

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

**June 4, 2019**

**Meeting Summary**

**Location:** Maryland Health Care Commission, Room 100, 4160 Patterson Ave., Baltimore, MD 2125.  
Remote Access Available.

**Purpose of the meeting:** Discuss initial findings from program inventory. Discuss two preliminary study themes with the goal of identifying possible recommendations related to those themes.

**Attendance (In person/phone)**

*Chair:* Ben Steffen

*Vice Chair:* Dr. Noel Brathwaite

Matt Celentano

Sherrie Xue Dai

Rebecca Dineen (phone)

Bonnie DiPietro (phone)

Dr. Geoff Dougherty

Maisha Douyon Cover

Anne Eder

LaWanda Edwards

Marianne Hiles (phone)

Amelia Jamison

Neal Karkhanis

Pam Kasemeyer

Sandy Kick

Dr. Dushanka Kleinman

Mark Luckner

Dr. David Mann

Dr. Russell Moy

Dr. Marian Moser Jones

Dr. Lillian Norris-Holmes

Dr. Meghana Rao

Megan Renfrew

Renee Roberts

Dr. Sandra Crouse Quinn

Emma Schreier

Debbie Quint Shelef

Kristin Silcox

Dr. Marie Thoma

Shanna Wideman (Phone)

Dr. Ben Wormser (phone)

Andrea Williams-Muhammad (phone)

Lara Wilson (phone)

**Agenda Item #1: Welcome & Introductions**

Ben Steffen, Executive Director at the Maryland Health Care Commission (MHCC) and chair of the workgroup, welcomed all attendees and facilitated introductions.

**Agenda Item #2: Dr. Marie Thoma's Presentation of Initial Findings from the Program Inventory & Discussion**

Dr. Marie Thoma from the University of Maryland presented preliminary findings on an inventory of existing programs in the State of Maryland. The inventory includes programs that address infant mortality (IM) or its risk factors (such as low birthweight or preterm birth) and have a focus on the

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preconception, prenatal, and/or postpartum period. Information on these programs is collected through a web search, review of publicly available data from websites and program documents, and a survey. The survey is ongoing.

The inventory currently includes 81 programs. 10 programs were focused on data-collection and surveillance (and were excluded from later analysis). 71 provide direct services. The 71 programs are nearly equally divided between state government, local government, and non-profit/other.

The three most frequently described services provided by programs included 1. Home visiting, 2. Health education (e.g. parenting classes, sex education, baby care kits, prenatal classes), and 3. Referral Services (including programs that may conduct screening for other issues like substance abuse, mental health, etc. and/or provide referrals). The least common services included: smoking cessation, substance abuse, mental health services, housing, breastfeeding support, nutritional support, and safe sleep resources (above and beyond health information – i.e. provision of resources and support such as providing a crib, assisting with lactation support, etc.).

The most common populations served by the programs were pregnant and postpartum women. Target audiences frequently included low-income or underinsured women, but very few programs explicitly described targeted specific racial/ethnic groups. 10 percent of programs are offered State-wide. High-population counties have more programs than low population counties.

Dr. Thoma described some of the novel or innovative strategies captured through the inventory. These included community baby showers, community events in barbershops, and using community health workers in at-risk communities. Supportive and supplemental practices could include provider training (often online and accessible, providing CEUs to incentivize training), and/or the provision of other support (child care services, language support, disability services.).

Limitations include the reliance on available web-based data extraction. Many questions cannot be addressed from a website or publicly available resources. Hopefully the survey will provide additional details, but finding appropriate and up-to-date contact information for programs has been a challenge, delaying survey distribution to program leaders.

***Questions for Dr. Thoma***

Mr. Steffen opened the floor for questions. Questions from workgroup members fell into two general areas: 1.) clarifying what had been included in the inventory (ex. MCOs, financial information, racial/ethnic make-up of population) and 2.) assessing how the search methods influenced the inventory's findings.

Dr. Thoma clarified, that the data in the inventory was limited by what is listed on websites or in public documents but the survey should provide more complete information, including about racial/ethnic groups served.

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MCOs did not come up during the search process. Since MCOS represent such a large portion of the state's total investment on this issue, Mr. Steffen urged Dr. Thoma to talk with Ms. Kick to see if there are ways to incorporate MCOs into the inventory in some way.

Ms. Renfrew and Mr. Steffen assured Dr. Thoma that they'd work together to distribute the survey to program managers. Once the survey goes out, there is a possibility of following up with phone calls to increase completion.

Two work members mentioned possibly including additional items into the survey. One item would be focused on 'sustainability', specifically, "How do program managers sustain these programs?" and a second item would be about 'capacity', specifically, "Do programs have the capacity to collect data" if not, how do they show impact? And another question on whether these programs are currently 'at-capacity' perhaps indicated by whether they have to turn-people away from services or if they have waitlists for services. The "sustainability" issue is already addressed by the survey. Hopefully, with this information, those at the state level could assist different programs.

As an incentive to complete the survey, a workgroup member suggested offering the programs something that is valuable to them - such as a report about the agencies, or information on where they stand relative to other programs, etc.

Two issues regarding the report were also raised. First, the utility of a graph presented in the slides was questioned. Ultimately the group decided that capacity would be a better measure than simply using the number of programs. This slide will not be included in any final report materials. Second, the question of why items hadn't been listed in order from greatest to smallest was also raised. Dr. Thoma assured the workgroup that future tables will be rearranged.

**Agenda Item #3: Update on Other Study and Related State Activities**

Ms. Renfrew provided the workgroup with updates related to the overall project. This was the 4th workgroup meeting, 3 more are scheduled. The current plan was to spend the remainder of the current meeting and the next meeting considering themes that have emerged in the work, to surface some recommendations for the draft report. The draft is due for internal review in August, with a revised report coming in October. The risk factors review has been revised, State staff are working in vital stats and cost analyses, and she is working on writing up materials related to a possible permanent council.

Ms. Sandy Kick provided updates on the State Medicaid program. First, the 1115 waiver amendment for national diabetes Health Choice prevention programs will be implemented on September 1, 2019. All nine MCOS are involved.

Ms. Kick also described an ACES pilot program with limited housing support. This discussion prompted another workgroup member to bring up a successful program, the Shepherd's Clinic, which deals with underinsured, low-income, mostly male populations in Baltimore. He described it as a rare center that works with a dual processing system to serve clients without insurance alongside those that are newly insured through the Affordable Care Act.

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Dr. David Mann provided an update on his work investigating the feasibility of looking at national and state data systems to possibly be able to determine the distribution of the determinants of infant mortality across urban and rural areas in Maryland. For example, does the prevalence of diabetes among women of childbearing age account for differences in infant mortality between rural and non-rural areas? His own offices are conducting an ecologic look, in lieu of population level data. However, he emphasizes that this is just something they're working on, it may or may not actually happen.

**Agenda Item #4: Discussion of Two Preliminary Study Themes**

**Theme 1: Efficient Coordination of Programs and Care**

The work group discussed “efficient coordination of programs and care” as a potential study theme. The workgroup agreed that getting people connected to the programs that they need is an important issue. Leveraging existing programs and funding streams is easier than creating and funding new programs.

The group talked about the need for a resource that was an updated inventory of programs for referrals, perhaps through a website or an app, which has easy access to contact information and websites or enrollment platforms. This would be a single source for community resources that could be easily accessed by case managers. Existing resources include Bertha’s Place (<http://www.tccwb.org/resources/aunt-bertha/>). One MCO is using a resource called HEALTHIFY (<https://www.healthify.us/>) for this purpose. The lack of coordination leads to unused capacity and duplication of efforts.

Another workgroup member emphasized the need to create processes and lines of communication that may outlive existing programs. For example, providing a structure to bring local health officers and policy groups together has produced productive new ideas. Front line people have info that policy people don’t have and vice-versa, creating value to both levels.

Funding proper care coordination is key. A workgroup member described an existing care coordination system that would ideally have \$700 per infant, but currently only has about \$200, limiting its effectiveness. The funding distribution should take into account the disease burden/level of illness and poverty level, so that resources are focused on people who need it most. Thrive by 3 Fund is one mechanism to allow investors to put money into a program.

Another issue is record-keeping. Ideally, records should be electronic and the system should be adequately funded. The risk assessment and referral process would be easier if made electronic. Data use agreements and data sharing practices need to be appropriate to protect client confidentiality while still making good use of data; reducing barriers to data collection and analyses. Electronic medical records for clinical care are well established, but electronic records for care coordination are needed. Building on existing programs, like the Pregnancy Risk Assessment (PRA), could help, rather than trying to get people to use a new system, which is harder. Is a data repository needed?

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The Pregnancy Risk Assessment (PRA) process interested a number of stakeholders. The forms vary by county. Some jurisdictions (Baltimore City) report on how they have reached out based on PRA forms, while others do no reporting. Aligning and strengthening existing systems is key. The Risk Assessment should be electronic and should communicate with other care coordination activities in a single systems.

It is important to engage both the public and private sector. They have different strengths and goals. The public sector does not have the funds to address these issues alone. And the private sector could benefit if they stand with the public sector to resolve these challenges.

**Theme 2: Consistent and Reliable Funding**

The work group discussed “Consistent and Reliable Funding” as a potential study theme.

Sustainability is important. Programs either need to be perpetually subsidized or become part of a solvent business plan. A strategy is a “shared savings” approach where organizations that save money from improved outcomes to capture and reinvest savings into the successful programs. Getting funding from the private sector or insurance payment is another strategy. Medicaid is a major source of public investment. Tax dollars are needed for subsidies.

Could local health departments, which depend on Medicaid, be mandated to provide services in exchange for grants? Existing home visiting programs are often pilots and lack insurance reimbursement. Requiring reimbursement for home visiting services would be an easy way to improve sustainability for home visiting services, which currently depend on grants. These programs reduce hospitalization and NICU days, so it’s cost-effective for insurance.

Certification for community health workers (CHWs) and other paraprofessionals like doulas is a step on the path towards reimbursement.

Perhaps perinatal health could be tied to “population health credits” under the Maryland Total Cost of Care model. Right now, Maryland only has credits for diabetes programs. Perhaps we could renew the discussion on whether this would be a thing to consider for credits. Connecting infant mortality to the Total Cost of Care model could elevate the conversation, connect with issue with a high-profile state-level effort. Under this system, hospitals should want to keep communities healthy and utilize preventive services. Systems can’t afford a lot of emergency visits, NICU charges, and readmissions.

The hospital rate setting system may have some issue with incentives—while hospitals are not paid for volume, reducing volume does not lead to a 1:1 reduction in fees.

Some programs and outcomes are worth subsidizing we have to make the “business case”. What is the “business case” for infant mortality? The cost comes from sick infants who don’t die who generate ongoing care and costs along their entire lifespan. And non-economic costs like the family impact of mortality.

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Some workgroup members argued that our society should invest in pregnant women and infants for moral, rather than purely economic, reasons. Infant mortality creates trauma for a household and an entire community. The cost of that trauma is poorly understood but is quite significant. This is something that we should be paying for with taxes. It's a bipartisan issue as the survival of moms and babies is essential to keep society going.

The business case still matters. In cash-strapped communities there are always going to be other issues that pull focus from this topic, as important as it is. When those situations happen, it is difficult to force local communities to choose between funding schools and funding these programs.

**Agenda Item #5: Next Steps**

Ms. Renfrew asked for comments on the April meeting summary.

The July meeting will continue conversations on themes and include more updates from the UMD team. Please direct questions, resources, and comments to either Ms. Renfrew or Ms. Edwards.