Centering Community Voices and Expertise

Community members carry essential knowledge and expertise about their communities and the challenges they face, as well as the solutions needed to achieve meaningful, lasting change. Community engagement isn’t an end point, but an ongoing, iterative process that involves sharing power, listening, integrating lessons learned and evolving in our work. PHI works closely with communities to address systemic inequities, and support their voices being centered and formative in research, policy and interventions.
Accelerating Birth Justice for Black Families

PHI’s Cherished Futures for Black Moms & Babies (Cherished Futures) was a multi-sector collaborative effort to reduce Black infant and maternal inequities and improve patient experiences for Black birthing people in Los Angeles County.

Over a year, Cherished Futures partnered with five participating hospitals (Antelope Valley Medical Center/AVMC, Miller Children’s and Women’s Hospital Long Beach, St. Francis Medical Center, Torrance Memorial Medical Center and UCLA Health) to improve birthing experiences and outcomes for Black moms in several areas, including breastfeeding.

Breastfeeding offers extensive and lasting health benefits that are particularly vital in the Black community, where infants face higher mortality rates and disproportionate preterm births. Breastfeeding is linked to a decrease in sudden infant death syndrome (SIDS) and helps prevent conditions such as diabetes and obesity later in life. For mothers, breastfeeding reduces the risk of cardiovascular disease (the leading cause of death among Black women in America), and lowers the risk of breast cancer, ovarian cancer, and type 2 diabetes.

Yet a number of challenges contribute to disparities in breastfeeding in Los Angeles County for Black mothers and their children. Areas of LA County with the highest rates of infant mortality also have the lowest rates of exclusive breastfeeding at three months and the fewest lactation support resources. Black mothers in the U.S. are nine times more likely to be offered formula by hospitals than white moms.
We have disparities in breastfeeding because of the disparities we see for maternal and child health, maternal and infant health; they’re very much mirrored to the breastfeeding rates,”

— ASAIAH HARVILLE, INTERNATIONAL BOARD-CERTIFIED LACTATION CONSULTANT (IBCLC) AND BIRTH EQUITY MANAGER WITH CHERISHED FUTURES.

AVMC, in collaboration with Cherished Futures, initiated programs to bridge the gap in Black breastfeeding rates, recognizing it as a strategy to improve short- and long-term health outcomes. The medical center now educates staff about the historical trauma and stigma around Black breastfeeding, stemming from when enslaved women were forced to nurse their enslaver’s infants, often at the expense of their own infants. “It’s really important for our nursing staff to understand that history and how that history has shaped Black culture in regards to the choice to breastfeed,” said Yvonne Reifenstahl, a registered nurse at AVMC. “Our goal is that the efforts that we’re doing here will be creating ongoing change within our community.”

AVMC launched a free monthly Community Black Breastfeeding Support Group, and dispatched lactation consultants to rooms designated for formula-only feeding to ensure that all families received support to make informed decisions.

AVMC’s efforts resulted in a striking increase in Black exclusive breastfeeding rates—from roughly 40% to 70%. Additionally, lactation consultations with Black patients rose from 30% to a complete 100%.

Supporting lactation is not solely the responsibility of the family but also of the community, including healthcare systems and institutions, as well as public health entities and policymakers. Cherished Futures offered recommendations across sectors to promote the initiation and prolongation of Black breastfeeding:

• **Enact Federal Paid Parental Leave**: The United States is one of the only industrialized nations without federal paid leave. According to the United Nations (UN), longer parental leave is associated with lower infant mortality rates and has a direct impact on breastfeeding initiation and duration. The UN reveals that for each additional month of paid parental leave, infant mortality is reduced by 13 percent.

• **Implement Lactation Education**: Lactation education is not mandated in medical and nursing schools. Without standardized lactation education for medical personnel, families can receive subpar education and support.
• **Increase Lactation Staff Capacity and Diversity:** Institutions should evaluate and analyze their current lactation staff capacity to determine whether the numbers are sufficient and reflect the diversity of their patient population. Institutions should also ensure that lactation education materials represent diverse patient populations.

• **Innovating Data:** Public health departments can ensure data on Black breastfeeding is regularly collected and reviewed to identify gaps and opportunities for increased support.

• **Cross-Collaboration:** Work more closely with hospitals in their service areas to enforce and support lactation policies.

The efforts of Cherished Futures and AVMC present a viable model of how collaboration between hospitals and Black leaders can create meaningful change in patient experiences and health outcomes in Los Angeles and beyond.

At the end of 2023, partners from Cherished Futures launched the California Coalition for Black Birth Justice (CCBJJ)—led by, with, and for Black women—with national and local expertise in clinical medicine, public health research, policy advocacy, and community organizing. *The California Black Birth Justice Agenda: Unifying the Vision for Systemic Change 2023*, their inaugural report, explores strategies for systemic change in the healthcare and public health domains to build longer-term, upstream, sustainable solutions that advance birth justice and equity for Black families. The agenda focuses on institutional accountability and data accessibility, Black Birth Justice workforce development and sustainability, and expanding access to community-based care, such as investing in Black-led birth centers, organizations and birth workers.
Asian Youth Advocating for Access to Mental Health Resources

The COVID-19 pandemic and racism fueled rising rates of depression, anxiety, stress, and physical health challenges in Asian American and Asian Immigrant (AAAI) communities, including suicide rates. Longstanding challenges such as cultural stigma within families and communities about seeking counseling, a lack of culturally rooted mental health providers and language barriers have made it difficult for AAAI communities to access mental health resources.

PHI’s Lotus Project provides a safe place to address stigma, overcome barriers and find solutions, facilitated by peers and experts from the Asian American community who have experienced and understand the barriers. In 2023, the Lotus Project held multiple educational forums on AAAI racism, mental health concerns, and how to better support AAAI communities. The forums also explored the profound impacts of intergenerational trauma on AAAI communities and highlighted community-led solutions for healing and change.
Through the Lotus Project, youth advocate interns Jessica Louie and Wesley Chen served as leaders in their high school community. They reflected and amplified the voices, stories, and experiences of other AAAL youth, while addressing mental health challenges in their schools and identifying solutions. During their time with the Lotus Project, Jessica and Wesley worked with other student volunteers to lead a mental health educational campaign and tailored it to meet the needs of other Asian American high school students. Jessica and Wesley educated their peers about mental health and collectively the students advocated for more school counselors through blog posts and social media outreach.

Jessica and Wesley were the only high school youth invited to speak at the 2023 White House Summit on Asian American, Native Hawaiian, and Pacific Islander Mental Health, where they elevated the barriers, including racism and stigma, which exist in their school communities and advocated broadly for improved access to mental health resources. The 2023 summit was the first Asian American, Native Hawaiian and Pacific Islander mental health summit convened by the White House.

“I hope for the adults, service providers, leaders, and changemakers in the room and across the country to please listen to youth voices and collaborate with us to implement change to improve the mental health outcomes of Asian youth.”

— JESSICA LOUIE, YOUTH ADVOCATE INTERNS, LOTUS PROJECT, PUBLIC HEALTH INSTITUTE
Improving Life with a Serious Illness

AC Care Alliance was founded in 2013 after five Black pastors from Alameda County realized people in their congregations with advanced illnesses and their caregivers needed more support, with surveys showing 30% to 50% of their congregants struggled with this issue. Pastors were often called in the final days or hours before death, but many families needed help much earlier with loved ones who had cancer, strokes, emphysema, uncontrolled diabetes, end-stage renal disease, Alzheimer’s disease, or other conditions.

After soliciting input from health systems, congregants, community groups, and national organizations, the advisory pastors—led by Reverend Cynthia Carter-Perrilliat—developed a holistic and faith-based lay care navigation intervention called Alameda County Care Alliance Advanced Illness Care Program (ACCA-AICP), based at the Public Health Institute.

Jill Joseph, MD, PhD, a professor emeritus at UC Davis Betty Irene Moore School of Nursing, worked with ACCA to refine the intervention, which was free of charge and focused on meeting the needs of participants. In a series of up to 12 phone and in-person visits, the navigators offered support in five areas of need: spiritual well-being, health, advance care planning, caregiving, and social supports (such as transportation, meals, housing). The program has since expanded from Alameda County to Contra Costa, San Francisco, San Mateo, Santa Clara, and Los Angeles counties.

“The beauty is that the care navigators come from the community they’re serving, so they have a greater ability to understand the experiences of the people they work with,” said Kate Meyers, a senior program officer for the California Health Care Foundation, which has awarded ACCA several grants. “The trusting relationships can be built sooner and better, which makes it easier for people to get the holistic support they are often not receiving from the health care system.”
ACCA’s care navigators are also equipped to help participants prepare for clinician visits by listing goals for the visit and prioritizing questions, or assist with completing advance directives if they are unable to speak for themselves due to illness. “They learn the importance of thinking about whether medical treatment will support healing or not and of selecting a health care agent to make decisions if they cannot do this,” said Valerie Steinmetz, a program manager at ACCA.

To further expand the program, Carter-Perrilliat’s team has been educating health care providers about the lay care navigation ACCA offers. In 2021, ACCA launched a pilot study with Kaiser Permanente’s Oakland Medical Center in which primary care providers refer patients to the program. More recently, ACCA formed a partnership to receive referrals from LifeLong Medical Care, a Federally Qualified Health Center located in Alameda and Contra Costa counties.

So far, more than 1,400 people have been served by ACCA’s Advanced Illness Care Program, with 55% completing advance directives and 85% receiving prayer during the visits, according to a program evaluation study led by the UC Davis Betty Irene Moore School of Nursing. The success of the program has captured the interest of faith leaders and healthcare organizations in Boston, Baltimore, Detroit, Ohio, and Washington, DC. Knowing this, Carter-Perrilliat is considering national expansion in the future.

As ACCA works to continue reducing health disparities by reaching Black people and other communities of color with serious illnesses, pastors and others on the frontlines are seeing encouraging signs of progress. For years, Brandon Reems, pastor of Center of Hope Community Church in Oakland, did not feel equipped to support caregivers in his congregation who were burdened by the responsibilities involved in taking care of declining, elderly loved ones. Now, he is able to offer them some relief.

Thank you to the California Health Care Foundation for permission to use this excerpt of their longer piece.
Trans Women Advancing Equitable Health Outcomes

The Public Health Institute’s Flourish Project was designed to address health-related barriers faced by transgender women of color in Alameda and San Francisco counties. The project focuses on reducing substance use and HIV, while improving health outcomes for trans women of color. To do so, it acknowledges the disproportionate disparities, discrimination and violence faced by many trans women—especially women of color—and how those can connect to housing insecurity, job discrimination, and survival sex work. When women rely on sex work because they have few options, they are at higher risk of experiencing violence, sexually transmitted infections, and incarceration.

Flourish began by hiring from within the communities they were working with, including trans women of color and former sex workers. Peer educators equipped participants with key health education, tools and support groups, and connected them to critical resources such as housing, employment, and mental health services.

Over 5,000 people were reached through outreach activities at community gathering spots like bars, balls and community organizations, and 334 trans women participated in and completed the program. Over 3,000 referrals were made through the Flourish Project’s weekly support groups to local CBOs that provide gender-sensitive services to trans women of color. Feedback from participants and observations indicated that sessions had a positive impact on mental health, increased safer sex practices, decreased substance use and increased access to hormones via a medical provider among women who completed the program. PHI’s Health Intervention Projects of the Underserved received a 5-year grant from Substance Abuse and Mental Health Services Administration to continue operating the Flourish Project through 2027.
Kenyan Women Shining a Spotlight on Reproductive Health Solutions

The burden of HIV, other sexually transmitted infections (STIs) and unintended pregnancy is disproportionately high among young women in sub-Saharan Africa. 13% of women in Nairobi are estimated to be diagnosed with chlamydia. In Kenya, the majority of pregnancies between 2015 and 2019 were unintended and nearly 1 in 5 adults in Kisumu, Kenya are living with HIV. But data alone do not tell the whole story.

In 2023, PHI’s CAMI Health and partners launched Word on the Street: Kenyan Women Share Their Reproductive Health Stories, an immersive mapping tool that brings epidemiological data to life through digital storytelling—elevating the sexual and reproductive health experiences, needs and solutions put forward by adolescent girls and young women, men, local influencers, and technical experts in Nairobi and Kisumu, Kenya.

By centering the lived experiences of these stakeholders on an interactive platform, the StoryMap serves as an advocacy tool to bolster the voices and needs of the most marginalized in the development of sexual and reproductive health products, particularly multipurpose prevention technologies (MPTs)—products designed to simultaneously prevent HIV, other STIs, and/or unintended pregnancy.

“A product that combines prevention for all three of them? HIV, STIs and pregnancy?” That would be perfect.”

— NJOKI, NURSING STUDENT & BRAND AMBASSADOR
Rise Up Leaders Advancing Global Gender Equity in Health, Education & Economic Opportunity

In 2023, Rise Up expanded their global network of gender equity champions in Brazil, India, the U.S., and Kenya through their Leadership and Advocacy Accelerator. The intensive program brings together local leaders to explore tools for leadership, team building, political mapping, policy change, goal setting, strategic planning, messaging, proposal and budget development, and more. Following the training, participants are invited to apply for grant funding to tackle complex education, healthcare, and economic challenges with innovative, people-centered advocacy approaches.

Rise Up Leaders are from and reflect the communities they serve, and understand on a deep, personal level the urgent gender equity issues in need of attention and advocacy. Today, the 2023 cohorts now join hundreds of other Rise Up Leaders working in communities around the world to advance gender equity—building new support networks and advancing protections for gender-based violence survivors in São Paulo, Brazil; advancing Black maternal health, housing equity and transgender rights in California; improving girls’ access to education throughout Kenya; and more.

In 2023, Rise Up also released an external evaluation that shares insights on how funders can more effectively support community leaders to help them achieve their goals in gender equity policy and social norms change. The findings emphasize the power of investing in local community leaders—not as grantees whose capacity needs to be built, but as the strategists and experienced professionals that they are. It also found that Rise Up’s model is highly effective in supporting leaders to drive impact: 90% of leaders said that Rise Up helped them develop essential advocacy and leadership skills.
One of my most significant takeaways from Rise Up was the importance of empowering grassroots voices. I integrated local girl leaders into the process, collaborating with them to understand their challenges and collectively working on the problem tree. We identified a pressing issue: the safety and mobility concerns in public transportation in Delhi, contributing to an increase in cases of sexual and gender-based violence. I have taken on the leadership of a girl-led advocacy project, involving 40 local girl leaders. Together, we are actively addressing this issue with decision-making bodies in Delhi.”

— RISE UP LEADER NISHTHA KAPOOR, DELHI
LOOKING BACK

Amplifying Women & Girls Leadership Around the World

PHI’s Rise Up activates women and girls to transform their lives, families and communities for a more just, equitable world through investment in local solutions, strengthening leadership and building movements. Since 2009, Rise Up’s powerful network of 800 leaders has successfully advocated for over 185 new and improved laws and policies, positively impacting more than 160 million people around the world. Their advocates and leaders have ended child marriage in Malawi, banned female genital mutilation for girls in rural Kenya, engaged men and boys to prevent gender-based violence in Mexico and improved the economic rights of girls and women in India.
Farmworkers are disproportionately impacted by extreme weather conditions and are more likely to be on the front lines and in the fields during dangerous weather events. According to the National Institutes of Health, farmworkers are 35 times more likely to die from heat exposure than workers in other industries. They are at increased risk for a range of health problems, such as heart disease, heat stroke, respiratory problems and lung cancer. During extreme climate change events, some farmworkers also risk losing days of pay and/or losing their jobs. Long-standing racism, discriminatory work practices and social barriers including immigration status, language barriers and poverty further compound farmworker health risks and health outcomes.

Through the Digital Stories project, farmworkers in Ventura County, CA documented the health challenges they experience as a result of working in the fields during extreme heat, wildfire smoke and flooding events.

Their powerful and heartfelt stories in their native languages—Purépecha, Mixtec and Zapotec—bear testament to the daily reality that often goes unseen by society and document the growing and urgent need to address these challenges. They also help to ensure that Indigenous populations are included in the dialogue around climate change and health, workers’ rights and more; and serve as an educational tool to help government agencies involved with agricultural workers be more aware of farmworkers issues.
Farmworker advocates like Rivelino Pascual are also advocating with other community partners for policy and practice changes to address the health impacts of climate change and advance health equity and climate justice for farmworker communities.

Rivelino is one of more than 40,000 farmworkers who contribute to the production of food grown in Ventura County, CA. In California, an estimated 400,000 to 800,000 farmworkers produce more than 400 commodities—representing over a third of the country’s vegetables and over three quarters of the country’s fruits and nuts that feed the nation.

The 2023 Digital Story Project was supported by the StoryCenter, the Public Health Institute’s Achieving Resilient Communities (ARC), Lideres Campesinas, and Mixteco Indigenous Community Organizing Project (MICOP).

“...The supervisor could see that we were tired and thirsty…and would make us work regardless. And we had to put up with it so that we wouldn’t lose our jobs. We would sometimes experience dizziness, headaches and nausea. We didn’t know that these were symptoms of too much sun exposure.”

— RIVELINO PASCUAL