

Infant Mortality in African American Infants and Infants In Rural Areas Study: Advisory Work Group

January 7, 2019

FINAL Meeting Summary

Location: Maryland Health Care Commission, Room 100, 4160 Patterson Ave., Baltimore, MD. 21215, Remote Access Available.

Purpose of meeting: To discuss forming a permanent Council on Infant Mortality, including disparities.

Attendance (In person/phone):

Ben Steffen	Lee Woods
Noel Brathwaite	Stacy Brown
Megan Renfrew	Lillian Holmes
David Mann	Carla Bailey
Reagan McDonald Mosley	Anna Rodney
LaWanda Edwards	Shanna Wideman
Laura Lawson	Geoff Dougherty
Adrienne Collier	Donna Strabino
Ann Jones	Shirley Devaris
Kendra McDowell	Lee Hurt
Marianne Hiles	Anna Rodney
Rebecca Dineen	

Note: There was a technical difficulty during this meeting preventing verbal participation by attendees using remote phone access.

Welcome & Introductions: Megan Renfrew, Chief of Government Affairs and Special Projects at the Maryland Health Care Commission (MHCC), welcomed all attendees and facilitated a round of introductions. Ms. Renfrew also provided an overview of the agenda and discussion guide for the meeting.

Key Themes from the Fall of 2018

Each subgroup met once during the Fall, in addition to the work group meeting in September. Key themes from these meetings include the following:

- Maryland has made substantial progress on infant mortality since the 1980's but racial disparities continue.
- The disparities that appear between rural and urban rates are largely attributable to race.
- Substantial work is being done on this topic in the State by many entities.
- While the state has access to substantial surveillance and claims data sets, this data will not be sufficient to answer all questions.

Infant Mortality in African American Infants and Infants in Rural Areas Study: Advisory Work Group, January 7, 2019, Meeting Summary

- A number of topics have come up in several meetings, including access to care, the importance of preconception health and education, difference in barriers to care based on geography, funding sources, stress and racial bias, social determinates and social services, the importance of the whole family unit/social support network, data sharing & electronic systems that promote continuity of care, care transitions, behavioral health, and substance abuse disorders.
- The importance of keeping this study focused on the target populations, producing strong evidence for change, and developing recommendations that lead to meaningful change, are all important goals moving forward.

Updates on Subgroups

Members were encouraged to join the subgroups as more participation is needed.

The Community and Consumer Experience Subgroup discussed conducting on the ground interviews with families who have important information to share. There was a sense from some that “the on the ground” stores have a strength and validity that can’t always be seen in data.

The Data Analytics Subgroup is focused on approaches to analyzing available data. Trend lines show the state is going in the wrong direction with respect to disparities, which are persistent. The Data Analytics Subgroup is considering a number of “factors” that impact infant mortality for potential further study.

The Innovative Programs Subgroup discussed successful programs, the need for more preconception care and education (including, potentially, through schools), the potential for pediatricians to provide support to new families, data access issues, international models, and other topics.

Meeting summaries from the subgroup meetings are available on the Study’s website:
https://mhcc.maryland.gov/mhcc/pages/home/workgroups/workgroups_african_american_rural.aspx

Review of Work Plan

There are five more workgroup meetings planned between April and October 2019. The last two meetings will be used to review the report for the legislature, due November 1. The MHCC continues to acquire contractors to support the literature reviews.

Discussion of Permanent Council on Lowering Rates of Disparities in Infant Mortality Rates

The statute that established this study requires that MHCC “make legislative recommendations regarding the establishment of a permanent council for lowering rates of disparity with respect to infant mortality”. Because of the scope of this study, this workgroup is only looking at data on

Infant Mortality in African American Infants and Infants in Rural Areas Study: Advisory Work Group, January 7, 2019, Meeting Summary

racial/ethnic and geographic disparities in infant mortality and have not considered other types of disparities (income, education level, etc.).

Ben Steffen, Executive Director of MHCC, led a discussion the proposed Council.

Workgroup members felt that it would be useful to have a central place to center the public focus and center focus on the issue of infant mortality. Maryland needs sustainable change, including impact on bias in the health care system. A Council could offer training, programing, or otherwise keep action moving forward. It is not enough to just collect data and develop knowledge if there is not a structure and plan for continuing to make change.

The Council could bring communities, state entities, and other stakeholders together to keep a focus on infant mortality in the same way that “health in all” policies keep a focus on health. This should include consideration of social determinates of health. The purpose of the Council should be broad and should include housing, transportation, business, food, and other entities that impact social determinates of health. A major barrier to women is getting access to all services in one place: health care, transportation, other services. The needs of urban and rural women are similar in that there are services available, but getting all the right services to a single woman at the right time and place is a challenge. It will take time to solve the many problems that exist related to infant mortality and a permanent Council would be able to continue problem solving over time. We need to deal with trauma and past history and also move past it. The Council should be focused on action.

A number of entities already exist within the State (and local) government that have some relationship to infant mortality: the fetal and infant mortality review (FIMR), the maternal mortality review (MMR), the child mortality review (CMR); the Office for Minority Health and Disparities, and the Maternal and Child Health Bureau in the Maryland Department of Health. The recommendations could suggest building out these efforts to fill gaps or creating a new entity. It would be useful to have a chart/crosswalk of the existing organizations in the State to allow comparison and make it easier to understand the gaps.

Infant mortality is very complex. Given the complexity of the topic, it would be helpful to simplify the administrative processes at the State and local levels, rather than add additional complexities. It is also important not to duplicate existing efforts, which could result in overstretched staff and stakeholders. Overlapping areas of concern are acceptable, as long as the entity brings new resources to the table, rather than stretching existing resources.

Simplifying the administrative processes at the state and local level is important. The FIMR and MMR are hubs, but there are gaps in who participates and their processes can be so professionalized/medicalized that it is difficult for grass roots community members to feel that they have a powerful role in the process. The State MMR is setting up a stakeholder group and the Baltimore City MMR is trying shift to a more consumer/stakeholder focus. Local FIMRs

Infant Mortality in African American Infants and Infants in Rural Areas Study: Advisory Work Group, January 7, 2019, Meeting Summary

(funded through State) don't usually have annual reports. The State MMR has an annual report, which could be a useful background document.

There are experts in communities who are doing the work and have expertise: midwives, lactation consultants, others. We need to seek out that expertise, involve community leaders and hear on-the-ground experience, and give those organizations authority to hold State entities accountable for change. Faith-based organizations, non-profits, community organizations, youth, Managed Care Organizations, insurance companies, and human resources professionals, would also be important stakeholder groups.

The Council could bring people together to focus on social determinates of health, and look more broadly at the factors and disparities that impact infant mortality. Council functions could include convening, data-gathering, monitoring function. The State doesn't need another think tank; it needs an organization that can mobilize and coordinate existing resources and change outcomes. This approach to change should be holistic. This Council could be broader in scope than this Study (i.e. broader than a focus just on African American Infants and Infants in Rural Communities).

Resources are also an important consideration. The FIMR is already funded and any new Council is likely to have limited funding. It is important to bring to the table the groups that may be experiencing savings from the group's actions, who may be willing to bring funding to the table as well.

The State has previously had disease-specific councils (ex. Arthritis), which could provide examples. MHBE has a standing advisory committee, which could be a model for how to involve stakeholders. There is a social determinates of health task force in Baltimore City that could also be a useful model.

Next steps

Develop crosswalk of state organizations [IN PROGRESS]

Review Maryland's approach to "Health in All" policy [DONE}

Megan—talk to Rebecca about past administration priorities & social determinates of health task group. [DONE]

Finalize contractors [DONE].

Set up subgroup meetings over the next few months. [ON HOLD]

Ben reiterated the importance of more participants for the subgroups; Megan will send out another list to members for signing up for subgroups. [ON HOLD]