

Guiding Principles and Recommendations for the Blue Ribbon Panel on African American Infant Mortality

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Project Background

The disproportionately high rate of infant mortality among African American women in Fresno County prompted First 5 Fresno County to commission a study to illuminate the problem and identify potential corrective strategies. The study report “African American Infant Mortality in Fresno County” conducted by the Central Valley Health Policy Institute (CVHPI) at Fresno State included a set of recommendations proposed by community stakeholders at a meeting held at Gaston Middle School on August 11, 2015.

As presented in the study report, community stakeholders proposed **three key recommendations** for addressing excessively high African American infant mortality in Fresno County:

- 1) Formation of a Blue Ribbon Panel of health care, education and community leaders to improve cultural appropriateness of health care for African American women and families.
- 2) Pilot a Centering Pregnancy Program for African American women to encourage social support, coordination of services and dissemination of accurate and timely health information prior to and following pregnancy.
- 3) Develop initiatives to address living conditions and life supporting (activities) for young African American women and families by focusing on jobs, transportation, housing, neighborhood resources and education.

Purpose and Activities

The purpose of the present project was to conduct foundational, supportive activities related to the first recommendation: the formation of a Blue Ribbon Panel. Towards that end, the Central California Children’s Institute at Fresno State (CCCI) implemented the following activities as part of this project:

- 1) Formation and staffing of a Community Advisory Committee (CAC) to guide the work of the next phase (establishment of the Blue Ribbon Panel) of First 5 Fresno County’s local efforts to reduce African American infant mortality. The CAC would be composed of several of the individuals from the Maternal and Child Health Expert Panel (previously part of the CVHPI study group) who would also serve as ambassadors for the initiative.
- 2) Convening a group of Community Informants who have had the lived experience of African American infant mortality. These informants were provided an opportunity to participate in empowerment and story-telling training that would enhance their ability to use their stories to influence policy and systems change.
- 3) Convene educational/community report out meetings on African American infant mortality to facilitate ongoing community dialogue, awareness and increased media attention on the topic.

- 4) Develop a list of recommended members to comprise the Blue Ribbon Panel who have been vetted for their interest, influence and commitment to the issue.

The intended outcomes of this work were:

1. The formation of a Blue Ribbon Panel that is **racially/ethnically inclusive and multi-sector**, to include women and families affected by the racial/ethnic disparities in African American infant mortality.
2. The selection of a panel of participants who are both **knowledgeable and well-positioned** to address the complex social, political, cultural and economic factors influencing disproportionately high rates of African American infant mortality.
3. **Ongoing engagement with and input from community stakeholders**, including those with lived experience, to ensure their voices are well represented in the proposed activities and recommendations going forward.

Timeline and Overview of Implementation

The project was launched in December 2016, and concluded in July 2017. CCCI implemented the activities outlined above by working closely with the CAC, Community Informants, and predominantly African American faith-based institutions and organizations in Fresno (i.e. Westside Church of God, Black Women Organized for Political Action and others).

The timeline for the project was as follows:

December through April 2017 Promote project in community to raise awareness and identify potential Community Informants

Upon project approval, CCCI project staff immediately began efforts to raise awareness of African American infant mortality in Fresno through a number of varied outreach activities, including visits to churches to hand out recruitment postcards (particularly Westside Church of God), canvassing major events such as the Martin Luther King, Jr. Holiday parade, contacting local African American civic organizations and non-profits such as the Westside Family Resource Center, Street Saints, LINKS, Inc. and Black Women Organized for Political Action (BWOPA), as well as the California Advocate newspaper.

A campaign slogan, “**#FresnoBlackBabiesMatter**” was adopted to capitalize on the national visibility of the Black Lives Matter movement, and to shortcut communication around the project’s long-term goal of reducing infant deaths. T-shirts with this slogan were worn by staff when conducting outreach and recruitment activities, and were later given as incentives to Community Informants.

A project Facebook page bearing the same slogan was launched in March 2017. At the height of the campaign in mid-April, the Fresno Black Babies Matter Facebook page had 1,531 hits.

Ultimately, six women with the lived experience of an infant loss agreed to participate in the project as community informants. Two of the six participants were recruited through Facebook. These women ranged in age from their early 20's to over 70 years old. Three of the women were members of the same family, and spanned three generations of infant loss. One of the six women dropped out of the project because she faced transportation barriers, as well as medical complications with a new pregnancy.

May through July 2017

Engage the Training Institute for Leadership Enrichment (TILE) to provide leadership and empowerment training to women affected by infant loss, and link their stories and experiences to action strategies for reducing African American infant mortality.

In May, trainers from TILE launched their African American Infant Mortality Prevention Empowerment Sequence and delivered its curriculum over four sessions organized around the following modules:

Training Session 1	Program Sequence Overview; Participant Personal Leadership Inventory and Myers-Briggs Assessments
Training Session 2	Your Leadership Toolbox: Support System, Tools and Resources
Training Session 3	Sharing Your Story; Who Represents You? Advocacy, Policy Process, Discussion and Implications
Training Session 4	Final Project Presentations: What's Your Vision for Reducing Black Infant Deaths?

A final (fifth) session was held as a celebratory event wherein participants debriefed the experience and were awarded certificates of excellence for their participation. A modest stipend also was provided to each participant for the sessions they attended.

Stories from Women with Lived Experience

The leadership and empowerment training series provided by TILE stressed the importance of women using their voices and stories to inform the development of policies and practices that will improve the life trajectory of African American women. Six African American women who had lost infants participated in a storytelling process, sharing their experiences and the life circumstances surrounding their infant's death. The Relationship Wheel (developed by the Learning Community, www.learningcommunity.us) was adapted and used as a visual prompt for facilitating storytelling and exploring how relationships with family members, friends, work or

school colleagues and health professionals either impacted and/or were affected by the infant loss.

Very similar to the conclusions reached by a recent meta-analysis of predictors of infant mortality (“Look at the Whole Me”, *International Journal of Environmental Research and Public Health*, 2017, Vol. 14, 727), we learned that African American women in Fresno are crying out to be heard and seen, not as dysfunctional and needy, but as valid voices that deserve to be heard by their families, their partners, their neighborhood institutions (including churches), and large systems of care. Across the board, women shared experiences of being belittled, violated or dismissed by their loved ones and/or health care providers. One woman told of how after her baby died, the hospital nursing staff brought her deceased baby to her on a cold tray. Another told of a physician placing his medical record on her protruding belly during a prenatal care visit. Yet another described how none of the hospital staff ever explained the cause of her baby’s death. Finally, one reported that the hospital cremated her baby without her permission. The phrase “the invisible souls of women” was coined during the project to capture the depth of their sense of not being valued, trusted nor respected by others.

The leadership and empowerment training proved to be a healing element of this project. The women reported feeling healthier, stronger and more valued by having the opportunity to learn about the political process and how their voices can be powerful tools for change. They were inspired by the opportunity to rub shoulders with women they perceived to be successful and wise. They indicated that it was healing for them to be engaged in a process of change for their communities and for other African American women. Being given a platform to share their stories made them hopeful that change can happen.

These women are resilient and have continued to press forward, in spite of how they were treated. They deserve to receive support during difficult times, have a safe place to share their stories, and grieve the loss of their infants, a grief that continues for years, if not decades later.



The following work plan objectives are designed to guide the Blue Ribbon Panel in addressing the highest aspirations of these women: to heal, to continue to grow as women, and to give back to their communities.

Guiding Principles and Work Plan Recommendations

These guiding principles and work plan recommendations emanate from both the stories of African American women with a lived experience of infant loss, as well as from African American professionals whose experience as African Americans, and their profession-related contact with the health care, social service and educational sectors, inform their perspective.

There were several priorities, beyond the four objectives presented below, that surfaced during this project. However, since the Fresno Preterm Birth Initiative (Fresno PTBi) is addressing some of them, they are not listed here. For example, the need for reproductive health education around birth spacing is being addressed by PTBi's Health and Education before Pregnancy Work Group. Reducing isolation among pregnant women is an emphasis of the PTBi Group Prenatal Care Strategic Focus. The four objectives in this work plan are intended to add value and complement existing efforts to reduce preterm birth and infant mortality in Fresno.

The goals of the Blue Ribbon Panel proposed work plan are to:

1. Bring both awareness and action to the larger societal “beyond health-care related conditions,” or social determinants of health, that influence African American infant mortality.
2. Complement current initiatives addressing preterm birth and infant mortality.
3. Emphasize the importance of enrolling an African American leadership majority on the Blue Ribbon Panel, including those with lived experience.

Guiding Principles

To be both effective and culturally responsive, the recommended strategies and approaches for change should:

1. Build the internal skills and capacity of impacted families to address individual and family level issues identified by women with the lived experience of an infant loss
2. Support investments that improve environmental and neighborhood conditions affecting health, such as accessible grocery stores, walkable amenities, safer green space, and fewer sources of pollution. Poverty reduction through livable wages and equitable employment would reduce economic stress, thereby further improving health outcomes.
3. Uphold the primacy of challenges that are unique to African American families, such as the need for empowerment education, and address those challenges accordingly.

4. The Blue Ribbon Panel should identify both short-term and long-range goals. Some of the recommendations will require extended periods of time and extensive resources to achieve, while others could be acted upon more immediately, and require a relatively smaller investment of resources.
5. The Blue Ribbon Panel should include not only persons selected because of their organizational affiliation or leadership position; members also should possess a demonstrated commitment to making meaningful and sweeping changes in how African American women and families are supported locally. Multi-sector engagement is needed, from business, education, health care, social services, land use, city planning, transportation and the faith community.

Work Plan Recommendations

Objective 1: Training In Anti-Racism and Cultural Responsiveness

Provide ongoing training and reflective supervision in culturally responsive, compassionate caregiving to transform health care and social service organizations.

Rationale

African American women report experiencing non-supportive, if not antagonistic, relationships with health care and social service providers. African American women perceive these poor relationships as culminating from racism and/or stereotyping. Providers are typically unaware of their implicit biases, and how those biases impede the quality of provider-patient relationships.

Approach

In order for culturally responsive and compassionate care to penetrate and transform systems of care, training must be ongoing, recurring over time, with opportunities for reflective practice provided as well.

Several providers of cultural responsiveness training are available locally. One curriculum that has been used widely with infant and early childhood and mental health practitioners is the VISIONS model (www.visions-inc.org). More than 400 health, education and social service providers in the Central Valley (primarily early childhood and mental health practitioners) have been introduced to the VISIONS model; however, there is a need to reach medical providers with the transformative VISIONS framework.

Objective 2: Resources for Healing Trauma and Building Trust

Develop innovative programs to heal trauma among African American families in Fresno County.

Rationale

The project's storytelling and empowerment process unveiled a complex web of historical, intergenerational and interpersonal trauma, which may have influenced the demise of African American infants. Much of the trauma experienced by the women in this project was never talked about, grieved, nor healed. A number of adverse experiences, including rape, domestic violence, family conflict, prior infant losses, and racism, were identified as influencers of long-term health outcomes, including the outcomes of future pregnancies.

The lack of trust among African Americans towards helping organizations and systems of care in Fresno is pervasive. Failure of helping systems to be responsive to the needs of African Americans has created a sense of doubt and hopelessness among both African American professionals and community informants in this project. Trust building and bridge building between the African American community and helping institutions in Fresno is sorely needed.

Approach

Restorative practices are increasingly being used in schools to create more positive approaches to discipline and create school climates wherein youth can thrive. Restorative practices also are being tested in other environments, such as the health care arena, to address various types of trauma, and to build productive and healthy relationships between health care providers and those they serve. Talking circles are a key strategy in restorative practice wherein individuals are able to give voice to their concerns and experiences in a safe, non-punitive environment. There is much room to explore the potential use of restorative practices for African American families in the health care and social service sectors to address unresolved conflicts, lack of trust, and disrupted relationships (www.iirp.edu).

In the case of women who have had an infant loss, are there ways to provide longer-term support that could more effectively facilitate their healing process? What role can churches and interfaith chaplaincy programs play? How can talking circles help facilitate healing? It is recommended that these questions be thoughtfully considered by the Blue Ribbon Panel.

Objective 3: Promote Family Resiliency

Enhance the capacity of faith-based organizations to provide family life skills education that emphasizes male involvement and healthy interpersonal communication.

Rationale

African American women report being under extreme stress when dealing with infant losses and other traumas. Family support often alludes them, as other family members themselves are often experiencing a disproportionate amount of stress associated with under- or unemployment, incarceration, workplace issues, neighborhood violence or health challenges.

Approach

The faith community is a significant source of support in the African American community. How can faith-based organizations play a greater role in providing emotional support to families? What strategies can be used to help African American families strengthen their healthy coping skills? Clearly, African American families are resilient in the midst of all types of opposition and challenges. How can we build upon the strengths of African American families, support them in continuing to do what's working, and provide help in areas where there is a need, and in natural settings?

The TILE storytelling and empowerment training series had a significantly positive impact on the way family members communicated with each other, listened to each other and supported each other. The potential for helping others through storytelling and empowerment training gave the women a way to "give back," and simultaneously, to heal their grief. It is recommended that these type of leadership and empowerment programs be continued and expanded.

Objective 4: Building On and Expanding What Works

Secure expanded and sustainable funding for programs that work, such as the Black Infant Health Program, the Cultural Brokers Program, and Street Saints; and actively support the needed investments identified in the Southwest Specific Plan.

Rationale

Many of the programs serving communities of color and more specifically, African American communities, are underfunded and struggle to make ends meet. The Fresno community saw an increase in African American infant mortality concurrent with the decline in funding for the Fresno County Black Infant Health program. These organizations offer vital community services, yet their ability to grow and thrive is not ensured.

Fortunately, significant work is happening in West Fresno to respond to what residents desire to improve their neighborhoods. The Southwest Specific Plan addresses jobs, economic development, affordable housing, amenities, parks and reducing toxic industries in the 93706 zip code. The Transformative Climate Communities Program (TCC) is a recent bill (AB2722) co-authored by Autumn Burke to make targeted investments in the most polluted and impacted neighborhoods. The 93706 zip code is one of the most impacted statewide, and could benefit from these investments.

Approach

Local and state level funders could pool their resources to create a “Funder’s Collaborative to Reduce Black Infant Mortality” to leverage more support for organizations and initiatives serving the African American community. Funds could be awarded to support general operating costs or capacity building, which often are not supported by grants. The funder’s collaborative also could support other strategies to build the capacity of these critically important organizations, such as strategic planning, technology enhancements, and professional development.

The Blue Ribbon Panel also should monitor whether the funding for the neighborhood improvements identified in the Southwest Specific Plan remains in West Fresno as it is designed to, and if not, speak out against redirecting the funds to other neighborhoods or to purposes other than that for which the funding was intended.

Blue Ribbon Panel Membership

The African American Infant Mortality Community Advisory Council discussed the importance of continuity in this work, and in those selected to be involved in the next phase of this work. To ensure that the work that has already been done is built upon, several members of the African American Infant Mortality Community Advisory Council are recommended to serve as members of the Blue Ribbon Panel. Those individuals are:

1. Wanda McIntosh, LCSW (private practice)
2. Margaret Jackson, Cultural Brokers Program
3. Dr. Venise Curry, Communities for a New California Education Fund
4. Fanta Nelson, Fresno County Black Infant Health Program
5. Jamilya Jackson (lived experience)
6. Simone Ireland (lived experience)

These individuals are recommended primarily because of their proximity to the issues facing African American families, particularly those who have experienced personal trauma or an infant loss. In addition, the Rev. Bruce McAllister, Pastor of Saints Church, also was strongly recommended as a faith community representative.

In addition to the above individuals, community members previously recommended at the Gaston Middle School meeting held in October, 2016 that the following sectors and/organizations also be represented on the Blue Ribbon Panel:

- 1) Fresno Housing Authority
- 2) Fresno Unified, Fresno Adult Education and Fresno County Office of Education
- 3) Law enforcement
- 4) Transportation Authority
- 5) Health care and hospital providers
- 6) Land use and city planning

To facilitate coordination of local collective impact efforts to reduce infant mortality, a representative from the Preterm Birth Initiative Steering Committee or its work groups should also sit on the Blue Ribbon Panel.

Finally, we encourage First 5 Fresno County to carefully consider the guiding principles above when selecting members for the Blue Ribbon Panel, and moving into the next phase of the work.