ENGAGING THE POWER OF TITLE V FOR EQUITY IN PRETERM BIRTH PREVENTION

Recommendations for Title V Programs: Co-Creating an Equitable Future with the Wisdom of Communities

This issue brief is part of a four-part series that explores the unique power of the Title V Maternal and Child Health (MCH) Services Block Grant to support anti-racist strategies and intentionally address the roots of racial injustice in maternal and infant health, including the prevention of preterm birth. Each issue brief describes how MCH programs can disrupt structural and institutional racism and shift power toward the expertise of people who birth, communities, and the organizations a community trusts to implement solutions. The series was produced with the support of the Pritzker Children's Initiative.

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ISSUE BRIEF

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State and territory maternal and child health (MCH) programs funded by the Title V MCH Services Block Grant deliver essential services organized into three levels of care: direct services, enabling services, and public health services and systems. The Title V MCH Block Grant guidance recommends that "states should assure that [MCH services] are family-centered, community-based and culturally competent."[1] However, each Title V program interprets this recommendation differently. Community engagement is essential for advancing a health equity agenda, but not all community engagement is the same. Foundational to advancing an anti-racist agenda that disrupts historical and current injustices, is the need to share power and knowledge and prioritize partnerships with thought leaders rooted in Black and Brown communities. In this issue brief, the authors will explore a path forward for ensuring community co-ownership of MCH priorities and for engaging in the continuous work that Title V programs must do to partner equitably with community-based organizations (CBOs).

What is anti-racism?

"Anti-racism is the practice of identifying, challenging, and changing the values, structures and behaviors that perpetuate systemic racism (Ontario Anti-Racism Secretariat)."[2] State and territory MCH programs must take urgent strategic action to identify how racism, especially anti-Black and anti-Indigenous racism, is embedded in programmatic and funding policies and practices within their organizations. To clarify, anti-Black racism refers to policies and practices rooted in institutions that "mirror and reinforce beliefs, attitudes, prejudice, stereotyping and/or discrimination towards people of Black-African descent. The term […] seeks to highlight the unique nature of systemic racism […] and the history as well as experiences of slavery and colonization of people of Black-African descent […]."[3] Due to the history of enslavement and violence against people of Black-African descent and Indigenous people in the United States, disparities in health outcomes are greatest for Black and Indigenous people. To be effective in ending these disparities, MCH programs must understand different types and levels of racism (individual, interpersonal, institutional, policy, and structural), and how these levels interact with and perpetuate within organizations and society.[4] With this understanding, MCH programs should embark on a path of deconstructing racism within organizational systems and advancing anti-racist programming and policies. Equitable partnerships with CBOs are integral to an anti-racist organizational strategy.

Community-Based Organizations as Essential for Culturally Rigorous Solutions

The term "community-based organization" is broad, as is community partner. For the purposes of this issue brief, a community-based organization is "a public or private nonprofit organization that is representative of a community or a significant segment of a community and works to meet community needs."[5] Title V programs should engage with community-based organizations that have staff and leadership who mirror the lived experience and culture of the people they serve and who are actively dismantling systemic inequities.

CBOs meet the unique needs of the population they serve by addressing root causes of disparities in several ways. They disrupt toxic stress caused by racism and discrimination. They address intersectional factors such as housing and food insecurity, safety, and racial dislocation. They also provide social and community support that builds resilience. By providing culturally reflective care, community-centered programs deliver supportive services that are protective for a variety of health outcomes, including perinatal health.[6] However, CBOs face consistent barriers. Public health agencies, health care systems, funders, and policymakers often do not recognize or lift up the work of CBOs.

For example, traditionally academic methods to assess the 'level of evidence' or 'effectiveness' of a program are resource-intensive and often do not incorporate cultural rigor in tandem with scientific rigor. Cultural rigor in program evaluation requires consideration, respect, inclusivity, and responsiveness to the culture of the community, "to ensure knowledge is gathered in an appropriate and meaningful way."[7] Although many CBOs implement programs that have been rigorously evaluated and have documented success in peer-reviewed sources, other successful and effective programs have not been formally evaluated. Evaluations are costly, and CBOs may not have financial or personnel capacity to perform a formal evaluation. Some CBOs may choose not to engage in scientific research and academic evaluation, due to the history of scientific experimentation on Black and Brown bodies that has led to injury and death.[8] Research is imperfect and can be unreliable, lack credibility at the community level, lack cultural rigor, and carry author biases. Some organizations may prefer to evaluate efforts using methods and measures identified by the community rather than through academic research methods. MCH programs and the wider public health community must embrace and respect these forms of evaluation and the resulting practice-based evidence. Scientific rigor without cultural rigor will not bring us closer to achieving justice in health. Due to the flexibility of the Title V block grant, state and territory health agencies can invest in these programs premised on practice-based evidence and organizational reported outcomes. Investing in the expertise of CBOs is a key strategy towards addressing root causes of inequities in preterm birth and other adverse birth outcomes. Title V programs can also provide technical support to assist with data collection and ongoing program evaluation to contribute to the body of evidence-based practices, for those CBOs that desire this.

Types of Partnerships Between MCH Programs and Community-Based Organizations

Funding to Achieve Priorities: MCH programs administering the Title V block grant make funding decisions based on their state or territory's selected national and state performance measures (NPMs and SPMs). Performance measures reflect the unique needs and areas of focus for each state/territory as assessed through the Title V needs assessment process. CBOs that address a specific community-identified problem or need are excellent potential partners in addressing NPMs and SPMs. For example, early entry into prenatal care is a national outcome measure (NOM) that drives the focus of state and territory MCH activities. Barriers to accessing prenatal care go far beyond geographic availability. The National Perinatal Task Force report *Building a Movement to Birth a More Just and Loving World* highlights that prenatal care must be high quality, free from bias, and culturally and linguistically reflective to be truly accessible.[9] It is not possible to meet this critically important standard without partnering with community-based and community-rooted organizations that provide culturally reflective services. Partnerships with CBOs within, by, and for communities threatened by structural inequities are necessary for any MCH program that wants to make equitable gains on their selected national and state performance measures.

Thought Partnership: MCH programs should specifically partner with CBOs that employ experiential experts. Experiential experts are individuals who have experienced the outcomes and circumstances that programs seek to address. Experiential expertise is essential to a well-rounded program that meets community needs, is anti-racist, and actively works to achieve racial equity in birth outcomes. MCH programs can consult CBOs that employ experiential experts to co-create organizational priorities, programs, and strategies; appropriately recognize and build upon the strengths of the impacted community; and meet their stated needs. Critical to this partnership is recognizing the emotional labor by experiential experts who draw upon their own experiences to serve an organization. Experiential experts and all community partners should always be paid at a rate equivalent to other expert consultants. MCH programs should consult with CBOs that employ experiential experts to address each NPM/SPM.

"Nothing about us without us" was coined by disability-rights advocates and has been adopted by communities across the country. Title V programs must embark on equitable partnerships with CBOs that meet this call to ensure the delivery of essential "social and community support as a means to mitigate the impacts of racism, stress, and other determinants that affect an individual's social conditions and, ultimately, health outcomes."[10] In the next section, the authors will discuss the pre-work and continuous work that Title V programs must engage in to create and sustain equitable partnerships with CBOs.

Foundations for Creating Partnerships

Title V programs may find it difficult to partner with CBOs that truly reflect the communities that disproportionately experience high rates of preterm birth and other poor perinatal health outcomes. This is the result of structural barriers and lack of trust due to historical and current harms created by state and local institutions and policies. A well-known example of historical harm is the Tuskegee experiment, which was conducted by the U.S. Public Health Service.[11] Sterilization abuse and reproductive coercion (including long acting reversible contraception (LARC) coercion), some sanctioned by medical and public health officials, continues today and has been used against Native American, Latina, and Black women as well as women with disabilities and incarcerated women.[12] In light of these harms, below are recommendations for pre-work and ongoing work that Title V programs must engage in prior to embarking on partnerships:

- Commit immediate resources and training for agency-wide efforts to understand and acknowledge that racism in all forms is the root cause of disparities and the issue that must be dismantled and addressed[13]
- Partner with CBOs and allocate resources for community-based assessments. This type of assessment can be carried out as part of the five-year Title V Needs Assessment, or as part of the ongoing assessment of priorities and practices. Investing in this initial assessment helps to build understanding of issues among all co-creators. HealthConnect One provides technical assistance to organizations seeking to perform a community-based assessment. Key elements of these assessments are:
  - Understanding strengths
  - Prioritizing current issues
  - Identifying solutions
  - Building understanding[14]
- Build meaningful relationships with CBOs and learn about their work before asking them for assistance[15]
- Engage with CBOs to "identify community needs and develop an equity-focused funding process."[16] It is important to include members of the community in making funding decisions. Read HealthConnect One's brief *Lessons from the Field: Building a Community Rooted Small Projects Funding Strategy* to learn about and consider challenges faced by individuals and small organizations to receive funding to do innovative work.[17]

Key Questions

What is it that we do now that prevents us from having already achieved health equity in birth outcomes? How do we measure success? Using prenatal care as an example, consider how we measure 'adequate' prenatal care. It is often measured by number of visits. Clearly, though, the number of visits is not a sufficient measure of adequacy. Other considerations are the content of those visits, the interactions between client and healthcare provider, the deeply entrenched structural and historical biases, and the larger context of a person's life experiences. Critically examining the ways in which the system operates and how we measure activities and outcomes can help Title V programs to deconstruct harmful and ineffective practices and policies.[18]

Mamatoto Village works with organizations and institutions to establish effective and equitable partnership models with CBOs rooted in a justice-centered framework. Aza Nedhari of Mamatoto Village provided the following considerations that Title V programs should explore when establishing community-based partnerships:

- Perform an internal evaluation of organizational culture and values before engaging with the community. Ask whether your values align with the community you are serving or with the organization you are planning to partner with. If this is not the case, it is important to do internal work related to aligning values. Elements to consider in this internal evaluation are:
    - **Integrity:** Does the community you wish to engage see your Title V program as having integrity? The answer will have an impact on the uptake of the service and the community's willingness to partner with your Title V program.
    - **Accountability to the community served and the people hired:** Will your Title V program invest in the growth, efficacy, and sustainability of the community you are partnering with?
    - **Transparency:** Is there transparency in data, financing, and administrative processes? Does the community see your Title V program as an entity with a successful track record?
    - **Commitment to ongoing examination:** Does your Title V program have policies that codify regular and ongoing evaluation? Does your Title V program have an organizational culture that is adaptable to constructive feedback?
    - **Justice-centered framework:** Does your Title V program extend beyond equity to promote collective responsibility among staff, collaborators, partners, and elected officials to protect the rights of pregnant people in your community? How is your Title V program ensuring that no person is mistreated based on race? Does the community that needs the most support get the most allocation of resources?[19]

- Choosing the right partner is essential to program success and uptake of programs by the community. Title V programs should consider the following when examining all existing partnerships with CBOs and when seeking new partnerships:
    - Consider the distribution of power in the partnership and examine what partnership practically and functionally means for your Title V program. Check in with your personal and organizational privilege and consider how that translates into assumptions and biases about the CBOs your Title V program is partnering with currently and hope to partner with in the future. The most visible organizations may not best suit the specific needs of the community you wish to serve. Establishing an impactful relationship will require work on your part to seek out organizations that can have a true, valuable impact on preterm birth and associated outcomes.
    - Heavily scrutinize organizations based in the community but whose leadership and organizational model do not reflect the community and instead demonstrate imbalances of power. Organizations whose staff and leadership do not reflect the community served are likely not the best partner.
    - CBOs should not only resemble the target community; they should have a track record of trust and transparency in their outcomes and data. They must have a track record of delivering quality, accessible care and engaging the community through a participatory and human-centered design framework.[20]

In the next section, the authors will identify some elements that are necessary for an equitable partnership between Title V programs and CBOs.

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Elements of an Equitable Partnership

As Title V programs embark on partnerships with CBOs to achieve racial equity in birth outcomes, they must intentionally examine and evaluate their partnership processes for equity. Below are some recommendations and considerations for creating and assessing partnerships with equity at the center of the relationship.

- Partnerships and Title V program goals and requirements must be *co-created*.[21]

What is co-creating?

A process of co-creating acknowledges the positionality of each person engaged in the partnership—where they come from, who they are, relationships with each other, power dynamics, economic relationships, and trust (or lack of trust) among partners and institutions. Co-creating requires respect and trust, which must be developed, invested in, and nurtured over time. The issue at the heart of the partnership must be relevant to all partners.[22] The needs expressed by the community and the methods to reach solutions are culturally informed and are created *with* and not *for* the community.[23]

- Honor and listen to families and community partners.[24] Understand that the staff of CBOs are contributing members in the community. Validate that their knowledge, insights, and contributions help your Title V program make meaningful strides toward organizational goals and objectives.[25]
- Do not rely on CBOs to undo longstanding institutional problems that harm communities.[26] Transparently acknowledge institutional histories of harm and embark on an organizational process of reconciliation and repairing relationships with communities that now carry a disproportionate burden of poor outcomes as a result of institutional harms.[27]
- Work *with* communities to identify barriers and solutions to preterm birth and other perinatal health challenges.[28]
- Create space and opportunities for families to share thoughts and feelings.[29]
- Include parents and community members directly affected by maternal and infant mortality and share findings transparently from maternal mortality review committees, fetal and infant mortality review committees, and other reviews of maternal and infant mortality and morbidity.[30]

- Title V programs should create pathways to help CBOs be sustainable by allowing them to leverage your institutional relationships and by providing technical assistance around competencies they want to develop.[31]
- Create shared ownership between Title V programs and CBOs. Recognize that when communities are given something that cannot be obtained without external input, it creates a dynamic of helplessness and drains the well of self-efficacy.[32]

Equitable partnerships require a great amount of care and time to develop and support, but these partnerships with CBOs are essential as MCH programs seek to address root causes that perpetuate inequities in preterm birth rates and other birth outcomes.

Many state and territory MCH programs do not have a history of partnering with CBOs that reflect communities disproportionately made vulnerable to preterm birth by structural inequities. Recognizing this truth is a critical step toward building trust and repairing relationships with communities harmed by health department structures and policies. With an honest understanding of our own institutions' roles in perpetuating inequities, programs must change how they respond to preterm birth. This is the time to acknowledge racism as the root cause of disparities and to prioritize the knowledge, wisdom, and solutions within communities to dismantle it.

Title V programs should create pathways to help CBOs be sustainable by allowing them to leverage your institutional relationships and by providing technical assistance around competencies they want to develop.

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