ACCESS, DATA, POWER, AND RESOURCES

A Roadmap To Health Equity

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INTRODUCTION

The COVID-19 pandemic has exacerbated underlying inequities in the U.S. health care system, disproportionately affecting communities of color. Those inequities make it clear that the U.S. needs systemic investment in public and community health systems—focused on serving the most marginalized individuals and communities. In this brief, we provide recommendations based on lessons learned from our shared experiences collaborating at the local, state, and federal level to respond to COVID-19 and address health disparities in the communities served. Our recommendations include four key pillars of health equity that reflect the challenges faced by implementers during the COVID-19 response: **Access, Data, Power,** and **Resources**. By ensuring those approaches include improved access to care, strong data systems, a shift in decision-making power, and access to resources, communities in the U.S. will be able to build a more equitable health care system.

BACKGROUND ON THE COMMUNITY-BASED WORKFORCE COVID-19 RESPONSE

Community-based organizations have been a pivotal piece of the COVID-19 response effort by providing social support to families in need (food, housing, and legal support, etc.), addressing barriers to accessing quality care (through Medicaid enrollment and community health worker services), and providing vaccine educational material through culturally competent outreach. More recently, these organizations have successfully led community outreach and engagement strategies to increase vaccine acceptance and access. Community-based organizations (CBOs) —and the workforces they employ—are a core component of health care delivery. A report[1] released by the Alliance for Strong Families and Communities (now Social Current) found that community-based organizations struggle with capacity needs ranging from data sharing to technology investments to knowledge and leadership exchange to staffing.

Recognizing the need for locally-led solutions, philanthropic, public sector, and community stakeholders have begun investing in expanding and strengthening this critical resource. The National Community-Based Workforce Alliance created a playbook[2] for working with community-based organizations to address COVID-19. Many other organizations have developed community engagement resources[3] including: vaccine toolkits, campaign materials, infographics, highlights of successes in COVID-19 response, successful outreach tactics, and data collection tools.[4] Public health departments across the country have partnered with community-based organizations in developing and rolling out vaccination strategy.[5] The U.S. government has also started to invest in these organizations. In August of 2021, the U.S. Health Research and Services Administration (HRSA) announced grants to community-based organizations to take on vaccine equity across the country.

Many community-based organizations employ a workforce that is critical for an equity-centered approach: community health workers. Community health workers are defined by the American Public Health Association as:[6] "frontline public health workers who are trusted members of and/or has [an] unusually close understanding of the community served. This trusting relationship enables the workers to serve as [an intermediary] between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery." The role

of community health workers are further defined and spelled out by the Community Health Worker Core Consensus (C3) Project.[7] Community health workers are critical as they have made strong contributions that are impactful in empowering communities, ensure equity and promote positive health outcomes that work towards eliminating health disparities.

President Joseph Biden as a candidate released a plan to employ 150,000 community health workers across the country in response to COVID-19 and health equity needs. Although the U.S. government has fallen short of that full commitment by the date of this publication, policy leaders have advanced the conversation with this notion via activities focused on empowering community-based organizations and community health workers. On October 15, the U.S. House of Representatives Tri-Caucus (Hispanic Caucus, Asian and Pacific American Caucus, and Black Caucus) leadership sent a letter[8] to U.S. Department of Health and Human Services Secretary Xavier Becerra, which stated:

> "Whether considering distribution plans for booster shots or increasing the number of people initially vaccinated, community-based organizations are a critical resource in this work. That is why the Department of Health and Human Services must use the remaining funds from the American Rescue Plan to increase the investment in community-based organizations, extend grant periods for this work to allow more flexibility in addressing COVID-19, consider funding for even more organizations to engage in vaccination efforts, and invest in the critical infrastructure that community-based organizations need to succeed."

Despite these community, political, and public health efforts, our nation remains far from achieving health equity. We know the importance of a community-based approach and have seen its success in the communities we serve. Our recommendations on access, data, power shifting, and resources are designed to move closer to health equity in the U.S.

RECOMMENDATIONS FOR ADDRESSING STRUCTURAL BARRIERS AND BUILDING VACCINE CONFIDENCE

Access Equity: Meeting People Where They Are To Break Down Siloes

Public health approaches must be designed to increase direct access to local communities by breaking down barriers, including those related to access to vaccine information, transportation, language interpretation, appointment scheduling, and distance to vaccine sites. According to the U.S. Centers for Disease Control and Prevention (CDC), disparities in initial COVID-19 vaccination access between urban and rural communities can hinder progress toward ending the pandemic. One out of five people in the U.S. reside in rural counties, where adult vaccination coverage was lower than in urban communities; a 38.9% coverage rate in rural counties compared to 45.7% in urban counties. In rural counties, 14.6% of individuals traveled to non-adjacent counties for vaccination, compared to 10.3% of people in most urban counties.[9] Further barriers are presented by lack of trust and lack of culturally competent care; health care providers, academic, and government institutions may not always be seen as trusted sources of information due to historical systemic oppression. Strong community-based workforces are well-placed to mitigate many of these barriers.

Community-based workforces, including community health workers, patient navigators, direct care workers, and outreach workers, are familiar faces in the communities they serve. Trusted messengers from a given community[10] can improve access to vaccine education and materials, equip individuals to make informed decisions about becoming vaccinated, and mitigate barriers presented by lack of trust in the larger health care system. Trusted individuals within communities, such as religious leaders, community health workers, local community organizers, community pharmacies, and barbers and hair stylists, can aid in addressing barriers to vaccine access.[11]

Beyond serving as trusted messengers in vaccine outreach, community-based workforces, including community health workers, have taken on a variety of roles such as contact tracing, health care coordination, community-based testing, vaccine readiness education, and navigation of social services throughout the COVID-19 pandemic.[12]

We recommend that **federal and state policymakers invest in community-based workforces to provide one-on-one outreach to ensure the vaccine is accessible to vulnerable populations and to support local health departments. Funding for community-based workforces will allow communities to leverage partnerships with local organizations and enable community health workers to bring the vaccine to safe and familiar places where people live and work.**

Bright Spot: Cultural Competency Realized Through Community-Based Organizations

Throughout the pandemic, organizations and government agencies have translated their materials and information into Spanish but did not always have the translations checked for reading level and cultural competency. When someone reads materials about the COVID-19 vaccine that have been mistranslated, it creates mistrust in the vaccine and the organization or agency that created the documents. To combat mistrust, community health workers have aided in checking for proper translation and cultural competency in programs such as Día de la Mujer Latina's vaccine outreach efforts.[13] Día de la Mujer Latina is a *promotora/*community health worker organization that conducts community health worker training and health education all over the country with a focus on Spanish speaking and Latinx communities. A *promotora* is a trusted member of the community who is trained on various skills to better guide vulnerable populations to access to care and disease management, and thereby improving health outcomes overall.[14]

Before the pandemic, the organization was focused on adult vaccinations and other preventative health care, such as pap smears and human papilloma virus tests. The group also engaged with communities, for instance, holding health fiestas in Hass County, Texas for 25 years in partnership with the county public health department. The success of these events is in part due to a high level of cultural competency: all social media posts[15] and posters are in Spanish or bilingual; they include a hotline number for community members to register and ask questions.

Over the course of the COVID-19 pandemic, Día de la Mujer Latina created a telehealth community navigation center, which is staffed by trained community health workers and *promotoras* "for debunking misinformation, reducing mistrust, and providing navigation services for our underrepresented multicultural communities for health and social services, including information on vaccines, clinical trials and COVID 19."[16] This call line will soon be a national resource, promoted by Univision and other television stations throughout the U.S., including Puerto Rico, as a part of a broader campaign around COVID-19 and the vaccine called, "No Más, No More," because misinformation and miscommunication causes mistrust. It is clear that promotoras are well positioned to dispel misinformation on the vaccine and build vaccine confidence.

Data Equity: To Better Target Public Health Interventions

Data should play an instrumental role in decision making. However, biases can occur at any point of research, including study design, data collection, data analysis as well as during the publication phase.[17] Common data collection methods, including questionnaires, structured interviews, or medical review, leave significant room for human error and incomplete data. A notable example of data inequities surrounding COVID-19 can be seen in the CDC demographic data tracker, which uses data that is publicly available from state and local health departments. Data sources ranged radically, for example—data sets had a range of missing demographic data, from 0% to 100% of cases reported. When the CDC first reported case demographics in August 2020, 51% of its cases were missing data on race and ethnicity.[18] These gaps in data hinder our shared understanding of how racial and ethnic inequities play out and impact COVID-19.

Beyond understanding larger trends, gaps and inconsistencies in data leave policymakers, public health stakeholders, and community-based organizations in the dark about how to respond to persistent needs. In the case of vaccination, incomplete data makes it difficult to understand who still needs a vaccine and how to tailor targeted vaccination strategies. In the first month of vaccination across the U.S.[19] race and ethnicity were unknown for approximately half the population who initiated vaccination, while certain jurisdictions reported no race or ethnicity data at all. Over time, data collection has improved to some degree in vaccination, but it still leaves gaps. As of November 1, 2021, forty-five states report people who have received at least one COVID-19 vaccine dose by race/ethnicity, however in some cases states still classify the race or ethnicity of certain individuals as unknown.[20]

We recommend that federal agencies, such as the CDC, roll out **high-quality, centralized data collection training and systems to improve accuracy and close gaps in data about COVID-19. An equitable data collection process should be accessible to the affected communities without substantial cost; work universally across platforms; and report into de-identified databases.**

The data collection process is primarily conducted by health care providers, who then report data through pharmacies, state or federal agencies, immunization information systems, vaccine administration management systems, or direct data submissions.[21] In order to streamline that data process, **we must equip providers with the necessary technical assistance and funding to execute a unified data collection and tracking process.** Data equity is necessary to prevent poor quality data collection, which limits the ability of health systems and community-based organizations to pivot when issues arise. If implemented correctly, equitable data collection procedures will empower community-based workforces, outreach workers, and public health professionals to make data-informed and strategic equitable decisions to reach those in greatest need. Unified protocols for data collection across states, including adequate training of researchers, can help to mitigate unwanted biases.

In addition, community-based organizations can be engaged in the development process for data collection and procedures. By understanding the local culture, community-based organizations can help collect accurate data from people in the community, and if provided access to the final data, can help identify trends and interventions that can work on the ground. However, community-based organizations need financial and capacity-building support (in the form of trainings) to supplement a strong data process.

We recommend that **federal and state policymakers invest in improving data collection procedures and utilize data driven approaches in decision-making.** The Biden administration has announced $80M to modernize the public health data workforce and subsequent investment from the CDC in modernizing technology. We recommend that **policymakers ensure these investments are permanent, long-term, and sustainable.**

Bright Spot: Simplified, Equitable Data Collection Can Inform Public Health Interventions

In partnership with the County of San Diego Health and Human Services Administration, 211 San Diego (an existing community information line) has been providing a free, 24-hour, 3-digit dialing code that offers communities access to health, social and disaster services to enable vaccination support. This support includes navigation of COVID-19 related information; connection to community, health, and social services; testing site appointment support and outreach; and vaccination appointment support for those without assistance or access to the internet or someone to help. When vaccination sites began to open, 211 San Diego received its highest volume of inbound calls in its history—14,000 calls in one day—from people inquiring about how to make appointments.

211 San Diego's community information exchange system enables it to collect and track trends and vital data about barriers to vaccine access. By asking detailed questions about why people were unable to make appointments and map the answers against race/ethnicity and zip code data, 211 San Diego has been able to gain a deeper understanding of barriers and unmet needs in specific populations and neighborhoods. The community information exchange system allows service provider partners to send a referral directly to 211 to help those with complex needs or barriers to access.

During the early days of local vaccination rollout, among eligible callers, 61% were unable to make a vaccine appointment, with up to one-third lacking a mandatory requirement such as a SSN, cell phone or email address to book and confirm an appointment. The 211 San Diego team discovered that one of every three vaccine-eligible callers did not have email; one in seven did not have a cell phone; and one in 11 did not have a social security number. Heat maps of these challenges enabled the team to geographically pinpoint specific communities that were most impacted by appointment barriers. With those heat maps in hand, this data played a key role in re-shaping the vaccine registration requirements at both the county and state levels.

Power Equity: Shifting Decision-Making To The Community

Communities served by public health departments and the health system at large are typically the last stakeholders to provide input and direction to localized health equity plans. For successful program, implementation and community buy in, community members and community-based organizations must have input on program spending, community investments, and other critical decisions. Shifted decision-making is critical when addressing systemic racial inequities like those that lead to disparate health outcomes between white and non-white Americans. Efforts to combat systemic racial inequities should be central in design, planning, and execution of strategies to promote public health and vaccine equity. Most critically, policies and practices should be bottom up, rather than top down, giving communities the autonomy to design outreach, education, and public health strategies that best fit their own needs.

Community-based organizations must have the flexibility to decide how to engage with the community on their own terms, and must be empowered with decision-making authority. Federal policies related to vaccinations should intentionally build in flexibility, as well as community control.

Bright Spot: Ryan White: A Model For Community Engagement And Decision-Making

The existing Ryan White program on HIV/AIDS,[22] serves as a model of community-level flexibility and decision-making and should serve as a guide for community-based planning to address COVID-19 and health equity. This model includes a required community consultation via a planning council made up of community-based organizations, labor organizations, health experts, and community members themselves. The Ryan White program allocates funds to local CBOs that provide comprehensive primary health care and support services, which help organizations effectively deliver robust HIV treatment and care.

While planning councils ensure that federal funding is responsive to community-specific needs, the Ryan White program also includes capacity development grants that community-based organizations and other nonprofit entities can apply. These grants aim to improve organizational capacity in either of two ways: care innovation or infrastructure development projects. In 2020, these grants allowed non-profit organizations to apply for funding to expand their capacity to implement, enhance, or expand community health worker services.

A community-led planning and implementation model can ensure that the funds from the American Rescue Plan Act (ARPA), Build Back Better Act, and future investments are used in an appropriate and efficient way to address community needs. **Lawmakers should consider giving priority to grantees with councils in place. These councils should be designed to give community-based organizations, labor organizations, and community members a platform to co-develop plans that expand the public and community-health workforce at the local level**. Such a requirement would empower community-based organizations that know their community well and ensure that their knowledge is shaping state and local health department strategy.

Community-based organizations and community health workers can be conveners of local constituent input, as they understand how to authentically engage the individuals they work with. Community-based organizations have learned that effective engagement with community members requires a meaningful investment of resources (time, funding, and staffing) to support their capacity to advocate for themselves and their community. Federal policymakers should seek feedback and work alongside community-based organizations and community health worker associations to better understand perspectives, priorities, and motivations around vaccination and other public health interventions at a local level. Federal policymakers need to hear from diverse voices from around the country. National intermediary organizations (such as Partners In Health,[23] Social Current,[24] National Association of Community Health Workers[25], and Health Leads[26]) can help mobilize community leaders to collect diverse perspectives.

Bright Spot: Decision-Making Done Right At A Community Level

Through collaboration with the Chicagoland Vaccine Partnership (CVP),[27] a coalition created in response to the COVID-19 crisis, organizations previously engaged in community-based outreach have been enabled to quickly pivot to pandemic response.

As part of the CVP grant process, each organization is offered flexibility to design the type of outreach plan that will best meet the needs of their community. They are empowered with decision-making authority for the plans they implement. In addition to providing access to vaccines, grantees have worked to attract community members to events that serve a broad range of needs that also include vaccination as another free resource as they understand the challenge residents have in addition the pandemic.

For example, the CBO Something Good in Englewood[28] addressed the issue of food insecurity by using grant funds to host drive-through food pantries where COVID-19 safety resources were also provided. The Chicagoland Vaccine Partnership now includes about 135 participating organizations. While its reach has broadened, its approach of leveraging community voices has come into clearer focus: through mobilizing trusted community leaders; educating community members about the latest COVID-19 science and offering public health skill-building; and elevating coordination among community-based organizations, government, health care, and philanthropy to boost vaccination efforts and support a public health workforce. [29]

Small community-based organizations are often the most effective in reaching local communities because they have a nuanced understanding of local needs. This advantage helps drive equity in hiring and program goals. However, small organizations tend to be at a disadvantage in applying for grant opportunities, when compared to larger organizations with more grant writing, financial compliance, and reporting capabilities. Small organizations are frequently excluded entirely from planning processes. A community planning council model would give these organizations a seat at the table, and potentially help smaller community-based organizations contribute to and serve their communities without the burden of grant reporting and other constraints.

Resource Equity: Sustainable Funding Is Crucial For Health Equity Efforts

Congressional investments in COVID-19 relief, from the CARES Act (2020) to the American Rescue Plan Act, have gone a long way in the fight against the pandemic. These investments have been pivotal to addressing health equity concerns at the community level, however systemic change demands more action and sustainable funding.[30] In the American Rescue Plan Act, $7.6B was allocated for the creation of a public health workforce. Out of those funds, $250M was allocated to the Health Research and Services Administration (HRSA) and granted to community-based organizations through regional and local partnerships.[31] HRSA also awarded nearly 100 community-based organizations to work with community leaders to increase vaccine confidence, and serve as partners with health departments and medical centers to host culturally-relevant vaccination events. However, these funds are short-term (12 months maximum), have limitations on expenditures, have a high burden of reporting, and required a very rapid turnaround for applications (three weeks), leaving many community-based organizations without the time and resources to access them.

We recommend that **future grant making be streamlined so that community-based organizations are better prepared to apply. This means more lead-time for applicants, dedicated funding for capacity building programs, streamlined reporting systems to reduce burdens, and coordinated technical assistance to ease work and align with partners on the ground.**

To build on efforts in the American Rescue Plan Act, lawmakers must increase sustainable funding mechanisms that promote health equity and formally recognize the social determinants of health. This will require capacity building investments aimed at helping community-based organizations increase staff, technology, training, and facilities to serve their communities. It will also mean sustainable funding for community health workers that is not driven by clinical outcomes alone.

Bright Spot: Sustainable Financing Means A Lasting Workforce

As outlined by the National Association of Community Health Workers (NACHW) sustainable financing is needed to ensure programs are not dependent on applying for program grants or contract.[32] It recommends that these programs be funded through reimbursements for activities, and funding based on services and value of care delivered.

Across the U.S., community health workers are primarily funded through project grants that are often short term, subject to annual appropriations or private philanthropic decisions, and focused on specific goals. With these limitations, community health workers are often limited on implementing the appropriate strategies to address community needs and are left unemployed or assigned to another project once grant funding has expired. This flawed process leaves employers, community health workers, and communities at large at a loss.

Community health work involves a long-term commitment to individuals, therefore long-term positions are essential and only possible through permanent revenue streams. Combining multiple funding resources can help reduce dependence on one source (such as Medicaid). Sustainable funding options for community health workers include:

- Medicaid 1115 Waivers, dual-eligible programs, or state plan amendments;
- Medicaid Managed Care Organizations contract requirements;
- Community health worker services covered voluntarily by Medicaid MCOs or Medicare Advantage plans as part of administrative or quality improvement cost;
- Bundled payments, supplemental enhanced payment plans, or risk contracts;
- Internal financing by providers in anticipation of reduced costs or enhanced revenue;
- Funding through federally qualified health centers; and
- Blended or braided funding are recommended as funding alternatives with integration of resources allowing for diversity of program activities while grants can continue to play a role to increase capacity.

CONCLUSION

Vaccine equity is an essential component of any strategy to mitigate the overwhelming impact of the COVID-19 pandemic, and further has taught communities lessons on how to deliver a more equitable health care system at large. To reach this goal, the U.S. must address inequities in four key areas: access, data, power, and resources. With adequate access to vaccines and resources, proper investments in the community-based workforce, improved data structures, and shifting power to communities, the overall health system will be stronger and more equitable. Public health structures that are more responsive to the communities they serve will lead to a nation better prepared for any future crises.

About The Vaccine Equity Cooperative

In the fall of 2020, Health Leads, National Association of Community Health Workers, Partners In Health, and Social Current, came together to form the Vaccine Equity Cooperative,[33] to share trusted resources, expand funding, and strengthen policy—all in support of community-based and public health workforces. This initiative—a collaborative approach to addressing structural barriers and building vaccine confidence—aims to further support the rebuilding of public trust necessary to address long-term disparities and prepare for future crises.

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