

# Discussion Guide: January 7, 2019 Work Group Meeting

## Infant Mortality in African American Infants and Rural Communities

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### Key Themes and Takeaways from Fall Meetings

- Each subgroup met once this fall.
- **Summary of Data Trends:** Maryland has made substantial progress on infant mortality since the 80's and 90's. However the racial disparities (black/white) in outcomes have continued for decades and are concerning. Despite the continued disparities, the infant mortality rate for African American infants in Maryland is actually better, on average, than the national rate for African American Infants.

In the past few years, the progress in the overall infant mortality rate has stalled, and is worsening in rural areas. When geographic data is race adjusted, it appears that this trend in rural areas is largely driven by the experience of African American families, suggesting that focusing on African American infants is particularly important.

- **Many different entities are working on this issue and the state, and that work is long standing.** The Maryland Department of Health and its components continue to lead a substantial amount of work on this topic, as do jurisdictions, academic institutions, health care providers, funders, and nonprofits across the state.
- **While the state epidemiologists and data analysts have access to rich surveillance and claims data sets, there are limitations to the available data that could prevent answering some questions.** For example, infant mortality occurs relatively rarely, which means studying small time periods or geographic areas is constrained because the number of occurrences is too low. In addition, we don't have surveillance data that provides straightforward metrics related to the stress impacts of racial bias. Inconsistencies in how racial and ethnic data is collected and coded in different data sets also presents a challenge.
- **Reoccurring topics of interest:** Issues that were identified in multiple meetings include:
  - Access to care (financial/insurance, transportation, preconception source of primary care, etc.).
  - The importance of preconception health and education about health (including the impact of preexisting chronic conditions on pregnancy risks). A related topic is how to improve the unplanned pregnancy rate, so that more pregnancies are planned.

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- Rural communities and urban communities may have different barriers to success and need different interventions.
- While there are a number of valuable funding sources on this topic (ex. Maryland Community Health Resources Commission), access to sustainable and adequate resources for evidence-based programs is crucial to making a big change in outcomes.
- The issue of stress related to racism and racial bias, as well as stress from other factors (financial insecurity, crime, domestic violence), and the impact of that stress on health. Trust of the health care system and the direct issue of unconscious bias on quality of care was also discussed.
- Social determinates and social services—how can we intervene in ways that are accessible to individuals so that they can get their basic needs met?
- Provider capacity—how do we build provider capacity to better connect families to the resources they need?
- The importance of the whole family unit (including fathers) and social support systems was discussed.
- The potential importance of the education system (including head start programs) to reach young people and new parents. New parents could also be reached through pediatricians, both for post-natal care and for preconception planning for subsequent pregnancies.
- The importance of functional electronic systems (ex. prenatal risk assessment) and shared data to effective care and referral to social services.
- Transitions of care are crucial. Example: How do families get support when their baby leaves the NICU?
- Behavioral health is important, and linkages between behavioral health (including support for the whole family) and medical health should be stronger. This includes needing to have treatment options for substance use disorder for pregnant individuals and new parents that can support physical health needs as well as recovery.
- The importance of strong data/evidence (“so that the topic can’t be dismissed”) and how to balance that with on-the-ground experience and stories.
- The importance of keeping this study focused on African American and Rural communities (although there are many other related topics, populations, and communities that are worthy of study).
- The importance of having recommendations that lead to meaningful change.

## **Review of Work Plan**

Final Report due November 1, 2019

### **Large Work group meetings**

April 9, 2019, 3-5 PM, Work Group Meeting

June 4, 2019, 1-3 PM, Work Group Meeting

July 19, 2019, 3-5 PM, Work Group Meeting

August 27, 2:30-4:30 PM, Work Group Meeting—Review Draft Report

October 1, 2:30-4:30 PM, Work Group Meeting—Review Final Report

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## Subgroup meetings

Community and Consumer Experience- January 18, 11-12:30

Other subgroups TBD- February-June. 2-3 additional meetings/subgroup.

## Other work

Data analysis: "Factors" and cost- Winter/Spring 2019

Literature Reviews: Winter/Spring 2019

Focus group or individual interviews- TBD

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

Chapter 83 of the 2018 State Laws of Maryland requires the MHCC to conduct a study regarding the mortality rates of African American infants and infants in rural areas. The statute requires that MHCC complete six tasks in the study. One of these tasks is to "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, we have only looked at data on racial/ethnic and geographic disparities in infant mortality and have not considered other types of disparities (income, education level, etc.).

## Discussion Questions

- What are the organizational gaps that this entity, if created, would fill?
  - How would this council interact with existing state entities, include the office of Minority Health and Health Disparities; the Deputy Secretary for Public Health; the [State Advisory Council on Health and Wellness](#) (which currently covers Heart Disease & Stroke, Diabetes, and Arthritis); the Morbidity, Mortality, and Quality Review Committee (MMQRC) for Pregnancy and Childhood, the State Child Fatality Review Team, and the State Child Fatality Review Team?
  - How would this council interact with local health departments, local child fatality review teams and local fetal and infant mortality review programs?
- What are the pros and cons of establishing a permanent council on this topic?
  - What are the downside issues? Could it sap energy from existing initiatives?
- If MHCC made a recommendation to establish a council--
  - What would be the purpose of the council?
  - What are the council's duties?
  - How should members be determined?
  - What are the members terms
  - How often should the council meet?
  - What are the council's work products/deliverables, and at what frequency?
  - How is the council staffed and funded?

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### Background Documents on State Organizations related to Health Disparities

- [MHHD Overview Document](#) (brief doc that includes mission, vision, and office program highlights)
- [2017 MHHD Annual Report](#)
- **MHHD Statutory Duties and Role:** [Md. HEALTH-GENERAL Code Ann. § 20-1004, § 20-1005, § 20-1006](#)
- [Morbidity, Mortality, and Quality Review Committee — Pregnancy and Childhood](#)
- [Child Fatality Review Team](#)

### Potential Elements for legislation establishing a council, with sample language

Establishment “There is an advisory council on \_\_\_\_\_.”

#### Statement of Purpose

Sample 1: “The purposes of this section and of the advisory council that it creates are to ..., including:....”

#### Membership

##### Sample 1—Expertise focused:

“(1) The Advisory Council consists of 12 members appointed by the Secretary.

“(2) Of the 12 members:

(i) 1 shall be a physician with expertise in [\_\_\_\_\_];

(ii) 3 shall be from the field of [\_\_\_\_\_]:

1. 1 shall be from the Maryland State Department of [\_\_\_\_\_];

2. 1 shall be from the [\_\_\_\_\_]; and

3. 1 shall be an [\_\_\_\_\_];

(iii) 1 shall be from the Maryland Department of Health;

(iv) 1 shall be a [\_\_\_\_\_] professional with expertise in the area of [\_\_\_\_\_];

(v) 2 shall be [TYPE OF CONSUMERS/PATIENTS/CAREGIVERS]; and

(vi) 1 shall be from the Maryland Association of [\_\_\_\_\_].”

##### Sample 2—Focus on appointment process:

“(1)The Council consists of:

(i) # individuals appointed by the President of the Senate;

(ii) # individuals appointed by the Speaker of the House of Delegates;

(iii) # individuals appointed by the Governor; and

(iv) the following members appointed by [INSERT NAME OF EXECUTIVE BRANCH ENTITY]:

1. # individuals nominated by [INSERT ORGANIZATION NAME]; and

2. # individuals with expertise on [INSERT TOPIC]

(2) The members of the Council must be residents of the State.

*Considerations for appointment.* -- In deciding which individuals to appoint or nominate:

(1) the [INSERT TITLE OF APPOINTER] shall, to the extent practicable, consider:

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- (i) the geographic and demographic diversity of the State;
- (ii) diversity in [XXXX]; and
- (iii) [INSERT ADDITIONAL CRITERIA].”

**Sample 3-Simple:** The “council shall consist of the following # members appointed by [INSERT TITLE OF APPOINTER], in consultation with [INSERT STATE ENTITY OR OFFICIAL(S)]:

- (i) # [DESCRIPTION OF MEMBER]
- (ii) # [DESCRIPTION OF MEMBER]; and
- (iii) # [DESCRIPTION OF MEMBER].

**Sample 4—Qualifications:** “**Qualifications of members.** -- Each professional individual selected for the Advisory Council shall be knowledgeable in the diagnosis and treatment of hereditary and congenital disorders.”

**Sample 5--issue of designees:** “The Council consists of the following members:

- (1) the Attorney General, or the Attorney General's designee;”

**Sample 6—Issue of substitutes** (*optional additional language after membership criteria*): “ If a member of the Council ... is unable to attend a meeting of the Council, the member may designate [DESCRIBE TITLE OR ROLE] or another senior management staff member of the agency or organization to attend the meeting.

### Term & Removal

#### Sample 1:

- “(1) The term of a member of the Council is # years.
- (2) A member who is appointed after a term has begun serves only for the rest of the term and until a successor is appointed and qualifies.
- (3) A member may not serve more than X term.”

**Sample 2—staggered terms; removal:** “(1) This subsection applies to members of the Council appointed under subsection # of this section.

- (2) The term of a member is 4 years, except that five members may serve an initial 3-year term as required by the terms provided for staggered members of the Council.
- (3) At the end of a term, a member continues to serve until a successor is appointed and qualifies.
- (4) A member who is appointed after a term has begun serves only for the rest of the term and until a successor is appointed and qualifies.
- (5) A member may not serve more than two consecutive terms.
- (6) The Governor may remove a member for neglect of duty, incompetence, or misconduct.

### Quorum

“A majority of the full authorized membership of the Advisory Council is a quorum.”

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### Chair

**Sample 1--Elected Leadership:** “(1) At the first meeting of each Council year, the members shall:

- (i) elect a chair for a term of # year; and
- (ii) select an executive board that consists of:
  1. # members who were appointed by [\_\_\_\_\_];
  2. # members who were appointed by [\_\_\_\_\_]; and
  3. # members who were appointed by [\_\_\_\_\_].
- (2) The Council may appoint any officers that it considers necessary.”

**Sample 2--Leadership based on title:** “The Attorney General, or the Attorney General's designee, shall chair the Council.”

### Meetings

**Sample 1:** “The Council shall:

- (1) meet at least # times each Council year and conduct # public hearings each Council year on issues of importance to [INSERT POPULATION OR REPLACE WITH TOPIC]; and
- (2) open all meetings to the public.

**Sample 2-Simple:** “The Council shall meet at least twice each year.”

**Sample 3- Includes location:** “The Advisory Council shall meet at least 4 times a year at the times and places that it determines.”

### Compensation & Reimbursement

**Sample 1:** “A member of the Council:

- (1) may not receive compensation as a member of the Council; but
- (2) is entitled to reimbursement for expenses under the Standard State Travel Regulations, as provided in the State budget.

### Staff

**Sample 1—Simple:** “The Maryland Department of Health shall provide for staffing of the Advisory Council.”

**Sample 1a—Simple:** “The Secretary shall designate the staff necessary to support the council”

**Sample 2-Shared Responsibilities:** “The staffing responsibilities of the Council shall be shared by the Department of Information Technology, the Governor's StateStat Office, and any other staff designated by the Governor.”

**Sample 3- Optional authority to hire consultants—**“The Advisory Council may employ consultants subject to the State budget.”

**Sample 4-Detailed:** “The [INSERT EXECUTIVE BRANCH ENTITY] shall:

- (1) provide staff support for the Council;
- (2) develop, in consultation with the Council, an initial application and application process;
- (3) work with established public or private [\_\_\_\_\_] organizations in the State to select representatives to apply to become a member of the Council;

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- (4) ensure that members of the Council provide a broad representation of all jurisdictions and populations;
- (5) organize at least # Council meetings per Council year;
- (6) assist the Council in preparing recommendations to the Governor and the General Assembly; and
- (7) appoint members of the Council from lists of nominations provided by the persons making the nominations specified in subsection # of this section.

#### Duties

**Sample 1-Advisory to Department:** “The Advisory Council shall:

- (1) Advise the Department on the implementation of the Program;
- (2) Advise the Department on the development of protocols to assist hospitals, health care providers, and audiologists in conducting universal newborn hearing screening and follow-up hearing evaluations of infants;
- (3) Provide consultation to the Department in the establishment of an educational program for families, professionals, and the public that can be integrated with existing State and local education agency programs; and
- (4) Review any materials the Department may distribute to the public concerning the Program.”

**Sample 2-Advisory to Executive and Legislative Branches:** “The Council shall:

- (1) inform the Governor and the General Assembly of issues concerning [\_\_\_\_\_];
- (2) examine [INSERT DESCRIPTION OF ISSUE]
- (3) recommend one legislative proposal each legislative session concerning an issue included in item (2) of this subsection for possible introduction;
- (4) conduct a public awareness campaign to raise awareness about the Council among [DESCRIBE POPULATION];
- (5) participate in [\_\_\_\_\_] activities or organizations;
- (6) advise [\_\_\_\_\_] on [\_\_\_\_\_] issues;
- (7) collect information from [\_\_\_\_\_] in order to inform the activities of the Council; and
- (8) cooperate with [INSERT EXECUTIVE BRANCH AGENCY/ENTITY] in [INSERT TASK].”

#### Priorities and Procedures

**Sample 1-Simple—**“In consultation with the Advisory Council, the Department shall develop guidelines for the operations of the Advisory Council”

**Sample 2—Workgroups:** “The Council may establish workgroups as necessary to complete the duties of the Council.”

#### Report

**Sample 1—annual report:** “On or before the last day of the year, the Council shall report its activities to the Governor and... to the General Assembly.”

**Sample 2—biannual report:** “Beginning [INSERT DATE], and every 2 years thereafter, the Council shall submit a report of its activities to the General Assembly in accordance with § 2-1246 of this article.”

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### Gifts, Grants in Aide:

**Sample 1:** “Gifts, grants, or aid.

“If the federal government, any of its agencies or officers, or any other person offers to this State or to any county any services, equipment, supplies, materials, or funds by way of gift or grant for purposes of XXXXX, this State, acting in accordance with the requirements of law, may:

- (1) Accept the offer; and
- (2) Authorize any officer of this State or of a county to receive and use the aid and assistance.”

### Definitions