

## *Working Paper*

# Disrespect and Abuse of Women of Color During Pregnancy and Childbirth

FINDINGS FROM QUALITATIVE EXPLORATORY RESEARCH IN NEW YORK CITY

### **EXECUTIVE SUMMARY**

With a rising maternal mortality ratio and significant racial disparities in maternal mortality and morbidity, the United States is in the midst of a maternal health crisis. While attention has focused on the clinical drivers of maternal morbidity and mortality, there is growing recognition of the need to understand how women's experiences with care may impact their health and well-being. This report summarizes findings from exploratory, qualitative research that was conducted in 2017-2018 on disrespect and abuse (D&A) during pregnancy and childbirth as experienced by women of color in select low-income communities in New York City.

#### Key Findings:

- Women of color, doulas, and maternity care providers recounted incidents of D&A similar to those reported globally, including racism and discrimination, verbal abuse, poor communication, neglect, and rough treatment.
- Racism and discrimination were particularly salient experiences for women of color, influencing their perception of how respectfully they were treated and the overall quality of care they received.
- Women of color and maternity care providers described the challenges both of navigating and of working in a fragmented health care system where it is extremely difficult to build trusting relationships that could support women and families to experience childbirth in ways that affirmed their personal power and dignity.
- There was broad consensus among all the participants that maternity care providers and health systems need to adopt a more patient-centered approach to care which would enable providers to be more sensitive to the needs of their patients and help ensure that women are treated with dignity and respect.

Framed within the larger struggle for reproductive and racial justice, this study highlights the need for both specific actions to address common forms of D&A as well as a broader transformation of the maternity care system.

## **INTRODUCTION**

Justice is a word not often linked to the process of birthing a child. But in New York City (NYC), a burgeoning reproductive justice movement is reframing the significance of childbirth, not just for individual birthing people, families, and communities, but also for government and the institutions, including health facilities, that convey its values and implement its policies.\* In recent years, the public health data on maternal outcomes has created new urgency: as maternal mortality rises in many parts of the country, the widening disparities by race and place have drawn concern, even anger. In NYC, for example, Black women die in pregnancy and childbirth at a rate more than eight times higher than White women.<sup>1</sup> Nationally, Black women with a college degree are five times more likely to die than White women with a college degree, and 1.5 times more likely to die than White women who did not finish high school.<sup>2</sup>

No single or simple factors explain these numbers and their evolution over time. Much of the attention has focused on clinical causes, including differing levels of pre-existing conditions such as obesity, high blood pressure, and diabetes; and on interventions for managing rising causes of death such as cardiomyopathy and sepsis. A growing body of research focuses on the clinical quality of care in facilities finding, for example, that the site of delivery (which hospitals people give birth in) explains some 47% of the Black-White disparity in severe maternal morbidity in NYC,<sup>3</sup> and that an estimated 60% of maternal deaths around the country are preventable.<sup>4</sup> Still other studies seeking to explain disparities focus on specific demographic factors such as education or insurance, and some physical determinants such as neighborhood environment -- although disturbingly few address empirically the specific social determinants such as unstable housing and food insecurity that loom large for people living in neighborhoods where maternal mortality and morbidity is highest.<sup>5</sup>

All of these issues matter. All of these issues also have histories. And those histories have common roots in the dynamics of structural racism in America, the deeply embedded system of hierarchical valuing that --both symbolically and in practice -- ranks White, Christian, native-born people as superior and Black, Brown and immigrant people as inferior. In an intersectional perspective, this racial hierarchy is entwined with other critical lines of social (dis)advantage, including gender, class, and wealth status. The NYC Department of Health and Mental Hygiene (DOHMH) explicitly acknowledges the role of structural racism and intersectional discrimination in generating health disparities in New York<sup>6</sup> and has adopted a sexual and reproductive justice approach to ground its strategies for addressing maternal and newborn health. One such strategy is for DOHMH to open itself in new ways to collaboration with birth justice advocates and community-based organizations (CBOs) serving communities of color.<sup>7</sup>

But good intentions take us only part way to birth justice. There remains a fundamental gap in our understanding of how structural racism actually works in the maternity care setting, both psychologically for individuals at both ends of the hierarchy, and institutionally in the operation of health facilities and other agencies. Moreover, there is scant empirical evidence to demonstrate whether and how structural racism -- *and the fight against it* -- link causally not only to maternal mortality and morbidity, but also to maternal wellbeing, to family and community flourishing.

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\* Reproductive justice is a movement founded by women of color in the 1990s to reflect their lived experience in societies and health systems marked by structural inequality. It includes "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities." <https://www.sistersong.net/reproductive-justice>

One piece to this larger puzzle is to understand how women experience the non-clinical aspects of their care during childbirth; and, ultimately, to assess the impact of that lived experience on maternal health and wellbeing. While each country or region of the world has its own unique history of reproductive oppression, the phenomenon of disrespect and abuse (D&A) of women during childbirth in health facilities has been documented in dozens of countries and on every continent.<sup>8</sup> In the global literature, D&A is defined generally as “interactions or facility conditions that local consensus deems to be humiliating or undignified, and those interactions or conditions that are experienced as or intended to be humiliating or undignified.”<sup>9</sup> Globally, D&A is cited as a potential cause of women’s dissatisfaction with the birth experience, decreased trust in health providers and systems, and delays in seeking care, all of which increase health risks for both mother and baby.<sup>10</sup>

Much less is understood about the nature and extent of D&A in maternity care in the United States. To gain insights, the Averting Maternal Death and Disability Program (AMDD), a leader in the global maternal health field, conducted a qualitative study in NYC to explore how D&A manifests for women of color from low-income communities and to begin to identify the multi-level drivers of the treatment that women experience as disrespectful.

This exploratory research was designed to inform and stimulate ongoing reproductive justice work in NYC, and to generate new hypotheses for further research. The report joins two other recent studies in the U.S. that focused on patient experiences and reported similar findings.<sup>11</sup>

## **APPROACH**

This study was designed as participatory action research drawing on community-based participatory research methods.<sup>12</sup> The primary methods to collect data were:

- **Focus group discussions (FGDs)**, which sought to explore how women were treated during pregnancy and childbirth as well as their expectations, perceptions and barriers to care during pregnancy and childbirth. FGDs<sup>13</sup> were conducted with 16 groups of three to 10 participants per group between July 2017 and May 2018. Participants included 55 Black and Hispanic women who had given birth within the past six months;<sup>14</sup> separate FGDs were conducted with 23 doulas<sup>15</sup> and with six male partners. The FGDs were conducted in three neighborhoods of New York City — Northern Manhattan, Central Brooklyn and the South Bronx — chosen for their high rates of maternal mortality and morbidity. Participants were recruited in partnership with local CBOs that provide social services to pregnant and parenting people of color in these neighborhoods. Those CBOs collaborated in the design, implementation and analysis of the FGDs. Questions were open-ended and worded to encourage the sharing of personal stories, observations and reflections.
- **In-depth interviews (IDIs)**, which sought to explore how factors in the hospital environment and health system potentially influence the non-clinical, interpersonal quality of care for women during pregnancy and childbirth. IDIs<sup>16</sup> were conducted between September 2017 and July 2018. Participants included 99 doctors, nurses, midwives, residents, lab techs and auxiliary staff who directly interacted with pregnant people<sup>17</sup> in four New York City hospitals. Questions were worded to encourage the sharing of observations of the behaviors of others, recognizing that providers might be hesitant to speak openly about their own personal biases — i.e., *Have you ever **seen** X?* rather than, *Did you ever **do** X?*

The providers interviewed primarily worked in hospitals and clinics that served the same neighborhoods of New York City where FGD participants lived. However, as this was an exploratory study that was not meant to measure D&A or to assign blame for specific behaviors, the research team intentionally recruited women for FGDs through community channels (rather than through facilities) and did not ask the women to identify the hospitals where they gave birth.

Responses from participants were recorded and transcribed. A team consisting of AMDD staff and CBO representatives analyzed a shared set of transcripts to create a comprehensive codebook and AMDD staff analyzed the remaining transcripts to capture women's, doulas' and providers' perceptions of what was happening during maternity care and how they felt about it. Preliminary findings from the study were presented for feedback to members of the communities where the research was conducted, and to the collaborating CBOs, staff at the participating hospitals, the NYC DOHMH and NYC Health + Hospitals, as well as CBOs and birth justice advocates convened by DOHMH as its Community Engagement Group. This feedback has contributed to ongoing refinement of the findings.

## **FINDINGS**

### ***Experiences with disrespect and abuse***

During the focus group discussions, women shared their personal birth stories and related experiences with maternity care. In some cases, women explicitly described incidents as disrespectful or abusive, or as mistreatment; in other cases, the women described experiences and interactions with providers and the health system that the research team identified as D&A according to what has been categorized as such in the global literature.<sup>18</sup> Providers also spoke about what they had experienced or witnessed in their facilities that could be classified as disrespectful or abusive care. Interestingly, there was significant overlap between what women experienced and what providers reported seeing, hearing and experiencing.

Using the categories identified in the global literature, five common themes emerged:

#### **1. Racism and discrimination**

Many **women** who participated in this study described experiencing racism. They felt that providers' use of derogatory statements and dismissive actions reinforced stereotypes of women of color as uneducated and irresponsible about their health. Similar to existing research,<sup>19</sup> women felt that such beliefs and attitudes resulted in poorer treatment.

*Haitian Creole women have a reputation for being a little loud during their labor, ... seemingly theatrical almost. I wonder if we assume that they're just pretending they're in so much pain and having so much difficulty, and then maybe we don't care for them with the same diligence as someone who can more easily communicate to us. – OB Resident*

Many **doulas** said they too believed that providers' words and actions often reinforced notions of women of color as inferior and had the effect of marginalizing and silencing women, especially during moments when they were trying to advocate for themselves. They felt that

providers operated with preconceived notions of the communities they were working in and that mistreatment was often a result of their inability to see beyond the stereotypes they held.

*A client asked to squat during labor and was told by the provider, 'Oh we don't do that here..., you think we're in the jungle in Africa?' — Doula, Central Brooklyn*

**Providers** in the study confirmed that racist beliefs and attitudes were common among their colleagues; that implicit bias contributed to women of color sometimes receiving differential treatment; and that poor women of color were given less time and attention, and their pain and other complaints taken less seriously compared to White patients.

## 2. Verbal abuse

**Women** reported experiencing different forms of verbal abuse. In some instances, they reported being threatened by providers — warned that if they did not do as told, they could die, or their baby could die. In other instances, they reported feeling judged or blamed — judged about their age, weight or decisions they had made during pregnancy; blamed for coming in too early or too late during labor, or for getting pregnant in the first place. They reported instances in which providers made condescending or rude comments about their age, marital status, the number of children they had and how well they were managing their pain.

**Doulas** corroborated women's experiences with reported threats, judgments and blame and the use of condescending and rude language. For instance, doulas reported instances in which providers threatened to call the city's child welfare authorities in order to get women to comply with what the providers felt was the best decision for their course of care.

**Providers** reported witnessing colleagues threaten women about their health or the health of the baby, judge and blame women for causing their own pain, or for being ignorant or uneducated coming into the pregnancy, and make fun of women for their education level, insurance status, marital status and weight (within earshot of the patients). Providers also offered an explanation: that some providers used threats when they felt a woman was making a decision that could result in a complication or death, or when they were merely frustrated with patients viewed as "demanding," "needy" or "difficult". Providers also suggested that the threats were a result of working long hours, being exhausted and wanting to speed up the labor and delivery of a healthy baby (on their terms).

## 3. Poor communication

**Women** felt providers deliberately withheld information or spoke to them using words the providers knew the women wouldn't understand. Nearly all the women described interactions with providers in which they felt they were being treated as less than human. They talked about providers lacking empathy and compassion, failing to greet or acknowledge them, address them by name and make eye contact or look at them while speaking.

**Providers** acknowledged that they struggled with having limited time and ability to make sure women understood what they were saying and what was happening to them and their babies. They spoke of a culture of talking down to women or telling women "just enough" to get consent to proceed.

*They came and they're like, 'Well, we're gonna take the baby and we're gonna go do a test.' What test are you gonna do? Where are you taking him? And they were like, 'Mom, we're gonna tell you that when we come back.' ... None of you are taking my child anywhere where I can't see what you're doing, especially if you can't explain to me. – Woman, Central Brooklyn*

#### 4. Neglect

Many **women** reported feeling that providers did not listen or respond to them with a sense of urgency when they spoke up about their pain or other concerns – resulting in a feeling of neglect or abandonment. They spoke of being ignored or having to wait long periods of time for someone to come when calling for help or asking for a provider. They felt that having an advocate or someone to convey the urgency of their feelings was a crucial factor in “being heard”. And they often spoke of the deep sense of disrespect they felt when they were dismissed for saying they knew something was wrong, asserting that they knew their own bodies and something wasn’t right.

**Doulas** agreed that women were often second-guessed or not believed when they voiced what they thought was going on with their bodies.

**Providers** largely agreed that they are not always able to respond to women immediately or as fast as they would like. A few providers mentioned that there were types of patients who may not be responded to as quickly as others. These included “difficult” patients who complained too much, were convinced they were further along in labor than they were, kept asking when it would be over, or asked why it was so painful. Other providers explained that while they could understand that women felt they were being abandoned, they were not; some justified their physical absence by asserting that women were always being watched on the monitors.

*I think sometimes as providers, we get ... exhausted and then overwhelmed and it becomes — you just don't really honor their wishes that much... Or you find their wishes kind of ridiculous. And sometimes, that might kind of [be] reflected in care. And then people are kind of left alone that shouldn't be. And that, certainly, I think falls into the realm of mistreatment. – L&D Nurse*

#### 5. Rough treatment

**Women** most often spoke about being treated roughly when it seemed that providers were in a rush, in which case they felt the providers were not taking the time to be physically or emotionally respectful toward them. They shared how they felt providers could be physically aggressive or callous just because they were “in a bad mood.”

**Doulas** also felt that their clients were often treated roughly during exams, when taking blood, and when providers were touching or dealing with women during labor.

**Providers** spoke about how failure to communicate about a physical exam could contribute to women’s feelings of mistreatment. They suggested that what a woman might consider to be “rough treatment” during a vaginal exam could come from having been examined without any advance warning of what the exam would entail, and the shock of experiencing unexpected pain or discomfort as a result.

### ***Health system conditions and constraints***

Broader concerns about difficulties dealing with a poorly functioning health system also emerged during the focus group discussions and interviews, providing useful context for evaluating the perceptions and experiences described above. The challenges women and providers faced while maneuvering within that system – and providers’ experiences providing care within that same system – came up time and again as a source of frustration, misaligned expectations and distrust.

### ***Women’s experiences navigating the health system***

For the women in this study – the vast majority of whom were covered by Medicaid, or public insurance – navigating the health care system took an enormous amount of work and time, placing a substantial burden on them to actively seek out prenatal care that was consistent (i.e. with the same provider) and compassionate. Their options for accessing care were largely limited to the public clinics that accepted Medicaid — clinics where the medical providers (often including medical school students and interns) rotated in and out.

Many women reported feeling they lacked choice, control and any continuity of care throughout their childbirth experiences. They described:

- seeing a different provider at every appointment;
- being asked the same questions by different providers who they felt did not bother to read their charts prior to the appointment;
- feeling uncomfortable sharing personal information with someone they had never seen before and had no reason to trust; and
- feeling discriminated against based on insurance status, with longer wait times and dismissive attitudes from staff.

The doulas also noted that continuity of care was a rare experience for low-income women in New York City, and that any prior negative experiences with the health system and other social institutions made women reluctant to speak up or complain about how they were treated.

### ***Providers’ experiences providing care***

Many providers confirmed women’s frustrations with accessing care. They painted a similar picture of a fragmented health care system that limited their ability to provide the type of care they wanted to provide to pregnant women. Many described demands and challenges of a working environment that left them overwhelmed and exhausted. Several echoed women’s and doulas’ sentiments that continuity of care was nearly impossible, with little opportunity to build meaningful relationships with patients.

*It would be a nurse’s fondest dream to sit in the patient’s room with her and support her the way that we’re taught to do it, but it’s not possible with today’s staffing ratios and physical considerations. – Staff Nurse*

Interviews with providers revealed three distinct tension points with patients. Many providers said that they:

- considered women’s birth plans as problematic, because they are often based on individual desires rather than actual medical considerations (conditions such as

- diabetes or hypertension that might make birthing in the planned way impossible) and so led to feelings of disappointment and failure for women;
- felt that women were uninformed about how hospitals function and how care is handled — misled by how childbirth is depicted on TV and in movies, women do not realize how long and painful it can be — all of which only increases tension and misunderstanding, especially in emergency situations; and
  - wished women were more aware and more understanding of providers' job constraints and competing priorities, explaining that a provider's slow response was not necessarily due to malice or laziness but rather an obligation to address other more acute needs.

The interviews with providers highlighted five major challenges in their work environments, including:

- lack of management support to do their job well (inadequate support staffing, inadequate clinical training for the level of responsibility they were given and the acute cases; lack of support when hierarchy was creating a toxic environment) leading to high burnout and staff turnover rates, with a negative impact on patient care;
- entrenched provider hierarchies (nurses feeling disrespected by doctors, little oversight and accountability for a colleague's poor performance, few feelings of camaraderie, tensions erupting into confrontations and disrespect that trickled down to patients);
- fear of litigation (leading providers to practice defensive medicine to prevent lawsuits rather than think about what was best for the patient);
- extensive and onerous charting and documentation requirements that significantly reduced time spent at bedside (which tied back to fears of litigation); and
- management of women's often-unrealistic expectations of what the childbirth experience should be, especially in cases where women had pre-existing medical conditions or other risk factors.

*I don't feel as though I've been appreciated. That's got to trickle down to the patients. — OB Resident*

### **Positive experiences**

Although this formative research was designed primarily to elicit descriptions and perceptions of D&A, it is important to note that women also described positive, compassionate interactions with hospital providers and staff – sometimes even with the same individuals who, in other moments, may have acted disrespectfully. In short, childbirth is an exceedingly complex experience, filled with meaning and emotions not fully captured here. Yet this full experience should ultimately be understood as the context for implementing the wide range of changes needed to achieve birth justice.

### ***What do women — and providers — want?***

All of the women, doulas and providers who participated in this study were asked what they would change to improve the quality of non-clinical maternity care. Here again there were striking similarities in the groups' responses.

For example, there was broad consensus among study participants that providers and health systems need to adopt a more patient-centered approach to care; that women need to be treated with dignity and respect; that providers need to be more sensitive to women's needs and vulnerabilities, and take time to communicate information clearly, explain procedures and manage expectations.

Participants also agreed that facilities should improve staffing levels to avoid burnout and to enable providers to spend more time at bedside with patients during the hospital stay and throughout the pregnancy. All favored community outreach by the hospitals to strengthen relations between facilities and the communities in order to enable better patient-provider relations even before a woman becomes pregnant and begins prenatal care.

And all favored training for hospital staff. The women suggested sensitivity, customer service and diversity training; doulas suggested cultural competency and sensitivity training; and providers cited the need for cultural competency and sensitivity training as well as customer service training. Providers also acknowledged the need to address the implicit bias that they said was common among colleagues and that they felt led to racist and discriminatory treatment of women of color.

### **REFLECTION**

This study shows that women of color in low-income NYC neighborhoods experience a range of disrespectful and abusive treatment during pregnancy and childbirth. Their experiences fall into many of the same categories of D&A that have been widely reported globally.<sup>20</sup> The findings highlight that D&A in the U.S. context is a product of a deeply fragmented health care system that consistently devalues women of color – and not solely a result of individual provider behavior.

Most striking is the significant overlap in what women and providers reported. As depicted by study participants, there are multiple points at which the two groups collide due to misaligned expectations, health system constraints and structural racism, creating a cycle of mutual distrust that fosters cynicism and burnout, and that discourages women from seeking care when they need it.

Strategies for improving maternal health and reducing racial disparities in the U.S. must address these non-clinical, systemic factors, as well as the individual behaviors experienced as D&A. This research, conducted in collaboration with individuals and agencies dedicated to improving the childbirth experience in NYC, suggests that simple training or awareness-raising workshops – whether for birthing families or for maternity staff -- will not be enough to achieve the kind of transformation needed and widely desired. The problem must be understood as both individual and profoundly structural, stemming from longstanding histories of mutual distrust between health facilities and the communities – a distrust that emerges from the tortured history of racism that challenges virtually every social institution in this country today.

For health facilities and health providers, this is not simply a communication or perception challenge. Pregnant people's trust – and their communities' trust -- must now be earned, not assumed. Maternal health programs – whether governmental public health efforts or private hospital initiatives – need to confront this reality. Using new methods of program design and implementation that center user experiences and that explicitly identify and try to tackle the mechanisms of building and breaking trust, the maternal health and birth justice communities can start to create an evidence base for system transformation.

Indeed, success at transforming the childbirth experience – even if it is gradual or uneven – can have an impact well beyond the walls of health facilities. At a deeper level, the work to claim and create birth justice functions as an intrinsic part of the broader movement to build a just society, to value the dignity and human rights of every person, and to ensure that all communities can flourish.

*Research by Lynn Freedman, Shanon McNab, Sang Hee Won, Anna Abelson and Amy Manning, supported by Merck for Mothers,<sup>21</sup> in collaboration with Columbia University Irving Medical Center's Department of Obstetrics & Gynecology, Perinatal Support Services-Columbia Head Start, Healthy Start Brooklyn's By My Side Support Program, NYC Dept. of Health and Mental Hygiene's Center for Health Equity, Healthy Start's Community Action Network, Brooklyn Perinatal Network and Black Mamas Matter Alliance.*

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12. The study protocol was approved by the Columbia University institutional review board, and verbal informed consent was obtained from all study participants.

13. Focus groups were approximately two hours long, audio-recorded and facilitated by moderators who were part of the research team, which included doulas and AMDD staff. Gift cards, food, on-site childcare, and transportation reimbursement were provided. Recordings of the discussions were translated (for Spanish-only), transcribed, de-identified, and analyzed.

14. Women of color being supported by the CBOs in any of the three neighborhoods (regardless of where they lived), who delivered in a hospital in New York City in the last six months\*, who were 18 years or older, and English and/or Spanish-speaking were eligible to participate. (\*Several participants had given birth prior to the six months because not all moderators

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screened women before the start of the FGD or chose not to turn anyone away from participating.)

15. Community-based doulas working with both NYCDOH and NGO programs who were trained to provide childbirth support to women of color residing in any of the three neighborhoods, who were 18 years or older, and English-speaking were eligible to participate.

16. Interviews were 30 minutes long, on average and audio-recorded; recordings were transcribed and analyzed. Participants received a \$10 Starbucks gift card as compensation for their time.

17. Providers and staff who were employees of a maternity hospital or prenatal clinic in New York City, who provided care to a pregnant person in a hospital or clinic in the last 12 months, were 18 years or older and English-speaking were invited to participate. Interviews were conducted with nurses, attendings (OB, MFM, generalists), midwives, fellows, interns, residents, students, social workers, anesthesiologists, receptionists/clerical staff, housekeeping/environmental service staff, lactation consultants and nursing assistants/technicians.

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21. *Merck for Mothers* is Merck's \$500 million initiative to help create a world where no woman has to die giving life. *Merck for Mothers* is known as *MSD for Mothers* outside the United States and Canada.