

Advancing Health Justice: Building a Health System that Works for Everyone



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INTRODUCTION

This paper makes the case for an agenda to improve the health of the American people. It recommends: focusing proactive advocacy and engagement initially on state and local government to provide a foundation for a transformational national health justice movement; strengthening the three-legged stool (coverage, quality, social determinants of health) to support a health system that works for everyone; and building a more diverse health justice movement as an essential step to delivering transformational change.

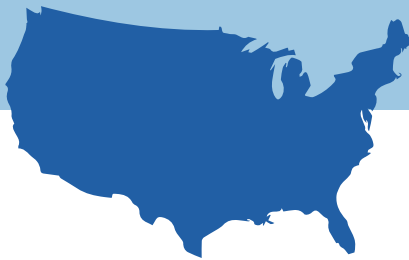
The 2016 election outcome has had a profound impact on the country's politics and culture. In addition to threatening all the gains accruing from Affordable Care Act (ACA)-related health coverage and access expansions¹, it has, to a frightening degree, exacerbated and elevated societal animosities based on race, religion, gender, sexual orientation and immigration status. To be sure, campaigns based on divisiveness and invidious comparisons have long been an archetype for a certain breed of American politicians. However, the crude forms of public communication that have characterized the Trump Administration have laid bare the undercurrents of anger and fear that motivate these political appeals. The effect of this strategic cultivation of divisions is to obscure the commonality of issues and concerns shared by large segments of the population, and to further endanger people who have historically been subject to discrimination.

It is true that the 2018 midterm election results have stalled congressional efforts to repeal or cut the ACA, at least for the time being, but administrative and judicial attacks

continue. In the longer term, the issue of health care as a right is far from settled, as are the questions of who gets what and how it should be paid for. Equally critical is the persistence of differences in health care coverage, quality and outcomes based on race and ethnicity, age, disability, income, education, gender and gender identity, and community/neighborhood of residence – differences that have been magnified by the current hostile environment. Political strategies that undermine protections for disadvantaged groups are guaranteed to exacerbate disparities in health and health care quality. And political strategies that weaken national standards for health system performance are guaranteed to exacerbate existing geographic disparities in health care access and outcomes, resulting in a health care system further differentiated by geographic region.

The counterweight to these malignant forces must be a strong, unified health justice movement that has as its principal goals the establishment of health care as a basic human right, and creation of a health system in which everyone has the opportunity to achieve the best health outcomes possible. This requires addressing structural injustices and disparities and ensuring the system is centered on people and grounded in the communities it serves. The question for health justice advocates is how to respond to the current political environment and, at the same time, continue to strengthen the momentum for addressing those longer-term goals. A core element of our response must be building a movement that fully represents the power and capacity of all the diverse populations it serves and asserting shared values of community and equity. This will require policy advocates and leaders from communities most affected by health inequities to invest the time necessary to co-develop a shared, solution-oriented agenda and strategy. Our experience working with advocates across the country who operate in a wide range of economic and political climates suggests that in order to successfully advance the movement for health justice, advocates need to pay attention to the where, what and how of their work: where they should focus their efforts; what broad substantive areas they should focus on; and how they should approach the work.

¹ Provisions of the ACA included tax credits to make health insurance affordable for Americans below 400% of the Federal Poverty Level (FPL) who do not have affordable employer provided insurance, a state option to expand Medicaid coverage to people below 138% of FPL with 90% federal funding and a range of consumer protections in health insurance that protect people against discrimination based on health status, gender, or age and guarantee that health insurance will provide at least a minimum level of coverage.



State-Local Partnerships Ensure Policy Improvements Work

The locus of policy making is a moving target. In our experience, there is an iterative and complementary relationship between federal and state/local action. Often, problems that states or localities identify and address are the first steps in policy progress, and the federal government will follow and create a new federal framework that, in turn, prompts additional state and local initiatives. Advocates have seen this pattern not only with the ACA, but also with children's health coverage, prescription drug coverage for Medicare beneficiaries, insurance market reforms, hospital community benefit, and payment and delivery system reforms. And when major federal-level policy is enacted, states and local communities are the places where the policy is actually put into practice. Examples are the Children's Health Insurance Plan (CHIP) and ACA outreach, education and enrollment work, expansion of school-based health and behavioral health services with Medicaid support, and the rollout of integrated care models for individuals who are dually eligible for Medicaid and Medicare.

Although there may be opportunities for modest policy improvements at the federal level over the next two years (and perhaps greater opportunities further in the future), the divided and highly acrimonious federal political environment means that right now the greatest opportunities to advance a health justice agenda lie at the state and community levels. In part, this is because there are hopeful signs in a number of states – both “red” and “blue” – of some momentum to improve health access, coverage and quality. At the same time though, there are states where critical health programs are under attack, and advocates need to vigorously defend against those attacks. Finally, as noted above, national leadership in health innovation often comes from the states. Future federal action is likely to be built upon state and local innovations.

Focusing attention and resources on state and local efforts also offers the best opportunity to build collaboration between state-level health policy advocates and local organizations and advocates, particularly those that are working with underserved and disadvantaged populations. Collaborative working relationships between consumer and community advocates with allies within other stakeholder sectors such as health systems and health plans can often be built in the more close-knit environments of state and local decision-making. And because states exercise significant policy and fiscal control over many of the essential systems that influence local communities and impact health outcomes (e.g., education, housing, community development, workforce, public health, nutrition), there are significant opportunities to strengthen connections between state and local advocates working on one or more of these areas to promote community health and demonstrate national leadership.

The Pennsylvania Health Access Network (PHAN) works to make the health care system more affordable and accessible for all Pennsylvanians. It promoted recent changes to the Commonwealth's Medicaid program designed to make it easier for individuals newly released from incarceration to access coverage.

In working with some county jails to make sure that was happening, PHAN found that only a small number of enrollments could be verified. With a grant to foster stronger community-advocate linkages, PHAN connected with Why Not Prosper (WNP), a community-based service organization for women reentering the community. PHAN learned from WNP that there were multiple administrative barriers to enrollment, something it would not have known without WNP's connection to people with these lived experiences. While the policy issues have not yet been fully resolved, PHAN and WNP were able to pinpoint the precise nature of the barriers and commit to work jointly to address them in the coming year. A key element in this collaborative advocacy effort is providing advocacy training for the women affected so that they are also part of the effort, which has positively influenced the women's personal recovery efforts. Grant funding and technical assistance facilitated this collaboration.



State-Local Advocacy Partnerships Strengthen the Power of Both Partners

Achieving health justice requires focus in three separate but related areas: health coverage and affordability; access and quality; and the social determinants of health. In essence, these represent the three legs of a stool. All three are necessary to achieve equitable health outcomes and improve financial security.

COVERAGE AND AFFORDABILITY

With respect to the first leg, universal coverage and the elimination of financial barriers to care is foundational. Without it, people are unable to access necessary medical care. But even if they do get care, they often pay a heavy financial price. Lack of coverage contributes to debt, bankruptcy and housing instability. High rates of uninsurance within a community affect not only the health and economic well-being of those who lack coverage but of the insured, as well.

There are a number of approaches to the coverage and affordability challenge ranging from building on the ACA to “Medicare for all.” In the near term though, there are steps advocates can take to move the issue forward at the state, and sometimes at the local level (such as coverage for immigrants through county and municipal health services). Important ones include expanding Medicaid where it has not been done; enacting state-level protections for pre-existing conditions in response to current legal threats; building on ACA affordability provisions with additional premium or cost-sharing assistance; and providing coverage to excluded populations (e.g., those affected by the “family glitch”²; and undocumented immigrants.)

ACCESS AND QUALITY

While the health access and financial security benefits of universal coverage are essential, they are insufficient by themselves to reach the ultimate goal of a truly equitable health system. This brings us to the second leg of the stool – ensuring access and quality. People of color, people with disabilities, people who are LGBTQ, people for whom English is not the first language, and many others often have difficulty obtaining health care that meets their needs even if they have insurance. Provider shortages in urban and rural areas, physical or language barriers, inadequate funding, and lack of diversity among providers are among the factors that limit access to care or undermine the quality of that care.

Idaho Voices for Children (Idaho Voices) leads the advocacy effort to close Idaho’s coverage gap by expanding Medicaid. As part of its strategy to engage constituents in key rural districts, Idaho Voices partnered with Centro de Comunidad y Justicia (CCJ), an organization that promotes community-based efforts to improve the status of Latinos in a state where the uninsured rate among Latinos is over 33 percent. Idaho Voices educated CCJ’s program staff on Medicaid expansion-related policy issues, and CCJ used that knowledge to build new grassroots engagement and establish a storybanking effort. In its community outreach, CCJ quickly learned that many immigrant families were forgoing critical health care and other social services due to potential changes in federal rules about use of government benefits and immigration status.*

After CCJ surfaced this issue, Idaho Voices added—and prioritized—opposing the proposed rule changes as part of its statewide policy agenda. Through this collaboration, Voices has broadened its coalition to include grassroots constituents in key rural districts and elevated the voice of the Latino community in the Medicaid expansion campaign. In November 2018, Idaho voters passed by a 60-percent margin a referendum expanding Medicaid, with the counties in support including those with CCJ-engaged communities. CCJ, for its part, has gained statewide allies and additional resources to work on an important immigrant rights issue. Grant funding and technical assistance fostered this successful state-local collaboration.

* Proposed changes in the ‘Public Charge Rule’ could threaten the immigration status of immigrants or their family members who access emergency Medicaid, Supplemental Nutrition Assistance Program (food stamps) and other services.

²The family glitch is a faulty affordability test that deems a whole family ineligible for Marketplace tax credits if one member has an offer of affordable individual coverage through an employer. The Family Glitch: What Happens to Coverage for Kids? Community Catalyst. <https://www.communitycatalyst.org/resources/publications/document/Family-glitch-flow-chart.pdf?1410541105%20> <https://www.communitycatalyst.org/resources/publications/document/CHIP-Making-the-Case-Sept-2014.pdf?1410541256>. Accessed February 13, 2019.

OUR VISION

**FOR A HEALTH SYSTEM THAT ADDRESSES
DISPARITIES & PROMOTES RACIAL JUSTICE**

**JUST
HEALTH SYSTEM =**

**A HEALTH CARE SYSTEM
THAT WORKS
FOR EVERYONE**



**SOCIAL
DETERMINANTS
OF HEALTH**

**ACCESS |
QUALITY**

**COVERAGE |
AFFORDABILITY**



Enough providers you can get to



Having culturally effective providers



Patient satisfaction



Health care systems support for community health



Connecting people to social supports



Affordable and reliable access to transportation



Affordable premiums



Affordable cost sharing



Has all the benefits you need



COMMUNITY CATALYST



Public Sector Advocacy Influences the Private Sector

New opportunities and risks are emerging as our health care system undergoes a significant transformation in how care is delivered and paid for. Some of those changes could help address long-standing shortcomings in the system by, for example: expanding the use of mid-level practitioners to alleviate provider shortages and improve primary care access; rewarding providers for reducing disparities; and integrating physical, behavioral/substance use disorder health services. At the same time, other changes could make things worse. The overriding concern among advocates is whether the new models and approaches are actually improving care and increasing consumer satisfaction, or simply saving money and shifting costs. For example, improperly designed financial incentives could give risk-based providers³ incentives to avoid patients with complex medical issues, to “red-line” certain communities⁴, or to utilize quality approaches and measures that don’t reflect patients’ needs and preferences or address disparities.

While this concern is present in the private sector, it is especially critical for advocates to monitor public sector models because that is where many of those affected by disparities receive their coverage and care. Making consumers and communities central to the planning and implementation of these new models offers the potential to create a more responsive system that is better able to meet diverse needs. This will require building new structures within the health care system that provide genuine and meaningful opportunities for consumers and community advocates to shape development and oversight of delivery system changes.

Alabama ARISE, a grassroots and policy advocacy organization seeking to improve the lives of low-income Alabamians, organizes and trains consumer and community leaders. When the state government proposed a major restructuring of the Medicaid program using regionally based privately managed care plans, ARISE successfully pressed state policymakers to require consumer involvement in the planning and implementation. The final law required consumer advisory boards for the managed care structure, with ARISE and the Alabama Disabilities Advocacy Program each appointing members. While the new law was never implemented, the state has since sought to expand managed care in Medicaid through a regionally-based health home program. In this go-round, the state has been more reluctant to require robust consumer engagement.

However, the private managed care plans and the state nursing home association, which are participating in the state’s Medicaid reform programs, have proven to be remarkably receptive to placing consumers on their boards and establishing consumer advisory councils, even in the absence of state requirements. Two different home health plan bidders have aggressively sought assistance from advocates in identifying consumers for these bodies. One plan actively engages with its consumer advisory group, including sending its senior leadership to meetings. So far, that plan has responded to consumer concerns by making its website more consumer-friendly and improving its transportation services. Another plan has addressed consumer concerns by instituting new complaint-tracking procedures. Grant funding supported ARISE’s development of these relationships and its efforts to recruit, train and support consumer representatives.

³ Risk-based providers, such as accountable care organizations or forms of managed care, use a payment model that requires the provider to bear some degree of risk for the costs of care and health outcomes. Such providers share in gains and and/or losses for cost of care. Health System Transformation Glossary. Community Catalyst. <https://www.communitycatalyst.org/resources/publications/document/Glossary-8-19-15.pdf?1440096806>. Published 2015. Accessed February 13, 2019.

⁴ Red-lining is the use of discriminatory practices that systematically deny or avoid services to people based on race, neighborhood, health status or other characteristic.



SOCIAL DETERMINANTS

Finally, the social determinants of health – poverty, unequal access to care, housing, geography, employment, education, and structural racism – must be confronted as they are significant contributing factors to health disparities, as well as obstacles to the coverage and quality objectives. We recognize the universe of social determinants is substantial and cannot be fully addressed by the health care system, but there are ways consumer and community activists can productively engage that system to address social determinants.

Some ways that advocates can push the health system to engage in social determinants of health work:

- Engage with local non-profit hospitals in their community benefit process;
- Press Accountable Care Organizations (ACOs) to promote the integration of care and social services in public sector programs, building on trusted community-based services;
- Encourage health system providers and insurers to make mission-driven capital investments in their communities;
- Recruit other health care stakeholders to engage in public advocacy around other social determinants issues; and,
- Actively participate in cross-sector community improvement collaborations acting on the intersectional nature of community health.

Local Health Institutions Address Community Priorities

The Northwest Bronx Community and Clergy Coalition (NWBCCC) is a member-led, multi-issue grassroots organization fighting for racial and economic justice in the Bronx. Poor housing conditions in multi-family buildings were a source of poor health, causing a spike in asthma-related hospital admissions. Recognizing the large community footprint of the Montefiore Medical Center, NWBCCC sought to find a way to connect its interest in building pathways to green jobs for local residents and creating healthy homes to address health needs identified in the hospital's community health planning process.

To prepare the community coalition to approach such a large and complex entity, NWBCCC decided to equip its members with in-depth knowledge through trainings about social determinants of health and the community benefit process. They also shared an analysis of Montefiore's existing finances and community health needs assessment process. NWBCCC then approached the hospital, seeking improved community engagement in the community health needs assessment and support for a healthy homes housing program to remediate poor housing conditions while providing new jobs for the community. The collaboration helped establish the Bronx Healthy Buildings Program and NWBCCC and the hospital jointly pursued and won a new grant to support the Program. Efforts to develop more meaningful and broader community engagement continue. Grant funding supported community training and technical assistance to NWBCCC.



What Matters to Patients Shapes Quality-of-Care Measures

Change doesn't happen without a demand, and creating that demand is the principal task of the health justice movement. An initial imperative is to build a more diverse movement. Our experience suggests this work is most effective when state-level advocates and community-based organizations work together to co-create an agenda for change. We think this is important for several reasons. For one thing, developing a diverse and inclusive health justice agenda requires an in-depth understanding of how policies impact the needs and concerns of disadvantaged and underserved communities. Advocates whose principal operating venues are state agencies and legislatures often are disconnected from community leaders who are working to give voice to community needs and solutions. In effect, we need a movement that authentically values the experiences and knowledge of directly affected communities and the policy expertise to understand what levers must be pulled to make lasting change.

For their part, effective community-based organizations have a deeper, more nuanced understanding of community needs and the people who are working to make a difference. And while they often know what policy improvements would address community needs, they may not have the time or resources to advocate for them. They also may not have the reach or infrastructure to coordinate state-level advocacy efforts that could influence critical decisions about housing, education, public health, etc. However, those organizations operating in communities that consist primarily of historically disadvantaged populations are much more likely to have leadership and membership who are members of those communities – providing knowledge, skills and voices that are essential to the movement.

The national drug overdose crisis and the broader increase in all substance misuse is spurring expansion of treatment. Without strong quality measurement and consumer oversight, that expansion may miss the mark and heighten disparities in treatment and outcomes based on race, ethnicity and income. Community Catalyst recently brought together a diverse group of state advocates and community peer recovery leaders in Massachusetts to learn about quality measurement and empower the group to influence state policies.

An intensive half-day training built their knowledge of the significant gaps in quality measures for substance use disorders treatment and helped them brainstorm advocacy strategies for influencing Massachusetts Medicaid (MassHealth). The group met with MassHealth to describe what treatment and services people with substance use disorders need and what outcomes are important. The group's effective delivery, combining powerful personal stories with policy suggestions, led MassHealth to request their ongoing involvement in defining quality strategies that can improve care and enhance patients' lives.

Strengthening the collaboration between organizations with different skill sets and constituencies not only increases the power of the health justice movement but also ensures that the goal is a health care system that works for everyone. Such collaboration will require that the participants identify and overcome barriers to collaboration so they can together find the value proposition for all. And a more diverse health justice movement with a shared equity agenda and strategy has an important role to play in articulating a set of collective values around community, opportunity and equity. The shared understanding across different kinds of people in different circumstances about the potential for anyone to face health issues can provide a starting point to find common ground and understand the unique harm caused by the uneven ground different populations stand on⁵. This will require a conscious effort to build a narrative designed to secure broader support to advance health justice and contribute to the broader public debate about the political direction of our country.

Parallel to the work that needs to be done to strengthen the collaboration between consumer and community organizations with different skill sets and constituencies, is similar work to strengthen relationships between consumer organizations and other health care stakeholders. While the interests and agendas of consumer and community groups will not always align with other stakeholders, neither will they always conflict. Stakeholder groups are not monolithic – consumers and community organizations can often find individual allies within stakeholder groups. Building partnerships with other stakeholders where possible can create a stronger movement and is often essential to achieving success. In addition, other actors in the health care system will often have important insights and perspectives that can lead to better solutions. For example, patients and physicians may have different perspectives on how to improve quality. However, by developing a shared understanding of problems and working together on solutions consumers and other stakeholders can often create win-win opportunities.

⁵ Ten Lessons for Talking About Race, Racism and Racial Justice. The Opportunity Agenda. <https://opportunityagenda.org/explore/resources-publications/ten-lessons-talking-about-race-racism-and-racial-justice>. Accessed February 13, 2019.

HOW COMMUNITY CATALYST WILL CONTRIBUTE

Over the last 20 years, we at Community Catalyst have had the privilege of collaborating with dedicated and creative consumer health advocacy groups across the country that have won an array of meaningful state and local policy victories and – ultimately – passage of the ACA. The task now facing this broad advocacy community is to take that collective work into the future by addressing the three critical domains identified in this paper: coverage and affordability, access and quality, and social determinants of health. Together, we will also continue to advance policy measures that reduce excessive and low-value health care spending while opposing measures that reduce spending by undermining coverage, access or quality.

More than ever, achieving this ambitious agenda requires a strong, diverse movement for health justice. Historically, Community Catalyst has helped build that movement by providing a comprehensive range of technical and financial assistance to state and local advocacy organizations, facilitating connections and learning among members of that community, bringing state and local experiences and voices into the federal debate, helping advocates and funders understand key developments in federal and state policy and private industry, and identifying and filling gaps in the health care advocacy landscape.

In recent years, more efforts have focused on direct support to local community organizations with training, information sharing and tools to voice their needs and engage more effectively with health care system stakeholders and policymakers. The Community Catalyst Health Justice Fund has consciously directed more financial support to organizations of color finding ways to address capacity constraints that sometimes pose barriers to receipt of grant resources. We have used a “System of Advocacy” approach that has provided both policy advocates and community groups with flexible tools they can strategically adapt to emerging needs and opportunities in their environment. This approach emphasizes the importance of building strength across the spectrum of capacities people need to make policy change. All of this work will continue.

To further the health justice movement, we will undertake new areas of work and significantly increase our level of effort in the following areas:

- Facilitate connections between state and community-based advocacy organizations so they can begin to understand each other’s perspectives and approaches and determine whether there is potential to develop partnerships around joint health equity policy agendas and advocacy strategies;
- Work with community-based organizations, as requested, to address their self-identified capacity-building/technical assistance needs;
- Fully incorporate into our communications and messaging support for state and community advocates strategies to build and articulate a strong narrative of shared values around community, equity and opportunity;
- Provide organized and systematic opportunities, e.g., conference calls, webinars and convenings, for state and local advocates across states to learn from each other;
- Continue to develop and advance a national agenda that supports health equity, including working to ensure that measures that reduce health care spending growth do not undermine coverage or quality; and
- Organize state and local input to both shape and advance that agenda.

Our System of Advocacy

Community Catalyst works with our partners to build each of the capacities and create a system of advocacy in every state. We do this by coaching our partners and grantees and fostering robust learning communities. Community Catalyst offers policy, legal, communications, and organizing and advocacy expertise so advocates are equipped with the right strategies, information and tools to succeed.



In addition, recognizing the particular role that structural racism plays in driving poor health outcomes and in impeding the social solidarity necessary to create a health system that works for everyone, we will place special emphasis on efforts to expand and strengthen the health advocacy community so that its leadership and grassroots are more reflective of all the people it serves.

To strengthen and diversify our movement, Community Catalyst will take the following steps:

- Continue our internal organizational work to recognize and address our own implicit bias and privilege, and gain a better understanding of the nuances of group identity and power dynamics;
- Cast a wide net to identify community-based organizations engaged in social justice work and led by people of color;
- Increase our fundraising and funding for community-based organizations led by people of color;
- Work with state advocates to provide the tools and training needed to engage effectively in health equity work including training related to structural racism in the health system;
- Support leadership development among people of color whether in local or state advocacy organizations; and
- Engage in aggressive fundraising to support both local and state organizations in promoting racial justice in health and health care.

With regard to timing, we have already initiated some of the tasks listed above, and we plan to roll out others in the coming years.

CONCLUSION

History demonstrates that social transformations generally take many years and sometimes many generations. Achieving true health equity is one such transformation. We are confident, though, that there is tremendous interest and energy – heightened in part by the alarm raised by the current political environment – in working toward this goal.

We at Community Catalyst can contribute to this goal by strengthening the power of the health justice movement through building collaboration between organizations with different skill sets and constituencies to better advance the goal of a health care system that works for everyone. A more diverse health justice movement that unites different kinds of people in different circumstances with a shared equity agenda and strategy is fundamental to achieving the transformation we seek.



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