

Voice Your Vision – Share Your Birth Story

A Conversation on Maternal Health in New York State

The New York State Department of Health
Commissioner's Community Listening Sessions

August and September 2018

Message from the Commissioner

As part of a comprehensive approach to address maternal mortality and reduce racial disparities in outcomes, Governor Cuomo asked the New York State Department of Health (NYS DOH) to partner with community activists to visit high-risk areas across the state to listen to local concerns regarding pre- and post-natal healthcare. Stakeholders, including pregnant women, women who recently gave birth, and those individuals disproportionately impacted by adverse maternal health outcomes were engaged to share the barriers they face that make it difficult to obtain routine prenatal care as well as discuss strategies to better increase awareness of the signs and symptoms of pre-eclampsia and other causes of maternal mortality and morbidity.

In partnership with the NYS DOH Maternal and Infant Community Health Collaboratives (MICHC) programs, listening sessions were conducted in seven communities: Buffalo, Syracuse, Albany, Bronx, Brooklyn, Harlem and Queens. The MICHC grantees were invaluable in organizing the Voice Your Vision – Share Your Birth Story Community Listening Sessions and engaged other community-based partners to recruit participants and to help facilitate the discussions. This series of participant led discussions engaged a total of 244 women, including recently and currently pregnant women and families, and women who have experienced an adverse birth outcome. With a structure loosely defined around issues related to family planning, pregnancy, childbirth, and postpartum care, participants were allowed the opportunity to drive the conversation themselves, identifying the unique themes and issues that resonated with them and their communities. NYS DOH is indebted to all of the community participants, who were unfailingly generous in relating their stories, expressing what would have made their experience better, and sharing in NYS DOH's commitment to improving the lives of mothers and babies across NYS. This report summarizes what participants shared.

Common sentiments expressed by participants across all seven listening sessions included:

- Feeling disrespected by providers.
- Not getting their questions answered and their concerns addressed.
- Insufficient time with the provider, and not receiving individualized care.
- Not receiving enough information to make proper decisions.
- Feeling pressure to agree to certain medical procedures.
- Lack of social support during the prenatal and postpartum periods.

Common suggestions from participants for addressing the racial disparities in maternal mortality included:

- More black and Hispanic health care professionals, reflecting the community they serve.
- Increase health care professional awareness of racial disparities in health outcomes.
- Train health care professionals on the impact of implicit bias on health care outcomes.
- Increase provider support during the postpartum period.
- Increase availability of social support for example, birthing classes, group prenatal care, doulas, midwives, community health workers and parenting classes.
- Increase availability of community services and resources, for example, community health worker services, home visiting services.

Feedback, themes, and quotes from these listening sessions were shared with the NYS Taskforce on Maternal Mortality and Disparate Racial Outcomes in the Fall of 2018. Taskforce members were provided an overview of barriers and opportunities identified by participants across the state, and were also able to hear directly from two mothers who attended these sessions. Taken into consideration with other birth outcome data, these findings aided in the development of a series of recommendations¹ from the taskforce, several of which directly address feedback from the listening sessions.

These recommendations were widely shared across NYS and helped to ensure an increased emphasis on maternal health and racial equity in the 2019 New York State Budget including \$8M over two years to support the following top recommendations of the Taskforce:

- Expansion of community health worker (CHW) services in NYS to ensure that more women and families have access to the social support, information, and advocacy of CHWs.

- An expert work group to optimize postpartum care in NYS, as well as ongoing activities to ensure a continuity of care during the postpartum period.
- Create a State Maternal Mortality Review Board
- Support education and training to reduce implicit bias in health care
- Create a data warehouse on perinatal outcomes to improve care across the state.

More information on the Maternal Mortality Taskforce recommendations and next steps can be found here: https://www.health.ny.gov/community/adults/women/task_force_maternal_mortality/

Across all seven sessions, participants consistently asked for respectful, individualized, patient-centered, accessible, quality health care. We have a collective role in addressing and breaking down the barriers to quality health care services. All NYS mothers and babies deserve the same opportunities to achieve optimal health and positive birth outcomes, no matter their race, ethnicity, community, insurance coverage, or hospital of delivery.


Howard A. Zucker, M.D., J.D.
Commissioner

Executive Summary

On April 23, 2018, Governor Cuomo announced a comprehensive initiative to target maternal mortality and reduce racial disparities in outcomes². The initiative includes efforts to review and better understand maternal mortality and morbidity, with a focus on racial disparities, expanding community outreach, and taking new actions to increase access to prenatal care.

Governor Cuomo stated “Maternal mortality should not be a fear anyone in New York should have to face in the 21st century. We are taking aggressive action to break down barriers that prevent women from getting the prenatal care and information they need.”

Having a baby is supposed to be an exciting time for a woman and those that care about her, but all too often women die while pregnancy, during or soon after delivery. Tragically, black women are approximately three times more likely nationally to die in childbirth than white women, and two to three times more likely to die than white women in NYS. Research shows that in New York City, highly educated black women still fare significantly worse than white women with less than a high school education³.

As part of the efforts to address maternal mortality and reduce racial disparities in outcomes, Governor Cuomo asked Health Commissioner Dr. Howard Zucker to partner with community activists to visit high-risk areas across the state to listen to local stakeholders, including pregnant women to explore the barriers they face that make it difficult to obtain routine prenatal care as well as discuss strategies to better increase awareness of the signs and symptoms of pre-eclampsia and other causes of maternal mortality and morbidity.

In response to the Governor’s request, the New York State Department of Health (NYS DOH) conducted seven community listening sessions across the state in the summer of 2018. Based on maternal and infant outcome data, the NYS DOH identified seven communities experiencing disproportionate rates of poor birth outcomes, especially among black women giving birth. Following this analysis, listening sessions were planned for Buffalo, Syracuse, Albany, Bronx, Brooklyn, Harlem and Queens. The NYS DOH Maternal and Infant Community Health Collaboratives (MICHC)⁴ programs were engaged as partners to plan and conduct the listening sessions. The MICHCs recruited other community partners to assist with engaging participants and to help facilitate the sessions. Community participants included recently and currently pregnant women and families, with an emphasis on engaging black women who have experienced an adverse birth outcome.

The listening sessions were titled “Voice Your Vision – Share Your Birth Story”. Each session lasted between two and three hours and included on-site child care. Unlike focus groups where the conversation is structured around a set of specific questions, these listening sessions were organized to allow participants to drive the focus of each conversation. Loosely centered around four topics (planning for pregnancy, pregnancy, childbirth, and the postpartum period), facilitators introduced each topic and kept participants on topic while scribes at each table captured participant feedback in real time. Each session had about 35 community participants (see *Table 1*). Sessions began with DOH leadership, including Commissioner Zucker framing the purpose of the

Table 1: Community Listening Sessions on Maternal Mortality

Location	Date	MICHC Partner	Total Participants
Brooklyn	8/9/18	CAMBA Inc., and Wyckoff Heights Medical Center	27
Albany	8/13/18	Albany County Dept. of Health	28
Bronx	8/16/18	Urban Health Plan	26
Buffalo	8/21/18	Buffalo Prenatal/Perinatal Partnership	43
Queens	8/30/18	Public Health Solutions	43
Harlem	8/30/18	Northern Manhattan Perinatal Partnership	40
Syracuse	9/14/18	Onondaga County Dept. of Health, and REACH CNY	37

session. Participants were engaged in a discussion on the barriers and issues impacting their birth experiences. After the discussion, participants took turns sharing their biggest take-aways.

After all seven sessions were conducted, the written record of participant feedback, taken by scribes, was analyzed and summarized to produce a statewide report identifying overarching themes. This report summarizes what participants reported at the listening sessions.

Common barriers expressed across all seven listening sessions included:

- Access to health care (limited facility choice, quality of provider and facility care).
- Poor communication with health care providers (especially feeling providers were not listening to them, that they were not given enough time with providers, and that few providers reflected their lived experience).
- Lack of information and education from providers.
- Racism and its impact on the quality of care received.
- Disrespect from health care providers, including support and administrative staff.
- Lack of social supports.

And common suggestions for addressing the racial disparities in maternal mortality included:

- More black and Hispanic health care professionals, reflective of the community.
- Increase health care professionals' awareness of racial disparities in health outcomes.
- Train health care professionals on the impact of implicit bias on health care outcomes.
- Increase provider support during the postpartum period.
- Increase availability of social support for example, birthing classes, group prenatal care, doulas, midwives, community health workers and parenting classes.
- Increase availability of community services and resources, for example, community health worker services and home visiting services.

Governor Cuomo's maternal mortality initiative includes a Taskforce on Maternal Mortality and Disparate Racial Outcomes tasked with providing expert policy advice on improving maternal outcomes, addressing racial and economic disparities and reducing the frequency of maternal mortality and morbidity in the state. Following the conclusion of the listening sessions, the NYS DOH presented a summary of the sessions to the NYS Maternal Mortality Taskforce at their second meeting, on September 24, 2018 to ensure the Taskforce developed recommendations that are in line with the feedback received from the community. At this meeting two listening session community-based partners, CAMBA, Inc. and Urban Health Plan, and two community members, a Queens session attendee and a Buffalo session attendee, shared firsthand accounts of attending the sessions as well as their own experience accessing maternal care.

Across all seven listening sessions, participants asked for better understanding of the reasons why black women have poorer pregnancy health outcomes, and acknowledgement of the impact of race and racism on those outcomes. Participants asked for action to address the racial disparities in maternal mortality, and particularly focused on how health care systems and practices may perpetuate continued racial inequities. Participants asked for the elimination of barriers that prevent women from getting quality health care services and asked for increased supports needed to help with a healthy pregnancy.

Participants affirmed that all NYS mothers and babies should have the same opportunities to achieve optimal health and positive birth outcomes, regardless of race, ethnicity, community of residence, insurance coverage, or hospital of delivery.

Listening Session – Participant Feedback

Seven maternal mortality community listening sessions were conducted throughout August and September 2018. The New York State Department of Health-funded Maternal and Infant Community Health Collaboratives (MICHC) programs were enlisted to organize and facilitate the sessions. The MICHCs worked with other community-based programs and stakeholders to help identify and recruit community participants. An emphasis was placed on recruiting women and families who have experienced an adverse pregnancy outcome. Participants included currently pregnant women. The listening sessions entitled, Voice Your Vision – Share Your Story, engaged 244 participants, mostly black women, across the state to share their experiences during pregnancy and childbirth with a goal of identifying the barriers and issues contributing to racial disparities in maternal mortality and morbidity. The listening sessions were structured to allow participants to drive the conversation by identifying factors that were most important or most impacted them.

While each of the communities participating in the listening sessions identified some issues or barriers specific to their own communities, common issues were identified across all seven sessions. Common issues emerging from all seven sessions were feeling disrespected, racism, feelings of disenfranchisement, and a general disconnect between the patients and the health care providers and systems. Six unique themes were identified across all sessions as the primary drivers for the disparate outcomes; challenges accessing health care in health systems, relationships with health care providers, impact of racism, lack of information and education, feelings of disrespect, and lack of social support.

What follows is a summary of the issues expressed by participants.

| Health Systems

Across all sessions, participants identified numerous challenges and barriers to accessing health care. Comments ranged from critiques of specific hospitals to discussions about the impact of insurance type (i.e. public vs. private coverage) on access and overall quality of care. Although there were some positive examples given, they were not the norm. Generally, comments centered on challenges associated with attempting to access any type of quality health care.

| Hospitals

A key focus of discussion about health systems was related to hospitals and care received during labor and delivery. Through this discussion one key regional variation was identified, with NYC-based participants focusing their discussion on a two-tiered system of care within the public and private hospitals throughout NYC. NYC participants described public hospitals as lacking the resources, staffing, and quality of care necessary to make them feel as though they were being properly cared for during labor and delivery in those facilities. Numerous participants described steps they had taken to try and receive care at facilities they preferred which, in NYC, were typically hospitals located in Manhattan.

“I switched health plans to go to a better hospital, not ‘the bad one.’”

“I don’t feel comfortable taking my baby to a Bronx hospital.”

“I blame losing the baby because of poor health care at the hospital.”

Many of the NYC participants were quick to connect poor birth outcomes with the hospital in which they received care; often stating their perception that NYC public hospitals were unsafe and problematic. In contrast, upstate participants were less concerned with the hospital facility but focused on the payor source (i.e. public vs. private insurance) as the source of their poor treatment and negative experiences. Although blamed on different factors (facility vs. payor source) depending on the location, overall concerns about quality of care were persistent across the state. One quality issue identified by participants was

the skill and experience of providers treating participants. Of particular concern was the frequent use of medical students in the facilities where women received care. Most participants expressed the belief that they were given less trained and/or competent health care providers because of their low-income status. This was often tied to participants expressing a lack of autonomy or input into decisions not only about the care they received, but the manner in which they were treated at the facility.

“I did not have an episiotomy; the baby ripped me and the doctor just brought in all these students to observe me, and he did not ask...”

“Do you want to spread your legs to all these different doctors?”

For many participants, frustration with hospitals was directed more at policies that they believed to be arbitrary, or sometimes discriminatory than the individual providers themselves. This often left the wishes and preferences of women at odds with institutional policies at many birthing hospitals. Participants across the state consistently described a strong desire to labor and deliver with minimal medical intervention. This included wishes to forgo epidurals, the ability to walk and move during labor and contractions, and the preference to avoid surgical intervention (C-sections). Women often described these wishes being overruled or ignored in favor of a hospital policy which most participants viewed as being enforced unfairly and to their detriment. One recurring experience was participants describing that they felt pressured to accept epidurals as a way that the hospital could ensure they were kept in one place and kept compliant. Participants also often cited increased payment as the primary driver for hospital policy and requirements.

“... they told me, according to hospital policy I had to have another C-section.”

“They’re trying to push for you to do other things that cost more money... They push the drugs on us like an experiment.”

Several participants at each session also provided some positive feedback on their hospital experience. Overall, those who described a positive hospital experience highlighted several key practices that were met with almost

universal praise. Among those “baby friendly” hospital practices including; comprehensive prenatal and postpartum education, skin to skin contact immediately after birth, rooming in, lactation support, and broad acceptance of labor support either from family or doulas. In addition, participants who had experience with the Neonatal Intensive Care Unit (NICU) praised facilities which allowed them to stay on-site with their infant. Factors associated with positive hospital perception were: doctors/nurses described as caring or attentive, the presence and use of midwives as part of the care team, and the ability to have a private room.

“I recommend (this hospital) to everyone, it was the best. It was the best prenatal classes ever.”

“They treated me good at the hospital during my birth.”

| Income/Public Payors

Underlying many of the issues participants identified relating to hospital care and other quality issues was the belief that they were being treated differently because of their low-income status and specifically, their utilization of public insurance. In both NYC and the rest of state, participants said that both the level of care they received, and their ability to have input on health-related decisions were compromised because they were on public insurance.

“If I had money, I’d have more choices.”

“You are already labeled. You’re already treated a certain way.”

Participants stated that their ability to select providers and/or birthing hospitals was severely limited by the use of public insurance and many felt they were stuck with substandard health care providers and facilities. Participants believed poor outcomes were predetermined by the health care system. In spite of these limitations, participants described ongoing efforts to become better consumers of health care services, specifically doing research to identify high quality providers with proven positive outcomes. Many women also talked about doing rigorous research to find providers with whom they shared philosophical approaches to pregnancy, labor, and delivery. In

all sessions participants identified a desire to work with midwives and doulas whenever possible. However, in spite of these efforts to become more sophisticated health care consumers most participants described being “shut down” by health care providers or systems because of limited options available to Medicaid recipients. Thus, even in instances where participants were able to find a preferred provider or institution, many were never able to actually receive services there.

“Whatever the insurance allowed me to get, that’s the best quality I can get.”

“Hospitals look at good insurance that makes them happy... they should think of us all the same.”

“Sometimes... money is deciding. You get kicked out of the room if you complain and can’t afford the ‘honeymoon suite.’”

| Care Delivery and Access

Finally, participants expressed frustration with many of the current care delivery systems with which they interact. In every session across the state one of the most common themes expressed was the overwhelming barriers most women faced when accessing routine health care. One of the most common barriers identified was excessively long wait times experienced whenever attending any kind of health care appointment. Regardless of provider type, visit purpose, or geographic location, women described a consistent pattern of long wait times, both before and during their scheduled visit, that made it nearly impossible for them to attend work or school the same day as a medical appointment. Further complicating this issue is the fact that the vast majority of participants stated that they are offered little to no sick time through their employer. Therefore, day long wait times which would be an annoyance for anyone accessing health care becomes an annoyance compounded by a substantial loss of income for most of the listening session participants.

“I knew my prenatal appointments were going to be all day.”

“Why aren’t you on my time? They are on their time. The needs of patients should come first.”

In addition to long wait times, participants described a patchwork system of care and referrals in which they almost never saw the same provider consistently. This lack of consistency made it difficult for many of the participants to feel truly connected with any one provider. Most described this lack of connection as severely impacting the quality of the provider-patient relationship. Participants described feeling they weren’t being heard, believing providers intentionally withheld information from them, and that the options for care presented to them had been pre-emptively limited because they were on Medicaid. Participants’ inability to see the same providers seemed to exacerbate their feelings of mistrust and anger with health care systems. When many participants described being at their most vulnerable and in need of a caring provider they often felt no one else was looking out for them.

“Always saw a different doctor that didn’t know me.”

“You become a dummy to society.”

| Health Care Providers

Participants consistently discussed concerns about the quality, compassion, and judgement of health care providers. Despite covering widely disparate geographic regions of NYS, each listening session generated similar conversations about health care providers. While participants would often single out one or two providers with whom they had positive experiences, the characterization of “providers” on the whole was often negative. Citing issues including poor communication, judgmental attitudes, and rushed time during visits, participants felt strongly that the health care providers treating them were not doing an adequate job of caring for them and their families.

| Communication

Among the various themes to arise at all seven listening sessions, poor communication between health care providers and participants was among the most consistent. Ranging from a belief that they were receiving too basic or limited information, to accusations that providers knowingly withheld information, participants described fundamental gaps in communication

between themselves and health care providers that they believed were a primary cause of poor birth outcomes.

“It feels so robotic, there is no relationship. I feel that they are not truly listening, they’re just trained to keep going.”

“Nobody would answer you.”

“Don’t talk down to me. Don’t hide things from me.”

A frequently mentioned issue was the belief that their concerns and issues were not being heard or taken seriously by providers. Participants described feeling that health care providers were rushed, that interactions with providers didn’t allow sufficient time for questions, that providers were not listening to their concerns, and, in some cases, providers were intentionally misleading them to get them to agree with a specific plan of care.

“People say things, but the doctor brushes it off.”

“You ask stuff and they [providers] just want to get rid of you.”

“I feel like when we have concerns we’re not heard.”

“They tell you lies and they put fear into you.”

Individuals described feeling as though they were not given enough information to make informed choices about their health care. They described feeling that providers were rushed through visits, that providers were only concerned about meeting a certain volume of patients per day, and that providers did not take enough time to communicate in a way participants could easily understand. Women who had experienced multiple pregnancies also described wide variations in information they were provided during their different pregnancies. A significant number of participants at each session stated that one or more of their pregnancies were high risk but, when pressed by scribes and facilitators to describe why they were classified as such, were unable to articulate a condition placing them at high risk. Many participants stated that they were unable to further define their high-risk status because their health condition had not been shared with

them in a way that was understandable to them. This lack of communication and subsequent confusion meant that many of these women were unable to feel like they were an active participant in decision making about their care. Throughout discussions around providers it became apparent that miscommunication was a root cause for many participant’s negative experiences with childbirth and/or their providers.

“I was never told why I was high risk.”

“I have yet to hear why I had six C-sections.”

“Some decisions are made and we don’t have a say.”

“I think (the) doctor assumed I knew what I was doing because I had another child.”

This lack of communication was often heightened during childbirth. Building on poor communication during the prenatal period, many women went into labor feeling a lack of trust between her and her provider. Many participants described childbirth experiences in which they did not feel understood or adequately supported by health care providers. Several women described already feeling afraid or apprehensive about the birth process only to have those fears compounded by the lack of communication from providers. For several women, this lack of communication manifested in providers who would not speak directly to them, but rather spoke only to their partners.

“My baby got stuck. They [providers] never talked to me about it. My child’s father was in the room and he told me. They never talked to me about it.”

Extending beyond the delivery room, many participants described confusion and mistrust around paperwork and consent forms, stating they did not understand much of the paperwork given to them and that, when asking for assistance, they were rushed or pressured into signing paperwork they didn’t fully understand.

“If you don’t sign, you don’t get services.”

These gaps in communication led many participants to feel a strong need to take extra steps in order to be heard and to advocate for themselves. Participants described the need to be informed before ever interacting with health

care providers so their concerns were taken more seriously. Participants described the need to advocate for themselves in order to be fully informed of their health status and their options for care. Women spoke of a strong sense of personal responsibility in holding providers more accountable and demanding complete information about their health and care options.

“You need to be able to speak up for yourself.”

“You need to have the confidence to be your own advocate for yourself.”

| Judgmental Attitudes

Many participants also felt that they were subjected to unfair judgements and bias from providers that compromised the quality of care they received. Participants described feeling judged by health care providers at all levels, including doctors, nurses and hospital support staff. Many felt that they faced the most bias from providers when discussing issues around fertility, childbearing, and lifestyle choices.

“You have to show them that you are somewhat educated.”

“Individually we all have our own stories... not all pregnancies are unplanned or don't have a father around.”

Feelings of bias were pervasive across the care continuum. Participants told stories of experiencing bias during well visits, prenatal visits and, during labor and delivery. Participants described being subjected to judgmental or pointed questioning, assumptions about their living situation or marital status, as well as a persistent need to go out of their way to prove that they were worthy of additional support or care. At each session participants described feeling as though their concerns were not taken seriously unless they could sound like they were educated. Women described feeling disrespected from hospital staff while giving birth, including being asked pointed questions about the presence or lack of presence of family members, especially in reference to their child's father. Many of those

describing their bias experience were quick to point out how, even the smallest experience with bias were sufficient to ruin their birth experience.

“You want to be able to trust your doctor, but we just didn't.”

| Time Spent with Providers

In spite of mixed feedback on provider interactions, the overwhelming desire from all participants was to have more time with providers during any kind of interaction. This included a desire for more time during routine prenatal care or 'healthy' visits as well as more time during labor and delivery. Participants consistently felt that the lack of time spent with providers was the primary factor causing misunderstandings, tension, and even antagonistic relationships.

“You never really see your doctors.”

“Appointments felt too quick.”

With the ability to spend more time with providers participants believed they would be able to ask more questions and develop a stronger rapport with their health care provider. Participants frequently stated a desire to connect with their providers, helping them to build a greater level of trust in the provider and the health care system in general. Without that level of trust, participants were often left questioning the rationale behind many of the decisions made by their health care providers. In the absence of truly understanding the provider's reasoning, participants were left to develop their conclusions and frequently stated their belief that providers made decisions based on money, a desire to finish quickly, or general apathy for the patient and their health. Across all sessions those conclusions often connected what they perceived as poor care with racism, prejudice, and lack of caring from the providers that treat them.

“Doctors never actually listen to you.”

“Doctors listen because she has to write down, but she doesn't really listen.”

“Doctors turn into robots, but this experience is special to each mom.”

| Racism

Undercutting all the discussions across the state was the pervasive awareness of the role race and racism continue to play in creating unequal outcomes for black women and babies in NYS. Both personal and institutionalized were frequently cited at all sessions as the primary drivers behind many of the unequal outcomes seen downstream.

“We’re high risk because we’re black.”

“It’s not about money, it’s about being black. Beyoncé and Serena have money, but they still had problems.”

Women at all sessions directly addressed many of the interpersonal and social experiences with racism they faced while accessing care before, during, and after pregnancy. Time and time again women described a constant awareness of their status not just as women, not just as low-income women, but specifically as black women giving birth in America. Many of the larger issues identified by participants, unfair treatment, judgmental attitudes, barriers to care, and the lack of sufficient supports were often attributed to unequal treatment based upon race. Throughout discussions about the impact of racism three recurring themes emerged; being subjected to unequal treatment, patient awareness of racial bias on behalf of providers, and the understanding that, for many of the participants, it was up to them to advocate for their own rights.

| Unequal Treatment

When discussing race, participants at all seven forums consistently shared common themes and feedback. One of the most frequently identified manifestations of racism, according to session participants, was receiving unequal treatment based on their race. Participants described a constant awareness that their ability to get high quality treatment or make decisions about their health care could easily be taken away or dismissed because of their race. Stories of providers and/or institutions refusing to take complaints seriously was a common theme at many sessions. Several women shared stories of trying to get a health care provider to listen to complaints of physical pain, concerns about potential complications, and/or other issues addressed during labor and delivery. One

woman even stated her belief that providers do not take pain complaints from black women seriously because she believed that health care providers are taught that black women have a higher tolerance for pain than white counterparts. Participants also described health care providers treating patients and their families as annoyances, and, when faced with push back from patients, going so far as to threaten mothers and families with police or Child Protective Services (CPS). Several participants described their belief that police and/or CPS intervention was an ongoing threat used against black mothers and families to “keep them in line” or to get them to comply with institutional policies.

“They look at your skin color and your pocket and judge you based on that.”

“I didn’t know black women died more, but I’m not surprised – we have the worst everything.”

Participants went on further to describe how they actively sought to fight back against racist assumptions by striving to meet “white” expectations. This often included efforts to make sure that they (and their children) were especially well dressed and groomed when seeing health care providers, taking steps to make sure they were seen by staff as highly educated and thus “worth” helping, and finally in some instances participants talked about employing their “white voice” to make sure staff treated them respectfully.

“When I feel myself getting really frustrated, I turn up my white girl voice.”

“The doctor spoke to me like a child. He scolded me.”

One area of the health care system where participants often believed they were subjected to racially motivated unequal treatment was when accessing family planning. Participants consistently described provider interactions where they often felt pressured to select invasive methods of birth control without fully understanding the potential side effects or risks. Drawing comparisons to historical efforts to limit the black population, women described the need to be hypervigilant about provider motivation and the belief that certain types of birth control were “pushed” on them with the specific goal of limiting their fertility. Several participants told stories contrasting their

experience with that of white patients, pointing out extra efforts hospital staff made immediately after delivery to encourage them to select a birth control method.

After having a baby,

“... nurse came in at 3 a.m. asking what family planning method she wants to use... Just because she’s Black or Latina, they want to make sure we stop having babies.”

Discussing birth control methods they’ve tried, a participant stated that,

“They [providers] do the weirdest things to us.”

| Bias

Much of the discussion around racism centered on conversations about experiencing persistent bias whenever interacting with the health care system. Whether it was the receptionist making assumptions about marital status on in-take forms, nurses asking women if their child’s father was incarcerated, or health care providers pressuring mothers to limit their fertility, participants described numerous experiences of bias within the health care system. Experiences with bias were a universal theme at all listening sessions with participants providing story after story about biased interactions with health care staff and institutions.

“Receptionist puts single on the form, automatic assumption because you’re black.”

“Because I’m black, (they think) my baby’s father is in jail.”

Consistent among these stories were themes of women feeling judged, feeling as though the quality of care they received was hampered by bias, and their constant questioning of the motivation behind providers’ decisions regarding their care. Regardless of location, almost all participants shared stories where they had experienced bias first hand. These regular occurrences were often so frequent that women would share stories that they had only just remembered. The cumulative effect of these experiences could clearly be seen in the pervasive belief among participants that providers were

making health care decisions for them based solely on race.

“Black women don’t know about VBAC.”

“Always want to induce black women.”

Across the state participants were also quick to suggest that many of the issues related to bias could be better addressed through more providers of color. Women consistently described their preference for doctors, nurses, and other health care staff that looked like them and were from the same kinds of neighborhoods. They believed that by engaging with professionals who shared similar backgrounds that they could gain a better understanding of each other and better address some of the complex social issues linked to poor maternal and birth outcomes.

“Black doctors understand us because they are us.”

| Rights

In order to ensure that they, and their children, are receiving the best possible care many participants discussed a need to advocate for themselves. Much of this discussion centered on conversations of better understanding their “rights” and the need to be proactive when asserting those rights with providers and institutions. The issue of rights was often discussed in the context of medical procedures and interventions that women described as being pushed or forced on them. Participants described many different scenarios or examples of when they felt the need to exert their rights to refuse or request certain kinds of interventions or treatments. Chief among these examples were: refusing medical procedures participants did not feel were necessary (i.e. amniocentesis, epidurals, and episiotomies), advocating to labor how they chose (i.e. wanting to walk, refusing monitoring that kept them in bed, wanting to avoid Pitocin), and instances where participants felt their infants were unnecessarily or arbitrarily removed from their care.

“Women of color are tired of feeling like we have to fight for rights that should just be given to us.”

“You gave your rights away when you walked in.”

The issue around hospital policies or procedures that saw infants removed from mothers' rooms brought up very heated conversation at almost every listening session. A majority of participants experienced and expressed concern for most of the mothers in attendance. Women described hospital staff taking their infants for supplemental feedings when mom had requested to exclusively breastfeed, or staff taking children for medical procedures that mothers didn't feel were necessary and/or didn't feel were fully explained to them. When discussing this specific issue women also described the need to balance their anger and fear with the "white" social expectations in the hospital, as there was the continued fear of being labeled an "angry black woman" and threatened with police or CPS intervention.

"You have to make a plan yourself because they don't tell you."

"Continually fighting to prove that you can understand."

"Afraid people will think I'm stupid."

One of the most common manifestations of this lack of communication was the persistent belief among many participants that, prior to pregnancy, their fertility was severely compromised. Time and time again participants shared stories of hearing snippets of limited information from providers about their health status, or being told partial or misleading information about their fertility. Without being given the proper understanding of their health status this led many women to assume they would not easily be able to get pregnant, if at all. Based on this inaccurate information many participants stated that they chose to forgo the use of contraceptive methods and subsequently became pregnant. While most women accepted the pregnancy as an act of "fate" several women did state that they wished they had been able to make an informed decision based on more accurate information.

"They didn't fully explain to me... but they gave me a handout."

"You know your body, you might not know the medical terms, but you know your body."

Participants felt strongly that many providers lacked a fundamental understanding of the lives and the unique challenges they face in achieving their optimal health. One example of this lack of information that was shared frequently related to what it meant to be "healthy" with much of the focus on nutrition education. Many women described providers recommending that they improve their nutrition habits, but stated that they weren't given specific, actionable suggestions to actually improve their health. Participants suggested that providers needed training or experience to better understand their lifestyle, so the providers could give more realistic advice or suggestions.

"We are given a piece of paper about nutrition. No one talks to us about nutrition beyond that. Some mothers here don't know what protein is. Some mothers here don't know what foods have iron in them."

| Information & Education

When discussing potential root causes for maternal health inequities, participants almost universally described a fundamental lack of information and education as a key contributing factor. Owing to the many reasons previously discussed, participants stated that providers did not provide sufficient information or education about family planning, gynecological services and pregnancy. Many participants identified this lack of information and education as contributing to their own poor outcomes and stated they were unable to comply with recommendations and/or were not informed how they could help improve their health.

Participants described feeling as though their providers did not provide them with sufficient information necessary to make informed decisions about their care. When describing interactions with health care providers participants discussed being made to feel as though they were uneducated, they felt that health care providers often talked down to them, and that providers did not spend enough time to answer their questions. It was this lack of information that led many participants to state they did not understand basic information about their health status before going into pregnancy, and that lack of information persisted throughout the pregnancy and birth.

| Classes

One recurring request at each of the seven sessions was for increased availability of free childbirth and/or parenting classes that were accessible to participants. Regardless of location, the majority of session participants described a strong desire to increase their knowledge and understanding of their own health, their options during pregnancy and delivery, and, in particular, better understanding of parenting skills. Participants stated a clear desire to attend free classes but were quick to specify that classes are only truly accessible if they're in the neighborhood in which people live and preferably, taught by people from the community.

"If I get it [free birthing classes] on 86th St., I should also be able to get it on 116th St."

"Nurse Family Partnership helped me understand how to care for my baby."

"Education has to be spoken – nobody reads the papers."

Participants often saw these classes as an opportunity not only to learn about childbirth and parenting but to meet other new parents with whom they could socialize and bond. Limited social and family supports were frequently identified issues for session participants, and many felt that educational classes would be an ideal way to help mitigate that problem while also presenting an opportunity for them to expand their social networks. In several sessions participants specifically mentioned programs like Centering Pregnancy⁵ as a positive experience, both for health care delivery and meeting their need for social supports. Participants discussed the importance of bonding with other mothers and how, for many participants, they continued relationships with their fellow patients after they had both delivered.

"I need support from my community."

"It was like I was going through something with a friend."

| Self-Education

Another common theme discussed at each session was the importance of becoming self-educated. Citing the reasons described above, participants

discussed information gaps between themselves and providers and a lack of classes during every session across the state. In order to mitigate this issue, most participants described how they took it upon themselves to learn more about health, pregnancy, and child birth.

"... you're just on your own."

"I want to be informed and know that I have choices."

"Try to do your own research."

Participants described using a variety of sources to inform themselves about pregnancy and childbirth. Across all sessions the most frequently used educational tool was the internet. This included use of websites as well as a range of pregnancy and baby apps. Participants consistently expressed frustration with the lack of communication between themselves and providers and viewed the internet as a tool to ameliorate these gaps. Women spoke of turning to the internet both as a way to prepare before visits (typically so they might seem "educated") and when they felt that providers weren't giving them enough information. Although participants did not give specific detail on which websites and apps they were using, the overwhelming majority of participants felt the information they found online was accurate and useful.

"... most of the information came from apps."

"... internet is your best friend."

| Disrespect

Another consistent refrain across the sessions was the frequent use of the word "disrespect" when describing treatment during pregnancy and delivery. Far and away the most commonly used word during any session, participants described an ongoing pattern of disrespect from providers, institutions, and society in general. When pressed for specific examples participants often focused on interactions with their health care providers (including both doctors and nurses) which demonstrated a lack of sensitivity that was often manifested in how the participants were spoken to.

| Feeling disrespect from providers

The conversation about disrespect from providers occurred at all sessions in all locations. During each discussion participants were clear to mention a wide array of providers with whom they had “disrespectful” interactions. This included doctors, nurses, Nurse Practitioners/Physicians’ Assistants, as well as other health care support staff. Women would frequently say this disrespect is rooted in pervasive racism from providers and society or other manifestations of bias (i.e. because the women are low-income, do not speak English, are unmarried, etc.). Among the common examples of disrespect discussed were feelings that their health concerns and conditions were not being taken seriously. These examples ran the gamut from feeling as though questions were dismissed to believing that providers refused to provide pain management out of a racist belief that black women don’t feel pain as much as their white counterparts.

“People are giving respect based on insurance status, it affects treatment by providers.”

“I know my body, don’t question me.”

“I feel like they brushed my concerns off.”

| Lack of Sensitivity

One of the most common issues associated with participants feeling disrespected was a lack of sensitivity from providers. Participants frequently reported feeling that they were not given enough emotional support from providers and even family members during pregnancy and delivery. Many participants believed this lack of connection and empathy from health care staff was a key driver in poor birth outcomes in general and some of their individual outcomes in particular.

“My son has a lot of issues that he wouldn’t have had if they just listened...”

“Felt as a first-time mom, I needed a softer approach.”

When asked to describe their preferred experience, participants would discuss health care providers (including both doctors, physician’s assistants, nurse practitioners, and nurses) who were sensitive and responsive to their needs. They

specifically discussed a desire for more emotional understanding and support, often connecting the brusque manner in which they’re treated to a lack of caring and empathy on the part of health care providers.

“At the end of the day, we’re people first.”

“Treat me like you treat your mothers.”

“Caring doctors are a must.”

| Disrespectful Interactions

Another common pattern of disrespect described by participants were interactions that extended beyond the patient. Participants across the state described persistent patterns of disrespect that included them as the patient, but often included disrespect toward their family and support members. A number of participants shared stories where their mothers, partners, and other children were treated in a manner which they found disrespectful. Much like other issues identified, the vast majority of participants believed this treatment was based on their race and/or socio-economic status.

“Speak to young mothers. Do not speak around them.”

“You have the right to be spoken to.”

“Doctors don’t respect us because they don’t value us.”

| Social Supports

A final theme that emerged at sessions across New York State was the lack of social and community supports women felt were necessary to improve the health and well-being of themselves and their children. Across the board participants described feeling lonely, isolated, separate from families and society and left alone to handle complex medical and personal problems. Many participants described feeling hopeless and powerless to improve circumstances for themselves and their children. Throughout this discussion, women identified three key gaps that were most burdensome to them: lack of support immediately following birth that continued during the postpartum period, reductions in community support, and the need for others to help advocate for women and children.

| Postpartum Support

A significant portion of all conversations at each listening session was devoted to the unique challenges of the postpartum period. Participants across the state described the struggle and shock following birth when they were abruptly cut off from many of the systems of support on which they had come to rely during their pregnancy. Regular visits to health care providers' offices were no longer scheduled, attention and affection many received during the pregnancy was now transferred to the baby, and many women described feelings of extreme isolation, sadness, and confusion.

"When I had my kids I didn't have no help. Family dropped me off and left me."

"I don't like to be at home because I feel lonely."

"You need that love and support."

For many women these feelings of abandonment manifested in real struggles with postpartum depression. Participants readily acknowledged some major cultural barriers within the black community when it comes to discussing mental health but were quick to point out the prevalence of postpartum depression in their lives and the lives of other women in their community. Participants consistently expressed a need for increased screening for postpartum depression, with many advocating the screening be done earlier. They also discussed the need for more support and follow up services for women diagnosed with postpartum depression and/or other mental health conditions.

"Doctors should talk more about postpartum depression."

"We don't get a lot of empathy."

"When I left the visit, I felt so disappointed. I wasn't able to share my postpartum depression."

| Community Supports

Integrated in the larger discussion of needed supports was the frequent observation that many of the community and social support networks

that mothers previously relied on no longer exist. Participants observed that more and more families live further away, and support that one may have expected from mothers, sisters, and other extended family was no longer readily available. Women talked about having grown up with a strong sense of neighborhood and community, a kind of shared responsibility for one another that was no longer present.

"We used to have a village and today it's gone."

"I needed support from my community."

In the absence of this sense of community participants frequently expressed a desire to find new ways to create community in their lives. This included a wide range of suggestions from participants, most of which were simple desires to find more places/opportunities for mothers to connect with other mothers. Women talked about wanting a central community location where they could go, along with their children, to meet other women with whom they could bond. Participants consistently expressed a desire to volunteer or make themselves available to support other mothers in whatever way they could. Some participants described ideas for a mom's mentoring program to connect new mothers with more experienced mothers. One participant even suggested pairing mothers as pen pals, just to ensure that all women have someone checking in on them after they've given birth.

"Moms need support, bottom line."

On joining a mom's group,

"It made me realize there were mothers like me."

In several instances this discussion also expanded to focus specifically on the need to expand support opportunities to fathers. While the vast majority of session participants were women, each session included several men. When asked about the role of men and partners in improving women's health participants almost universally discussed a need for men to be given some of the same opportunities for education and support as women. Expanding on that, male participants expressed a strong desire to be meaningful partners during pregnancy, childbirth, and in particular, during the postpartum period.

However, many men (and most of the female participants) stated a need for men to receive more education on parenting skills. Similar to their female counterparts, male participants wanted opportunities to learn how to become better parents and better partners.

“Men need support services, they are also going through something.”

| Advocates & Professionals

Participants also spoke of the important role that local advocates, professionals, and paraprofessionals could play in supporting women during the perinatal period. This included universally positive discussions about community health worker (CHW) programs⁶ and the specific health workers that many women had worked with. Given that many session participants had been recruited from local CHW programs, it was no surprise that CHWs were a frequently discussed topic. Participants at all forums described the positive role CHWs had played in their lives and that of their families. Those who had experienced home visiting services firsthand offered almost universal praise and strongly advocated that those services be expanded to allow more families to benefit.

“My CHW helped me while my baby was in the NICU and kept me pumping for him.”

“I wouldn’t have made it through without my CHW.”

Another common theme around support expressed by participants were positive experiences for those who had used doulas and/or midwives during their pregnancy. Those participants able to obtain doula services during pregnancy offered high praise of the experience and often credited the doula with helping to improve their health or their baby’s health. When discussing their doulas, participants described a collaborative relationship built on trust and respect in which they felt heard and valued. Many shared stories of what their doula had taught them, how the doula had helped them to better understand their pregnancy, and how working with doulas gave them the confidence to advocate for themselves and their babies.

Participants shared similarly positive stories of their experience with midwives across the state. There was overwhelming support for the

inclusion of midwives in the continuum of care available to pregnant women across NYS. For those participants receiving care from a midwife, they universally expressed a more positive experience throughout their pregnancy, with a particular emphasis on feeling that they were a more active participant in the care they received. Those participants tended to highlight increased time spent with the midwife, better communication between the provider and the patient, and feeling like they were part of shared decision making with their provider. Overall, those differences between the care from midwives versus OB/GYNs, as described by participants, fostered a stronger, more trusting relationship between the health care provider and their patient.

“I don’t know what I would have done without the support of my doula.”

“Doctors have a lot to learn from midwives and doulas. Doctors see a procedure; doulas see a mother.”

“My midwife made me feel listened to.”

| Participant Suggestions for Improvement

While much of the conversation at the sessions focused on previous experiences, participants were careful to also provide ideas and suggestions to improve the birth experience throughout the discussion at each of the sessions. On balance, these suggestions often tended to be small, actionable changes that could easily be made on the community or provider level. However, when scaled up to population or institutional level many of these suggestions could have the potential to create positive change for women and children in NYS.

Increased Social Supports: Citing the lack of support from partners and family members as a key factor impacting negative health outcomes, participants were also eager to discuss ideas they had to expand opportunities for mothers to develop stronger social networks. Looking to replicate the “village” many participants believed was no longer supporting them and their family, participants suggested a variety of ways that local parents and community members could meet, build relationships, and ultimately collaborate to support the health and wellbeing of moms and babies.

One of the major recurring suggestions was that communities offer accessible, free spaces where mothers and children can gather to learn and meet new friends. Women suggested models similar to the Baby Café⁷ where women are encouraged to drop in and use the space to get information and resources as well as breastfeed their children when out in the community or running errands. Many women described feeling extremely isolated and lonely in the weeks and months after childbirth and stated a simple desire to find other mothers with whom they could talk.

Participants also expressed a desire for more free, accessible educational classes and/or support groups within their communities as another way to meet peers and other parents. Among the types of classes frequently mentioned were those on prenatal health, childbirth, parenting, and Mommy & Me. In order to be of the most use, participants explained that classes must be offered at times convenient for working parents, within the neighborhoods where participants lived, and free. Several participants also pointed out that educational classes also gave them the opportunity to expand their circle of social support and potentially develop collaborative solutions to some of their shared barriers, especially related to child care, logistical support during the immediate postpartum period, and help advocating for themselves with providers and community institutions as necessary.

More Postpartum Support: A persistent theme across all listening sessions was significant challenges, both physically and mentally, during the immediate postpartum period. Some participants focused on the physical challenges during this period (i.e. fatigue, post-surgery pain and complications) while others described experiencing moderate to severe post-partum depression and anxiety. Throughout these discussions, participants described often having no adult support in their lives, either from partners or family members, and being left alone with their infant almost immediately after hospital discharge.

Recognizing the unique and often complex needs during this time-period (especially as it relates to post-natal complications and/or illness), session participants continually discussed the need to provide women with more support during the post-partum period. As described by participants, “support” often meant both practical and logistical

assistance (i.e. watching the newborn to allow mom to shower, helping to care for other children in the home) as well as mental support (i.e. another mother to talk to, earlier screening for postpartum depression by providers).

A common recommendation across all sessions was earlier assessment and intervention for postpartum issues, especially depression. Many participants felt that waiting six to eight weeks for their initial follow up visit was too long and wanted earlier opportunities to contact their health care providers. Several women suggested a checkup during their first week home with a newborn, either in-person or via phone. Others thought that establishing a network of local moms and community members who were willing to provide logistical and practical support for new moms would be a way to support women during the postpartum period and build long lasting social support networks.

Several women provided specific suggestions to improve health care delivery within the postpartum period. The most commonly suggested change was to schedule mother/infant dyad visits, especially during the immediate postpartum period. Women described feeling much more likely to access healthcare services for their infants than themselves and thought that leveraging those maternal instincts by allowing mothers to receive health care services during infant well visits would help more women access timely care. Participants felt that dual visits would help address many of the logistical issues (transportation, other child care, time off work) that make attending multiple appointments challenging.

Birthing/Parenting Classes: One of the most frequently suggested interventions at sessions across the state was increased access to educational classes, especially birthing and/or parenting classes. Participants shared a preference for getting information through interactive classes and expressed a desire to see more educational classes offered at no cost within their local neighborhood. In addition to suggesting more classes, participants also expressed a desire for those classes to be taught by individuals indigenous to their community to allow parents to better relate to instructors and the material. Citing the communication difficulties many participants experience with health care providers, participants viewed educational classes and their instructors

as a bridge between inaccessible health information and community residents in need of additional support.

The desire for additional classes and preparation was most evident when discussing the prenatal and birth experience. This request dovetailed well with the persistent communication and knowledge gaps described by participants at each of the sessions. Much of the anxiety and distrust described during labor and delivery often had more to do with communication gaps, and a lack of understanding of the birth process and the potential complications than actual antipathy between patients and health care providers. By expanding opportunities for prenatal childbirth education, women can gain a stronger understanding of the birth experience, so they are more prepared for changes and able to communicate more effectively with health care providers.

Community Health Worker Services: Listening session participants consistently expressed their appreciation for their relationship with their Community Health Worker (CHW). Participants used words such as trust, understanding, knowledgeable and “looks like me” to describe CHWs and cited CHWs as being a source of social support, information, advocacy and connection to services both during and after pregnancy all tailored to their individual needs and circumstances. CHWs provide outreach to find and engage high-risk pregnant and postpartum women, and provide education, social support and assistance with access to continuous and coordinated health and social services. In addition, CHWs provide a culturally competent link between community members and health care providers and can serve as member of the care coordination team.

Most women who had previous experience with CHWs also expressed a desire to expand the scope of their services, specifically so that the CHW may engage with the mother and family for a longer period of time. Most participants expressed a desire for ongoing support and assistance with care coordination that extended beyond the longevity offered by most CHW programs. Participants believed that continued access to a CHW would help facilitate easier transitions for them and their children (i.e. from home to work, from early childhood care to elementary school

etc.) helping to improve their utilization of available community services.

Community Services & Resources: In order to meet many of the complex needs identified at each session, participants frequently expressed a desire to see an expansion of existing services, resources, and support for community-based programs to help address gaps in services. Participants spoke of often being unaware of existing resources, particularly struggling to find local information online. Many described being told by service providers of other community services and resources but being practically unable to access those services as online information was limited, the hours of operation were not conducive for working individuals, and/or the location was not accessible. Several participants expressed appreciation that the listening sessions themselves had better connected them to existing community resources of which they had previously been unaware.

For those participants able to access existing services, many saw a need to expand the bandwidth of service providers in their area. Specific requests often focused on allowing families to engage with services over longer periods of time (i.e. more than just the first year). This included suggestions to expand existing home visiting programs (i.e. Community Health Workers, Healthy Families New York, Nurse Family Partnership, etc.), and supporting community-based programs such as the Maternal and Infant Community Health Collaboratives. Participants also highlighted the importance of increasing visibility and accessibility of other community support programs especially mental health providers, food pantries, substance use providers, and more.

Health Care Providers: Participants shared story after story highlighting their personal experience and challenges interacting with health care providers, so it was no surprise that many of the suggestions for improvement centered on how to promote effective communication and trust between providers and patients. Evaluating the suggestions provided, it became apparent that participants had highlighted four main strategies they saw as essential to improving interactions between health care providers and patients.

One of the first mentioned suggestions was to increase the number of providers of color

working in low income communities. Participants expressed a strong desire to see health care providers that looked like them and were more representative of their respective backgrounds and lived experience. Many believed that the source of conflict between them and their health care providers was a lack of shared experience and understanding. Participants believed that health care providers of color would be more willing to listen and devote more time, better able to understand them and better able to reflect their experience, thus ensuring a better quality of care for mothers and babies.

Many participants suggested that better training for all health care providers to help them recognize that racial disparities exist and to understand the root causes of health disparities would positively impact the provider/patient relationships. Participants believed that enabling providers to better understand social determinate issues that create barriers for patients accessing care would make providers more empathetic. Participants want health care providers who better understand their patient's lived experience and who can speak to the challenges and barriers many of their patients face. Participants believed that by encouraging a better understanding of these issues among health care providers they would get better guidance and council from providers, specifically suggestions that patients would be more able to put into practice.

Another series of suggestions that participants emphasized were ways to make health care services more accessible. Numerous participants described working jobs that offered little or no paid time off and thus were eager for any opportunity to access health care or other

supportive services during nights and weekends. For many, the lack of night or weekend hours at their health care provider's office means they are forced to choose between financially supporting their family or accessing needed health care services. Another major barrier participants identified was the restrictive office policies enforced by many healthcare providers and facilities. A major issue discussed was prohibiting patients from bringing children to visits, especially postpartum visits. For many participants they simply lacked access to affordable child care to make health care visits easily accessible. Participants also described lengthy wait times exacerbating the necessary time off work and punitive late or no-show policies that have seen several participants no longer able to access care from a given provider because they were unable to make a scheduled appointment.

Overwhelmingly, the most consistent suggestions from participants were ways to improve communication between patients and all health care providers. Communication gaps were often cited as the primary source of frustration, confusion, and fear during and after their pregnancies. Many participants described feeling dismissed by health care providers, rushed through appointments, and, as never having established bonds or trust between themselves and health care providers. This lack of trust also seems to be a key factor underlying much of the dissatisfaction experienced during labor and delivery. Participants are not given the time or attention they need from health care providers to develop the level of trust and comfort that may be necessary to truly understand why plans may have to change during labor and delivery.

Conclusions

Among the many overlapping themes and ideas shared at all seven listening sessions was the frequent expression of gratitude that these sessions were being held at all and appreciation for being listened to and asked about their experiences. Participant after participant shared not only their story, but their eagerness to be part of creating solutions to improve outcomes for themselves and their communities. Men and women attending sessions across NYS continually spoke of their wish that these conversations continued as part of ongoing work to improve their communities. They shared a willingness to give their ideas, their time, and their commitment to making these strategies a reality for people across the state. Plans continue to be developed to share this statewide summary, along with specific summaries from each of the host communities, with those individuals who participated in these sessions across NYS.

Call to Action

Black women are approximately three times more likely nationally to die in childbirth than white women and two to three times more likely to die in New York alone. Research shows that in New York City, highly educated black women still fare significantly worse than white women with less than a high school education. Across the state, listening session participants asked for:

- Better understanding of the reasons why black women have worse pregnancy outcomes;
- Acknowledgement of the impact of race and racism on pregnancy outcomes;
- Action to address the racial disparities in maternal mortality with a focus on how health care systems and practices may result in continued racial inequities;
- Elimination of barriers that prevent women from getting quality health care services; and
- Increased social and community supports needed to help with a healthy pregnancy.

Listening session participants stated that they felt race, racism, community, insurance coverage, and hospital of delivery all impact birth outcomes. Addressing these societal and health care system factors would involve efforts at many levels,

including the policy, health care provider and community levels. The following recommended actions stem from the listening session results.

| Policy-level

- Increase diversity among health care providers at all levels (including: doctors, NPs/PAs, and nurses)
- Address social determinants of health (income, housing, education, neighborhood)
- Provide stronger protections for pregnant workers to ensure employers provide reasonable accommodations
- Increase understanding of the social and systemic causes of maternal mortality
- Support group prenatal care, community health workers, childbirth classes, parenting classes
- Expand opportunities to access doulas and midwives
- Increase patient ability to access health care institutions and providers of choice

| Health Care Provider-level

- Provide patient-centered, individualized culturally sensitive care
- Encourage implicit bias training – understand the role of implicit bias in the quality of care delivered and its impact on health outcomes
- Increase awareness of the racial disparities in birth outcomes
- Support quality improvement initiatives including assessment of patient experience
- Encourage assessment of patient outcomes at the provider level to assist patients with making informed decisions of where to seek services
- Increase patient-provider contact during appointments to improve communication
- Improve continuity of care to establish a more trusting patient-provider relationship

| Community-level strategies

- Support community-based programs and services
- Increase awareness of the availability, location and quality of services
- Provide educational programming to support informed decision making

Appendix 1: Listening Session Feedback – by Location

In addition to identifying themes and ideas that were consistent across the state, the analysis of participant feedback also helped to uncover some local concerns and issues. Whether a unique local issue, or a common issue specifically highlighted during a particular session, the following feedback is grouped by geographic location and highlights the most frequently discussed topic of conversation at each of the seven individual sessions.

| Brooklyn

This first listening session clearly identified some key themes that were repeated across the state but had special emphasis in NYC. The primary recurring theme through most of this session was incredible dissatisfaction with the public hospital system in NYC. Participants described a pervasive belief that public hospitals, especially those located outside of Manhattan provide a substandard level of care that put themselves and their children at risk for adverse birth outcomes. Women described overwhelmingly negative experiences at public hospitals, attributing much of their negative experiences to hospital policy which they believed was dictating the care they received.

Participants stated a clear preference for birth experiences with minimal medical interventions, the ability to walk, and support for breastfeeding immediately after delivery. Many described doing research on their own prior to delivery and attempting to communicate these wishes to health care providers only to never see the same provider, or have their wishes dismissed or overridden at the hospital. Most participants attributed this lack of autonomy and respect to hospital policies, poorly trained health care providers, and overworked, burnt out hospital staff. To combat this experience participants requested providers stay with them longer, answer questions and actively involve the patient in decision making about care whenever possible.

| Bronx

Conversations in the Bronx included many of the same themes seen in other NYC-based sessions, especially when discussing experiences associated with different health care facilities (i.e. public hospitals). Participants outlined their preferred birth experience, worked to

communicate this with health care providers but often left feeling stymied by their lack of information and education on labor and delivery and their rights as patients. Participants again described feeling as though they had been pressured into accepting increasingly complex levels of medical treatment/interventions without being properly informed or consented by staff at public hospitals.

Participants described increasingly adversarial relationships between patients and providers, especially during labor and delivery. However, many were quick to state their comfort advocating for themselves whenever necessary. Participants stated a desire to increase their own education on health issues to help improve their skills advocating for themselves and their families.

| Albany

Albany's listening session, the first occurring outside of NYC, including the addition of a new dimension to the issues, one unique to upstate New York. Rather than focusing discussions on the difference between hospital facilities, Albany participants largely focused their conversation on the different treatment received at any local hospital based on the type of insurance presented. This angle on the conversation about payor and facilities made sense as most participants in upstate sessions described receiving care at one of two major birthing hospitals in their respective cities. Therefore, for those participants upstate, the facility itself wasn't as big a predictor of care but rather what insurance payor (i.e. public or private) was covering the birth; with participants identifying births covered by Medicaid receiving substandard care.

Women described feeling very judged by health care providers at both major birthing hospitals when presenting with public insurance, a major contrast in experience for those women who had previously used private insurance. They felt that once it was known they were on public insurance health care providers including doctors, nurses, and administrative staff all began to treat them differently. Participants felt that care being provided was not culturally sensitive and often reflected bias and judgement on behalf of the provider.

| Buffalo

More than almost any other session, Buffalo residents spent a significant portion of the time discussing their experience prior to pregnancy. Beginning with an overall discussion highlighting the frequency of unplanned pregnancies among the participants and their community, Buffalo session participants went on to discuss the shortfalls many had experienced with the existing birth control options. Many felt that they were not given full information on the potential side effects and risks of birth control options, believing that providers often intentionally downplayed side effects and risks to get more women to select a particular method of birth control. Women discussed a desire to have more natural options, not wishing to have unwanted or unfamiliar substances or devices in their body. Understandably this conversation around dissatisfaction with available birth control methods then dovetailed into a broader conversation about opting out of using any birth control method and subsequent experience with unplanned pregnancies.

As with other sessions, Buffalo participants also had a lot to say about their relationship with and expectations for health care providers. While expressing an overall dissatisfaction with the current level of patient-provider interaction, Buffalo participants went on to describe characteristics one would see in an ideal health care provider. This included a wish for more female providers, providers who were better trained (and especially, able to understand social determinant factors in addition to overall health status), and providers who were able to spend more time with patients. Ideal providers are those who aren't overbooked and who are able to take the time to develop relationships with patients and provide individualized care.

| Queens

Keeping on trend with other NYC-based participants, individuals at the Queens listening session described two-levels of care available in NYC split between public and private hospital facilities. Women again described feeling coerced or “bullied” into C-sections based on hospital policy rather than necessity. This feeling of coercion was especially true for women who had multiple pregnancies. The discussion continued as

participants spoke of complications and concerns they experienced following their C-sections. Many participants felt high rates of C-section were a reflection of provider bias, a dismissive attitude toward patient concerns, and the result of seeing multiple providers throughout their pregnancy.

Another topic that was frequently discussed during the Queens forum was the need for additional supportive services for pregnant and parenting moms. Many women mentioned that they were (or had been) unaware of services available to them and their families. They described an increased need for transparency in finding and accessing resources within their neighborhoods.

| Harlem

Like their other NYC counterparts, Harlem participants focused much of the conversation on issues related to the hospital facility in which they delivered. Overwhelmingly participants stated a desire to labor and deliver as “naturally” as possible. When asked to give specific examples of those expectations, participants stated a wish to avoid C-sections (especially those that they believed not to be medically necessary), a wish to be able to move around, and the desire to avoid epidurals or other invasive procedures. Many also felt that going into labor and delivery they had not been given adequate information about birth and their options for delivery. While they would often spend several hours in provider's offices they spent little time with providers themselves. Despite these clearly articulated desires, participants described feeling pressured to accept increasingly complex medical interventions during their delivery. Many stated feeling they were pressured by hospital staff into accepting C-sections and other interventions because hospital policy required it.

Harlem participants were also eager to share their thoughts and ideas to improve the health of women and children in their community. Reflecting on the lack of community support within their neighborhood, and specifically lamenting this gradual change over time, participants identified increased needs to build up community support once more. Participants discussed a desire for increased supports directly related to health care and birth (i.e. more availability of doulas, earlier access to postpartum care) as well as a broader vision of support that addressed social

determinants of health (i.e. better access to healthy foods, safer living environments, more community-based organizations (CBOs providing support services). Participants believed that Medicaid coverage wasn't sufficient to meet the complex needs of women and families in their community. By expanding support services to include the intersection of health and community, Harlem session participants believed that mothers and babies would be better supported to thrive in Harlem.

| Syracuse

Conversation during this final session focused extensively on issues related to the patient-provider relationship. In particular the discussion centered on gaps that participants were identifying in their experiences and relationships with health care providers in the Syracuse area. Participants described feeling that their concerns and wishes were often dismissed and overruled, especially

during delivery. Participants described wanting to feel more connected to their providers, and to know that they have an active role in making decisions about their own health and health care. In a few extreme cases participants went so far as to describe their relationship with providers as hostile calling them “sneaky” and “rude.”

The lack of satisfaction with providers was also evident when participants expressed frustration with the lack of choice available to them. Whether it was lack of provider or facility choice, participants believed that their options were generally limited, and often believed that the type of insurance coverage they had was a primary predictor of the level of care they received. Echoing many of the discussions during the upstate New York sessions, Syracuse residents felt that using Medicaid drastically limited their choices and ensured they would receive a substandard level of health care.

| Endnotes

- 1 https://www.governor.ny.gov/sites/governor.ny.gov/files/atoms/files/maternal_mortality_Mar12.pdf
- 2 <https://www.governor.ny.gov/news/governor-cuomo-announces-comprehensive-initiative-target-maternal-mortality-and-reduce-racial>
- 3 NYS Taskforce of Maternal Mortality and Disparate Racial Outcomes; “Recommendations to the Governor to Reduce Maternal Mortality and Racial Disparities”; March 2019. Available from: https://www.governor.ny.gov/sites/governor.ny.gov/files/atoms/files/maternal_mortality_Mar12.pdf and: <https://www1.nyc.gov/assets/doh/downloads/pdf/data/maternal-morbidity-report-08-12.pdf>
- 4 NYSDOH Maternal & Infant Community Health Collaboratives Initiatives: https://www.health.ny.gov/community/adults/women/maternal_and_infant_comm_health_collaboratives.htm
- 5 Centering Pregnancy is an evidence-based group prenatal care model. More information on Centering Pregnancy can be found: <https://www.centeringhealthcare.org/what-we-do/centering-pregnancy>
- 6 Community health workers (including promotores de salud, community health representatives, community health advisors, patient navigators, and others) are frontline, culturally competent, public health workers who serve as a bridge between underserved communities and healthcare systems. NYSDOH programs can be found here: https://www.health.ny.gov/community/pregnancy/home_visiting_programs/ and here: https://www.health.ny.gov/community/adults/women/maternal_and_infant_comm_health_collaboratives.htm
- 7 Baby Café is a community based drop-in center providing breastfeeding education and support. More information can be found at: <http://www.babycafeusa.org/>