentioned by more than one respondent as being struggles for people in their communities:

- » Access to education, hampered by student debt.
- » Dangerous working conditions, including for essential health care workers.
- » Loss of tribal land and ceremony, and problems inherent in a reservation environment.
- » Immigration status and the broken immigration system.
- » Language barriers.
- » Incarceration and the justice system.
- » Violence, including domestic violence.

Respondents differed in their ideas of the role health systems should play in addressing any of these large problems. A respondent in a state that has not yet used Medicaid managed care to address social determinants of health wanted health and payment systems to do so.

“There’s a real barrier to health when I can’t use the medical advice I’m getting and I’m just being told to change behaviors that social determinants make it is impossible to address.”

In another state, some respondents were grateful for food, diapers and other relief that some health systems helped to supply or deliver during the pandemic. Several people spoke of the inadequacy of health care providers’ social service referrals, with front-line staff trying to refer people to social resources that are nonexistent or inadequate to begin with.

Health systems are major economic powers in their communities. Respondents thought health systems should play a greater role in addressing the factors besides health that affect their patients by being good citizens themselves. Here is how one respondent expressed what should be the responsibility of health systems:

We actually have to change the nature of the resources in the communities. Addressing social determinants of health is more than making referrals or connections. It’s about changing the face of the communities themselves in terms of having the resources to take on issues that people face. ... The health care systems have to own up to their own responsibility with regards to whether they have facilitated or actually increased the challenges around the social determinants of health. That includes the fact that they are basically high-priced items. [They

consume] a lot of resources in a given community by the prices that they charge people. Second, [it is] also about how they play a presence in specific geographies, whether they're creating jobs or whether they're exacerbating the problems with affordable housing. There needs to be an honest assessment of how health systems not only address social determinants but how they're aggravating social determinants to the detriment of low-income communities.

RECOMMENDATIONS FOR STATE POLICYMAKERS

In the section that follows, we have consolidated the input we received during our interviews and focus groups and our review of key equity stakeholder literature into recommendations for state policymakers. The recommendations are categorized according to the themes that emerged from our direct community engagement and are focused on the areas of greatest community need where policymakers should focus their work.

1. Equip community organizations to work for equity

States should engage directly with community-based organizations working toward equity. Specifically, state policymakers should be proactive in identifying opportunities to include community-based organizations in policymaking and in funded health initiatives. They should consult community-based organizations that serve and are led by people of color about state health policy initiatives and solicit their comments. In addition, because community organizations may have small staffs, state policymakers should reach out when there are requests for proposals that have the potential to improve equity.

2. Mobilize to fight racism and bias

State health agencies and policymakers should be proactive in efforts to combat racial myths that undermine health care. Overt racism as well as the underrepresentation of communities of color in clinical trials have contributed to race-based myths about who is at risk for various diseases and who can benefit from health interventions. Public health departments can counter myths through disease prevention and disease education campaigns. For example, these should range from HIV campaigns that explain that undetectable = untransmittable (meaning a person living with HIV who has an undetectable viral load cannot

sexually transmit the virus to others) to campaigns that help patients and providers recognize, manage and treat multiple sclerosis in people of color.³⁷ Beginning in 2022, state Medicaid agencies can now cover the “routine costs” of participation in clinical trials, a provision that can help increase diversity in these trials. States should help residents with Medicaid learn about available trials relevant to their conditions and pay for transportation to associated appointments.³⁸

State policymakers should increase the number of professionals in health care who are people of color and ethnic minorities, including professionals in behavioral and oral health. This will require affordable medical education and deliberate recruitment of a workforce that includes people of color. State workforce planning agencies — which can use a variety of federal grants, state assets and funds generated from health care systems — should make this a major goal.³⁹

States should provide reimbursement for community-based doulas, midwives, and culturally centered birthing practices. States should consider options to reimburse doulas through Medicaid at a level of payment that makes doula care a viable career. Reimbursing doulas adequately as a preventive service allows them to bill Medicaid directly rather than under a physician’s billing system and can allow doulas to provide more home visits and a wider array of services.⁴⁰ When crafting certification and reimbursement rules, Medicaid agencies should involve lay birthworkers and individuals representing diverse backgrounds, cultures, and experiences. States can also use maternal and child health block grants to pay for doula care and care routed in traditional and ancestral knowledge. Midwives, associated with reductions in maternal mortality, can be an especially important resource in “maternity care deserts.”⁴¹ Federally, 60 bills have been introduced in the 117th Congress to expand the use of doulas and midwives, including the Black Maternal Health Momnibus Act, which will take a major push to get through Congress and signed into law.

States should fully integrate community health workers (CHWs) into care teams. State policymakers should recognize the broad skill sets CHWs can bring to care teams and should facilitate their employment. CHWs should be at the center of any state certification process, where they can provide valuable input into what works. Medicaid state plan amendments, Section 1115 waivers and managed care contracts can provide an important source of funding for this workforce, and states should ensure that CHWs payment methodologies result in adequate pay for the full scope of their services.⁴²

States may wish to register their support for legislation being considered in Congress, such as the bipartisan Building a Sustainable Workforce for Healthy Communities Act. This would create a long-term funding source to grow the CHW workforce via a competitive grant program for eligible entities (including state and local governments, Indian tribes or tribal organizations, urban Indian organizations, and community-based organizations) to develop or expand CHW programs.

3. Address disparities through research and measurement

States should examine and correct metrics that determine who gets care and improve oversight of health systems. Specifically, states should assure that racial algorithms do not undermine accountability for health systems for underdiagnosing or undertreating conditions for people of color. For example, researchers have found that an algorithm that determines who should get high-risk care management based on their previous health care costs discriminates against Black people who have serious diseases yet low previous health care costs due to access barriers.⁴³ In their quality oversight activities, state Medicaid managed care organizations should assure that managed care plans are not using racially biased medical algorithms to determine who gets care. State legislators can also pass legislation prohibiting the use of biased algorithms and allowing medical professionals to override algorithms when, in their judgement, a patient needs additional care.⁴⁴ Regulators, through hospital and health facility oversight surveys and accreditation reviews, should ensure that health care providers take pain seriously, provide nonpharmacological pain treatment and do not dismiss the expressed concerns of any racial or ethnic groups.

State policymakers should require health systems to measure health care disparities and reduce them. States should ensure that health systems collect data by race, ethnicity and language for all relevant populations in their communities. This may include breakdowns of the Asian American and Pacific Islander population and data on populations from the Middle East and North Africa to better understand health status and barriers faced by various immigrants and refugees, linguistic minorities, and people who have faced long-standing discrimination. States should establish a pathway toward quality improvement that reduces disparities, especially in Medicaid, marketplace plans and publicly funded health care systems.

4. Provide equitable access to coverage

States that have not yet expanded Medicaid for adults and for postpartum people should do so. States that have yet to increase health care access through Medicaid expansion should take advantage of the increased financial incentives in the American Rescue Plan. In addition, states should take the option to provide 12 months of continuous coverage for children as well as 12 months of postpartum coverage following pregnancy.

States should avoid Medicaid losses as the public health emergency ends.

Specifically, states should take action to make permanent improvements that simplify and streamline enrollment processes. When the COVID-19 public health emergency ends, states can improve automatic Medicaid renewals using available data through the ex parte process. This has benefits for enrollees and state agencies as eligible people maintain coverage, coverage gaps and associated costs are limited, and states experience less administrative burden.

States can identify other data sources that will provide updated contact and eligibility information to use in the ex parte process. Leveraging the Supplemental Nutrition Assistance Program (SNAP) is a particularly powerful source for ex parte redeterminations as a significant number of Medicaid enrollees also participate in SNAP. States should also partner with Medicaid managed care organizations to obtain updated contact information.

States should program their eligibility systems so that anyone found ineligible for Medicaid can be transferred to other coverage sources.

Some states allowed remote phone and online Medicaid applications for the first time during the public health emergency. In addition to continuing these practices, states should explore other easy enrollment practices, such as using tax returns to connect people with Medicaid and marketplace coverage.

States should provide health coverage to people regardless of immigration status. States should use options available to them in the federal Medicaid program and the Children's Health Insurance Program (CHIP) to provide coverage to lawfully residing children and all pregnant people regardless of the date they entered the country. Using state funding, they can and should provide health

coverage to people in all age groups regardless of immigration status. A number of states are phasing in such coverage, starting with children and older adults.⁴⁵ Federal legislation currently pending in Congress, such as the LIFT the BAR Act and the HEAL for Immigrant Families Act, would make coverage more widely available.

5. Provide equitable access to care

State policymakers should collaborate with tribal organizations in the administration of health programs. It is up to Congress to appropriate significantly increased funding to the Indian Health Service (IHS), which will serve to address complex issues, including replacing outdated IHS health care facilities or promoting self-governance through direct funding to tribes. However, states can work with tribal and intertribal organizations to partner on the administration of federally and state-funded programs and to maximize the impact of state and federal funds. Many times there are underutilized opportunities for innovation in how programs are administered through state and tribal collaborations.

States must provide language access services in dialects spoken in the community. States should fund both professional interpreter services and community-based organizations to adequately provide language access to all health care services and coverage programs. Consistent staffing dedicated to the community, beyond contract interpreters, is critical to address community needs. States must also ensure that health care facilities are meeting their language access obligations. States and facilities should be aware of smaller linguistic groups for which there are particular national obligations, such as with people from the Federated States of Micronesia. Cross-state arrangements with expert community-based organizations could help serve such groups.

States should work to combat public charge fears. Many immigrants remain fearful that using health care services could jeopardize their own or their families' immigration status. Federal rules and court cases clarify that this is not the case (except with regard to certain federally funded long-term care benefits). States can provide outreach in many languages to assure people that they are welcome and encouraged to use community health services. It is in the public's interest for everyone to have access to health care.

When needed, states should supplement services that are federally matched in Medicaid programs with state-funded services. States should allocate state funds, for example, to provide services to people with disabilities who are on long waiting lists for Medicaid home- and community-based care.

6. Implement and expand culturally centered behavioral health care

States should incorporate culturally centered, community-based models of behavioral health care. This might include incorporating peers as full and respected members of behavioral health teams; providing integrated and co-located mental, physical and oral health care; and providing reimbursement of tribal healing practices and other culturally centered evidence-based group practices. States should examine the benefits, access and network adequacy in their children's mental health programs, enhance services available in schools⁴⁶ and provide dyadic care models (for parent and child) in Medicaid programs. Equally important is that states require both private and public insurers to have adequate behavioral health networks and to actively recruit providers reflective of the communities they serve. As the 988 telephone hotline for behavioral health crises comes online this summer, states must ensure that hotline staff members are able to provide warm handoffs for both crisis and follow-up care and can provide help in all languages spoken in the community.

7. End inequities generated by health systems that have ramifications beyond health

State policymakers should require health systems to be good citizens that combat racial inequities. Health systems should make care readily accessible in low-income neighborhoods, and states should require or incentivize them to meet specific community needs. For example, state planning agencies can determine needs for health centers, facilities licensed to provide emergency services and mobile health units in various communities, and determine what (if any) requirements or financial incentives are appropriate. States can hold health systems accountable for: investing in affordable housing and not displacing it⁴⁷; providing their workers with adequate pay and paid leave; diversifying staffs by examining diversity, equity and inclusion policies; creating workforce pipeline training programs; and addressing social and environmental determinants of health. State health planning agencies

should also require notice and review of planned health care consolidations,⁴⁸ and both state attorneys general and state hospital regulators can act to prevent health care consolidations that would reduce care or impose religious restrictions on the care available to entire communities.

States should improve free and reduced-price care policies and oversight. The federal government requires nonprofit hospitals to provide some free and reduced-price care, but leaves them to set their own guidelines. States should set specific requirements for nonprofit hospitals to ensure they are meeting community health needs assessment and community benefit requirements. In particular, states should monitor financial assistance programs to ensure that nonprofit hospitals are applying the federal tax benefits they receive to direct patient care. States should consider extending free and reduced-price care requirements to all hospitals. People's health should not be shortchanged because they have poor credit histories.

A photograph showing a woman with long dark hair and a young girl with dark hair in a pink plaid shirt. They are both smiling and looking towards a healthcare professional whose back is to the camera. The professional is wearing a white lab coat and glasses. The background is blurred, suggesting an indoor setting like a clinic or office.

Community organizations that serve and are led by people of color can share important insights about how to address the problems they see.

Conclusion

While the challenges of achieving equity are acutely felt at the community level, there are a number of policy solutions that states can take to improve equity and outcomes for communities of color. This paper not only reveals the top issues and challenges faced by communities of color, but it also identifies potential health policy solutions that may provide meaningful progress toward addressing disparities. Through interviews, focus groups and our review of the literature, we have uncovered a vastly complex, intersecting network of systemic failures within health care and beyond that is deeply rooted in racism, discrimination and injustice over generations.

Through the lens of health advocacy, our research reinforces the notion that improving the health of all people in our country and providing them with high-quality and affordable health care requires a careful look at existing health care disparities alongside broader inequities. Community organizations that serve and are led by people of color can share important insights about how to address the problems they see. These organizations know the communities they serve best, and have important experience to lend in developing policy solutions most likely to yield success in reducing disparities. Policymakers must listen to these leaders and enact bold systemic changes to diversify health care workforces, to improve access to care and coverage, and to hold health systems accountable for combatting inequities within health care. More importantly, policymakers can — and must — listen to these voices in order to tackle racial and economic inequities in their communities and beyond.

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