UNLOCKING POTENTIAL: THE NJ PRITZKER LEADERSHIP TEAM
MATERNAL AND INFANT HEALTH CONSENSUS DOCUMENT
OCTOBER 11, 2019

How to use this document: This consensus document is intended to document key information and decisions made during a planning meeting. This information will be reviewed by meeting participants for edits and additions and then finalized. The finalized consensus document will serve two purposes: to document the outcomes of the planning meeting and to inform an overall infant and toddler plan.

New Jersey Maternal and Infant Health Meeting October 11, 2019

The purpose of this meeting is to continue planning for the Pritzker grant which chose to focus on home visiting, child care, infant mental health, maternal and infant health and systems-building. Maternal and infant health outcomes were not part of the original Think Babies agenda but emerged as an important initiative of New Jersey's First Lady to address the longstanding issue of Black infant and maternal mortality. Given the importance of this issue and the energy associated with the First Lady's agenda, maternal and infant health issues were included in the Pritzker planning grant scope. The goal for the meeting was the learn more about the First Lady's vision and to think together about how the systems align and how we assure the success of all the system programs and initiatives. These notes are structure as notes rather than decisions or action steps given the focus of the meeting.

Maternal and Infant Health Landscape

Key maternal and infant health indicators (including low birth weight, preterm births, and infant and maternal mortality) have not improved significantly over the last decade in New Jersey, and significant racial and ethnic disparities persist. New Jersey ranks 45th in the nation for maternal deaths according to the United Health Foundation. 37 women die, on average, for every 100,000 live births in NJ, compared to 20 nationally. An African American woman in New Jersey is five times more likely to die due to pregnancy complications than a white woman. An African American infant is three times more likely to die in their first year of life than a white baby.

Although the overall infant mortality rate in New Jersey is lower than the national rate (4.7 per 1,000 live births versus 5.9 per 1,000 live births in 2015), the disparity between White, non-Hispanic (NH), and Black, NH, is significant. In 2015, the infant mortality rate for White NH was 3.0 per 1,000 births, while for Black NH, the rate was 9.7 per 1,000 births. The infant mortality rate for Black, NH, is more than three times that of White, NH, and this disparity has remained constant for at least ten years.

The federal Centers for Disease Control and New Jersey's Department of Health are also looking closely at c-section birth rates; The number one cause of maternal mortality is hemmorhage, and one of the leading causes of hemmorhage is a condition caused by C-sections, called placenta accreta. The cesarean rate among low-risk, first time, full-term, in-position (NTSV) births in New Jersey (NJ) have seen an increase from 23.5% in 1990 to 36.3% in 2009. The provisional rate for 2016 is 30.3%. Although there has been a modest decrease in NTSV cesarean rates, current data

shows that we are still far from meeting the Healthy People 2020 target of 23.9%. For mothers, C-sections often mean higher rates of hemorrhage, transfusions, infection, blood clots, and postpartum depression. Also, to the detriment of both mother and baby, breastfeeding rates are lower following C-sections. Additionally, once a mother has had a C- section, she has a greater than 90% chance of having the procedure for subsequent births —leading to higher risks of major complications, such as hysterectomy and uterine rupture.

There are many potential causes of these disparities, but recent research has highlighted the effects of social determinants of health such as economic disadvantages (i.e., underemployment, or unemployment), limited education (e.g., low educational attainment), environmental barriers (e.g., housing instability, structural racism), and social/behavioral factors (e.g., nutrition and exercise) as major contributors to health outcomes.

The First Lady's has a primary focus on the pre-natal to birth stage and has three key strategies to address the poor maternal and infant birth outcomes, including: convening state government departments to focus on MCH issues; convening partners and stakeholders via the Annual Black maternal and infant Health Leadership Summit; and convening and providing resources to communities via the First Lady's Family Festival event series (funded by the Nicholson Foundation). Many of the solutions identified at the last Summit were actually enacted into law such as: Medicaid episodes-of-care; increasing Medicaid coverage to eligible mothers for up to 180 days after delivery; and ending Medicaid payment of unnecessary elective c-sections.

An important initiative of this administration, led by the Department of Health, is the program Healthy Women, Healthy Families, that reallocated state funds to focus on disparity of birth outcomes. "The Healthy Women, Healthy Families (HWHF) Initiative works toward improving maternal and infant health outcomes for women of childbearing age and their families, while reducing racial, ethnic and economic disparities in those outcomes through a collaborative coordinated driven approach." Strategies include: Community Health Workers, Central Intake Hubs, fatherhood engagement, breastfeeding supports, and group prenatal care. There are many aspects of this initiative including grants to health hubs and the delivery of equity training to system professionals. The initiative has three pilots that deploy 40 community-based doulas in Trenton, Camden, Newark who support moms through pregnancy, birth and the postnatal period. In May, legislation passed that enables Medicaid to reimburse for these doula services.

Discussion: Maternal and Infant Health Landscape

The group raised questions about how consumers come to know about and connect with the services that are being offered to them. There is a need for a coordinated information campaign with consistent and clear messages. There are opportunities and a need to engage nontraditional partners in communicating to families. Most consumers do not navigate to the DOH website but rather learn of services from their churches,

neighbors, childcare programs and libraries. Engaging these partners requires financing and capacity; for this reason, 20% of the Healthy Mothers, Healthy Families grants are required to support nontraditional partners.

The group discussed how to address institutional racism and the negative experiences that black mothers have when accessing services. Some suggested solutions include developing clearer protocols and publishing reports cards that indicate the practice' adherence to care standards (universal accountability for quality). Others suggested the need create contractual and financial mechanisms to ensure that consumer voice informs accountability. There was also consensus that training needs to be coupled with reflective supervision to support behavior change. The group recognized that systemic change in the medical field will require medical schools and allied health professional organizations recruiting a diverse workforce and embedding interprofessional education, trauma-informed approaches, and cultural humility into their preparation."

The group recommended educating and providing services to both female and male teenagers in middle school (and prior to their reproductive years) could be impactful to share key messages around reproductive health, contraception and how to be an empowered consumer of health services more broadly.

The group discussed ways to ensure the institutional barriers and incentives for quality services are in place. These may include bonus payment for indicators being met as well as denying payment for risky or poor services. For example, Medicaid will no longer reimburse for elective c-sections.

Members of the group raised the opportunity to highlight the providers who are providing excellent and compassionate care as exemplars for others. There is a need to understand why people are not engaging in prenatal care and to learn effective strategies and approaches to engaging and retaining women in high quality care. The issue of respectful maternity care is more than nice language but an important indicator of quality. A 2019 survey (that included NJ women) found of more than 2,100 U.S. mothers found that 1 in 6 reported 'mistreatment' during childbirth, including being ignored, threatened or berated, or losing their autonomy. Women of color were even more likely to report such experiences.[i]

Navigation access to high value maternity care and transparency in data regarding NJ maternal care facilities was also raised as a priority issue. These data may include: Individual hospital cesarean rates, episiotomy rates, or VBAC rates. Currently NJ does not have a mechanism like California to help consumers/ families find facilities that offer high quality care and avoid overuse of procedures.

New Jersey does not have a comprehensive childbirth education system; there are no shared records or listings of where child classes are health, for how long, how much they cost, and why should participate. Childbirth classes are an important resource to prepare expectant parents for the birth process and to provide parenting resources such as how to care for a newborn and how to identify care providers.

There are national exemplars of health systems and institutions who have identified their responsibility to close the disparity in patient outcomes. This is a leadership responsibility and the decision to collect and use consumer data and to address implicit bias needs to come from top officials and executives in these systems. There is more thinking to do around how the state can incentivize these activities.

Group Discussion: Access for Families

Recognizing that parent and caregiver voice and experiences are critical to ensure that systems are designed to meet their needs and are easily accessible, we need to engage them directly. The purpose of this discussion was to think about how to effectively engage parents and ensure the right information is collected to inform planning. There were many, varied issues addressed in these discussions.

Family Festivals are seen as a positive method for family engagement and to share local resources. The events are positively framed and offer the opportunity for in-person connections. The group asserted a need for specific follow-up activities to be in place to ensure participants used resources and their needs were met.

Transportation was discussed as a significant barrier for parents with small children in accessing health services.

Consumer preference and needs data should inform service provision and organizational accountability.

The workforce needs to be sensitive and attuned to the needs of consumers. This workforce needs to understand trauma-informed care and be prepared to address social aspects of wellness including social isolation. Programs like Centering Pregnancy are designed to enhance the social connections of women (and address health needs).

Starting education and outreach early in lifespan is seen as a critically important step to ensure young women and men make good decisions and access care early in their reproductive journey. Middle school health education programs could be enhanced to provide this information.

There are opportunities in the current systems to enhance supports to families; the groups discussed the role of Central Intake, Child Care Resource and Referral, community health workers, and others to provide supports. The overarching belief is that in-person and intensive supports are needed to ensure families needs are understood and they are referred (and engage in services) with the right providers. There was discussion of developing navigator or ambassador roles (akin to ACA recruitment navigators that were very successful in NJ) to support this and the need for these roles to be reflective and embedded in communities. Technology can also support better connections to the system; a group discussed establishing enrollment kiosks in multiple venues (WIC office, pediatricians, grocery stores, etc) to support benefit and program enrollment.

Equity is identified as a key challenge to system performance. Many meeting participants relayed stories of families and their own experiences of being treated poorly by providers and system professionals. The discussions focused on how to ensure accountability for consumer experiences, how to ensure consumers participate in decision making, and how to shift the culture and paradigm from where it currently is.

There needs to be intentional engagement of fathers as advocates for maternal and infant health and as an important consumer of MCH services.

Group Discussion: Alignment and Coordination

The group discussed how all of the services we have addressed over the last few months (home visiting, child care, infant mental health) including maternal and infant health are a part of a continuum of services for pregnant women, infant and toddler children and their families. The group questions how these can be aligned and articulates a need to align these services to ensure there is appropriate scale and reach to meet community needs.

The group discussed the opportunities that health information exchange (HIE) data systems are working to help connect service providers. There is currently lots of tracking under way and therefore opportunities to conduct electronic referrals and more robust data exchange.

Central Intake could be an avenue of entry to families for all of these services including housing, child care, early education, home visiting and health care services.

There is a need to assure that families have in-person outreach services and experience a 'human touch" that supports them in becoming engaged with the system and its services. The group articulated a priority for human interaction over electronic connection.

There are concerns about how families get connected to services. Programs such as Family Connects may offer a solution whereby families get services during the prenatal period or immediately upon delivery. This is a personalized connection with services immediately following birth that build connections to families and get families enrolled in needed services. How might Family Connects be integrated into Central Intake?

The group conceptualized a role for Central Intake or other coordinating entity that assures enough service to families who need them. This entity can ensure there is case conferencing with more integrated services for high risk families and coordinate the service providers. There is a need to assure that families have equitable access to services across the state; a robust Central Intake with proactive outreach can ensure that the most vulnerable families are connected and that geographic equity can be achieved.

Group Discussion: Communications

The group discussing communication and messaging talked about how the conversation during this discussion focused on equity and racism and it raised questions about our agenda to date.

The group felt strongly that there are specific actions that needed to be taken regarding the issue of race. Firstly, there is a need to clearly state as a community that the issue is race and to define and describe how this harms NJ families. Secondly, as a community, New Jersey leaders and community members need to state that this is not acceptable. And lastly, the community needs to determine and describe how it will address this issue and its negative impacts on children and families.

The group felt strongly that the language and use of the term "equity" needed to be replaced with the term "race."

The group discussed the need for a public education and messaging campaign at the community level with specific actions for various actors to take. The group acknowledged that the data is very powerful but stories of New Jersey women and families are critical to this campaign.

The campaign needs to have various outlets and methods including social media.

There is a need to apply this to the broader agenda around infant and toddlers; the leadership team can look at every aspect of the system and understand how the issues are impacted by race and then to trace the experiences of families and how their engagement and ongoing experiences are impacted.

[i] https://www.statnews.com/2019/11/08/new-parents-providing-feedback-difficult-childbirth-experiences/?fbclid=IwAR3imdp2JIus9r5zuoiEq1ooLEQBqwA1fGBoKj_yJ7wZ7IOUP_LhS99jCfg
https://www1.nyc.gov/assets/doh/downloads/pdf/ms/respectful-care-birth-brochure.pdf