The Giving Voice to Mothers Study Report:
Communities defining quality and safety in pregnancy and childbirth care

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Executive Summary

Following an extensive participatory process, we co-designed a study to assess the quality of perinatal services in the United States as experienced by two national cohorts of understudied health service users: childbearing communities of color and those who planned community births. We received responses from 2700 people from all 50 United States to a survey (2016-2017) on experience of childbearing care. Participants were recruited by community partners who provided clinical or community health services via snowball sampling, social networking, and referrals from parents and consumer advocacy groups in various states. Two thirds of responses came from New York State, and 8% from California. Just over half of participants were between the ages of 31 and 39 years at the time of their most recent birth. Most (90%) were born in the US and spoke English at home. Within those respondents, 15% self-identified as Black, 10% as Hispanic, 2% as Indigenous, 4% as Asian, 2% as multiracial, and 67% as White. The majority (80%) had completed post-secondary education and obtained an associate or college degree. Half of respondents planned a community birth and half planned to give birth in a hospital. Half paid for maternity care via private insurance, and 14% used Medicaid/Children’s Health Insurance Program (CHIP).

PREFERENCES FOR CARE

Participants reported on what is important to them during maternity and newborn care. The following factors were rated as important or very important by more than 90% of respondents:

• Leading decisions about pregnancy, birth and baby care
• Having a trusting relationship with my care provider
• Having a doctor or midwife who is a good match for what we value and want for pregnancy and birth care
• Not being separated from my baby after birth
• Having enough time to ask questions and discuss options for care
• Having support people of their choice present for labor and birth
• Knowing the midwife/doctor who will care for us during birth
• Choice of birth place (home, birth center or hospital)

INEQUITABLE ACCESS TO HIGH QUALITY PERINATAL SERVICES

Unmet demand for preferred model of care

People of color were less likely to receive continuity of care, i.e., they were less likely to have a known doctor or midwife who provided the majority of prenatal care attend their birth. Most Black women reported that it was very important or important to have continuity of care, yet they were the least likely to report continuity of care.

Two in three participants reported that midwives were most directly involved in their prenatal care. Women of color were less likely to access midwifery care compared to White women. Black women were least likely to be able to access midwifery care.

Black women were the most likely to report that they want to lead decisions around their pregnancy, birth and baby care, yet they reported the lowest autonomy in decision-making scores and had the least access to models of care that support decision-making.
Similarly, 95% of Black women said it was important or very important to them to have enough time to ask questions and discuss options for care, yet they were the most likely to have very short prenatal appointments (10-15 minutes), on average.

**Disparities in mistreatment**

Most respondents rated their overall sense of privacy, dignity, and respect as very good or excellent; however, there were notable differences by race, place of birth, and type of provider. Care in community settings and by midwives was associated with greater respect, privacy, and dignity. All perinatal service users of color reported lower overall rates of respect, privacy and dignity, than White women. Indigenous women were most likely to report disrespect, and loss of dignity and privacy.

**Experiencing at least one form of mistreatment by healthcare providers was most common among Indigenous women (34%), followed by Latina (25%) and Black women (23%).** Respondents who identified as White were least likely to report that they experienced being ignored or refused care when they requested help from providers. Differences in mistreatment by race were more pronounced for some indicators; particularly, verbal abuse and failing to meet professional standards of care. Verbal mistreatment, in the form of being shouted at or scolded by health care providers, was reported twice as often among Hispanic and Indigenous women compared to White women. Furthermore, Black, Latina, Asian, and Indigenous people were more likely to experience being ignored or refused requests for help by care providers.

**Autonomy in decision-making**

Autonomy is the opportunity and ability of an individual to make choices based on their own values and needs. Individual autonomy in health care decision-making is a key component of quality care and is noted as a priority for health systems improvement (10), as it could lead to better birth outcomes (11). In this survey, autonomy was captured using the Mothers Autonomy in Decision-Making (MADM) scale, a validated tool comprised of seven items that assess the degree that maternity care providers respect and facilitate the ability of women to lead decisions about their care (12).

**Women of color (especially Black women), young women, less experienced mothers (i.e., those being pregnant for the first or second time) and those with low socio-economic standing, pregnancy or social risks were more likely to report low autonomy in decision-making.**

Having a midwife as their prenatal care provider, having a home birth and a vaginal birth were all linked to higher autonomy. Autonomy was more likely to be constrained for service users who had obstetricians as their primary prenatal care providers, those who gave birth at the hospital, and women who experienced an emergency Caesarean or instrumental vaginal birth. Respondents whose labor was induced; those who were transferred from the community to the hospital; and/or who reported newborn health problems were also more likely to report low autonomy.

**Access to culturally concordant care providers**

One in seven women (17%) agreed or strongly agreed with the statement ‘Finding a midwife or doctor who shared my heritage, race, ethnic or cultural background was important to me’, with large variations across racial groups: 46% of Black women, 9% of White women, 25% of Latina women, 13% of Asian women and 25% of Indigenous women agreed with the statement.
Of the women who said it was important to them to find a health care provider who shared their heritage, race, ethnic or cultural background, 69% of Black women, 4% of White women, and 49% of Latina women had difficulty locating a doctor or midwife who shared their heritage, race, and/or cultural background.

**Pressure to have or to avoid interventions**

Participants reported on experiences of pressure from healthcare providers to have or to avoid interventions, tests or procedures. The most common procedure that women felt pressured to accept was continuous fetal monitoring (24%), followed by medications to start or speed up labor (13%), a Caesarean (11%), and epidural anesthesia (7%). **Women of color were more likely to report feeling pressured into all of the listed interventions and procedures**, compared to White women. When Black, Indigenous, Latinx, or Asian persons declined procedures, they were twice as likely to report that providers kept asking them until they agreed.

**Non-consented procedures**

One in two respondents declined care that was offered to them at some point during their labor/birth. Most women (92%) reported that they declined because they “thought it was not necessary”.

Women identified procedures that they were not informed about prior to these procedures taking place. The most common procedure that women were not asked permission for was having an injection to assist delivery of the placenta (afterbirth). Over a quarter were not asked before their bag of waters (amniotic sac) was broken, and one in three were not asked before an episiotomy (surgical cut of the vagina during childbirth) was performed. Black and Asian women were most likely not to be consulted before an episiotomy. Overall, Black, Indigenous and people of color were more likely to experience non-consented procedures compared to White participants.

**Experiences of respectful care**

Respectful care during encounters with health care providers was measured by a community-developed and validated scale called Mothers on Respect Index – MORi (13). Respondents rated their experiences of their interactions with care providers such as experiences of stigma and discrimination, and comfort asking questions. Although most respondents felt comfortable asking questions, more than 20% reported that they did not feel comfortable declining care or that their personal preferences were not respected. Black and Indigenous people were most likely to report overall disrespectful interactions with providers.

**Women who had unplanned Caesareans or instrumental vaginal births reported higher rates of disrespect and mistreatment.** Other social or demographic characteristics that made it more likely to experience disrespectful care included being under 30, no previous experience with birth, low socioeconomic standing, and/or a history of incarceration, substance abuse and involvement of child or family services.

Proportions of respondents across racial identities who declined care were similar (i.e., 52% of women of color versus 54% of White women) yet women of color were twice as likely to report that their care providers pressured them or performed the procedure anyways (i.e., against their will), whereas White women were more likely to report that their care provider accepted their decision to decline care.

People more often reported respectful care if they were supported by a midwife, experienced a community birth and/or delivered vaginally.
Unmet demand for doula support

A doula was defined as follows in the GVtM survey: “Some women have a ‘doula,’ or a labor support specialist. This person usually stays with a woman throughout labor and birth to provide emotional support, comfort measures, and information.” Of the women who did not have a doula during labor/birth (n=1318), 546 (41%) would have liked to have had the care of a doula during their most recent birth. Preferences for doulas varied by race, with high demand among Black (58.7%), Latina (62%), and Indigenous women (55%) and lower demand among Asian (39%) and White women (34%).

Continuity of care was disrupted for many women who transferred to the hospital: one in three (31%) reported that their midwife was not able to stay with them after transfer, and 15% said that their midwife did not provide care after hospital discharge.

Preferences for place of birth for a future pregnancy varied by race. Preferences for hospital birth were slightly higher for Asian women and demand for home birth was especially high for Indigenous women, with over 70% of respondents stating that they would definitely want an “at home birth.” Black women reported high interest and least access to community birth.

COMMUNITY BIRTH

The most common reasons reported for planning a community birth (i.e., at home or a freestanding birth center) were:

• Control over my childbirth experiences
• Comfortable, peaceful environment
• Low intervention options for care
• To avoid disturbance of my labor
• To avoid having to fight for my desired birthing experience
• To avoid a Caesarean section
• Safety
• Confidence in my own body
• Better for baby
• To avoid separation from my baby
• To avoid hospital policies and procedures
• To avoid time limits

Each of these reasons was cited by more than 90% of women who planned a community birth.

Most people who planned community births (82%) felt judged or criticized for their choice of birth place. Participants reported that they were judged or criticized by the public, friends, in-laws, healthcare providers, parents, and work colleagues.

Respondents reported on the care they felt they needed and who assisted them to access that care. They reported receiving assistance from providers with smoking cessation, but almost no help to access other important resources and referrals. Unmet needs include nutrition counseling, doula support, safe housing, food assistance, insurance coverage, and access to programs and counseling to support their mental health, or address intimate partner violence.

HEALTH AND SAFETY DURING PREGNANCY

The GVtM survey included several items that assessed health and safety concerns that childbearing women might experience. The four most commonly cited sources of worry were 1) experiences of being pregnant and giving birth, 2) peace of mind/stress/mental health, 3) children’s health and 4) access to women’s health services. Black and Indigenous respondents were most likely to voice concerns about their experiences of being pregnant and giving birth and were also more likely to worry about safety at home, violence against their family or community, stress, access to affordable housing and access to healthy food. Half of all Black and Indigenous women noted that they were worried about their mental health and stress levels, compared to one in three White and Asian women.
When asked how often participants felt safe in their neighborhood during pregnancy, White and Asian women were most likely to respond that they felt safe every day of the week. In contrast, 9% of Black women and 7% of Indigenous women felt unsafe some or all of the time during their last pregnancy.

**POSTPARTUM EXPERIENCES**

Most women (86%) reported that they were able to have skin-to-skin contact immediately after birth – i.e., their baby’s naked body against their skin with no clothing, blanket, or diaper between mother and baby the first time they held their baby. The proportion of women who reported skin-to-skin contact varied by type of birth provider and place of birth: skin-to-skin contact was reported by most women who gave birth in the community with a midwife (97%), 87% of women who gave birth at a hospital with a midwife, and 69% of women who gave birth at the hospital, with a doctor.

Almost 70% of women reported getting help with breastfeeding initiation from their maternity care provider, but there were differences in frequency of support by place of birth and provider: 89% of women who gave birth in the community with a midwife, 65% of women who gave birth at a hospital with a midwife, and 43% of women who gave birth at the hospital, with a doctor, reported support.

**CONCLUSIONS AND RECOMMENDATIONS**

The experience of care is a key element of optimal perinatal1 care. This survey aimed to better understand disparities in accessing preferred care and racially driven disparities in experience of mistreatment and lack of autonomy in a sample of women from across the United States. Almost all respondents prioritized building a trusting relationship with their provider and finding providers that understand what they value the most, with continuity of care facilitated by having the same provider. Although midwifery care in community settings was linked to higher reports of respect, privacy and dignity overall, women of color, especially Black women, were least likely to have access to midwifery care. Black women reported higher incidents of mistreatment, lower autonomy in decision-making or freedom to ask questions, and higher reports of non-consented care. Many women of color, including Black and Indigenous women, talked about the importance of being able to choose a provider who shares their culture. Attendance at prenatal classes was also lowest among Black and Indigenous women. Feedback from communities about these findings echoed the need for increased access and use of innovative education tools and classes delivered by care providers of color with adequate representation in outreach and education materials.

Study methods are described in the Full Report.

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1 We use perinatal to describe the continuum of health care experiences from preconception, through pregnancy, birth, postpartum, newborn, and early parenting.
Preliminary findings of the GVtM survey were reported back to five communities across the country: East Point City, Georgia; Orlando City, Florida; Espanola, New Mexico; Minneapolis, Minnesota; and Pittsburgh, Pennsylvania. These towns and cities have a large population of people of color (25-86%), as well as people who live below the poverty line. Community engagement leads and local midwives who help underserved groups brought the results to local meetings, inviting new families and providing them with an opportunity to inform how the data speaks to their experiences and how it could best be used to inform their communities.

Overall, many groups expressed the importance of having a care provider from within one's own culture and community. It was important to the parents that their care provider understood their lived experience and concerns and was able to provide care that was realistic and relevant to their culture and values. Representation was also an important theme in the discussion groups. Many women wanted to see not only more midwives and doulas of color but sought more innovative ways to engage and inform young communities of color about pregnancy and birth using digital media such as live streams and social media.

The findings from this survey regarding themes of respect and not being heard also strongly resonated with the communities. Participants in the group wanted increased training for health care providers around informed consent, bodily autonomy, and communication, but also more engaging and immersive resources around maternity and birth for their own knowledge.

In New Mexico, where access to care in reservations and remote areas was discussed, participants noted that having one care provider for duration of pregnancy, labor and birth was important to building trust. The communities had also discussed the importance of creating a space for storytelling, and how they wanted their real-life experiences to accompany the data.

Community building and peer support were central to many of the discussions, as the women wanted ways to dispel myths and share information among people having the same experiences, such as creating a safe space to talk about postpartum depression.