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Executive Summary

In late 2020, the Ohio Department of Health awarded CelebrateOne with funds to address inequitable birth outcomes that disproportionately impact Black moms. Over the past year, CelebrateOne used these funds to engage a group of community members who have lived experience and have been impacted by maternal morbidity and mortality, to conduct research on the topic. These peer researchers engaged a broader community of women of color, listening to their stories around birth — before, during and after — to uncover opportunities and potential solutions that may change the trajectory and health for Black moms and their babies. The results of this research have been shared with leading regional agencies who work on maternal health, and these agencies have begun to define strategies for delivering on the opportunities identified in this work.

Through this grant funding, CelebrateOne achieved the following goals:

1. **EQUIP COMMUNITY MEMBERS IN HUMAN-CENTERED DESIGN**
   A group of 4 peer researchers were trained in HCD and built their leadership skills/capacity.

2. **CO-CREATE WITH COMMUNITY MEMBERS**
   The peer researchers designed and facilitated focus groups with 32 women to understand challenges young parents face (housing, employment, access to prenatal care, etc.) as it relates to infant mortality and morbidity.

3. **ACTIVATE THE LEARNINGS**
   Promising opportunities and lessons learned were used to engage organizational leads in developing new actions and strategies from the work.
This report provides a detailed description of the work funded in this grant and includes sections on research recruitment, research results and emergent strategies.

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<th>Project Timeline</th>
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<td><strong>February – March</strong></td>
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RESEARCH RECRUITMENT

Peer researchers, who are BIPOC (Black, Indigenous, People of Color) with lived experiences of pregnancy and/or birth complications, were recruited by CelebrateOne to participate in multiple training sessions with Design Impact. These women learned the process of designing and facilitating listening sessions to foster change in their community, and also learned about human subjects research. There were three peer researchers who participated in these trainings, design process, and facilitation of the listening sessions.

The peer researchers and larger working group from Design Impact, CelebrateOne, and Nationwide Children’s Hospital (NCH) worked together to create a listening session guide. The guide included questions to elicit the information deemed important by CelebrateOne for strategic planning, while also including questions that women with lived experiences (the peer researchers) felt were necessary to understand how we might improve birth equity and outcomes for moms and babies of color.

Peer researchers and CelebrateOne staff worked to post and send fliers advertising the listening sessions to those in their networks. Women who were interested filled out an online eligibility survey and provided contact information, allowing CelebrateOne staff, peer researchers, and NCH research staff to reach out to explain the listening sessions and work through the informed consent process.

Participants were eligible if:

1. They were able to understand and speak English without an interpreter
2. They identified as a woman of color
3. They were at least 18 years old
4. They had experiences related to pregnancy or birth complications
5. Their experiences occurred in 2016 or later
6. They lived in Franklin County while pregnant or when they gave birth
A total of 32 women participated across 6 listening sessions which were led by a peer researcher who participated in training by Design Impact related to creating and facilitating listening sessions to impact change in the community.

The listening sessions were held virtually on Zoom, and each lasted approximately 90 minutes. Listening sessions were concluded at 6 due to content saturation, occurring when similar themes continue to emerge from participants.
Listening Sessions Demographics

**AGE**
(n=31)
- 18 – 24: 13%
- 25 – 31: 23%
- 32 – 38: 35%
- 39 – 45: 29%

**HIGHEST LEVEL OF ED.**
(n=31)
- Less than grade 12: 10%
- Grade 12 or GED (High school graduate): 19%
- Some college, Associate’s degree, or technical school: 10%
- 4-year college graduate/advanced degree: 48%

**PRIMARY LANGUAGE**
(n=31)
- English: 97%
- Spanish: 3%

**RACE & ETHNICITY**
(n=31)
- Non-Hispanic Black or African American: 81%
- Hispanic, Latinx, or Spanish only: 10%
- Two or more races or ethnicities: 6%
Listening Sessions Demographics

**MARITAL STATUS**
(n=31)

- Single, never married: 23%
- Member of unmarried or partnered couple: 19%
- Married: 48%
- Divorced/Separated: 10%

**EMPLOYMENT STATUS**
(n=29)

- Employed for wages (part-time/full-time): 55%
- Out of work for less than 1 year: 21%
- Out of work for 1 year or more: 7%
- Homemaker: 10%
- Self-employed: 3%
- Student: 3%

**# OF PREGNANCIES**
(n=30)

- 1: 10%
- 2: 27%
- 3: 23%
- 4: 13%
- 5 or more: 30%

**# OF LIVE BIRTHS**
(n=30)

- 0: 3%
- 1: 13%
- 2: 30%
- 3: 23%
- 4: 3%
At the conclusion of the sessions, these notes were compiled and summarized in order to get an initial understanding of the emergent themes. The recordings were transcribed by NCH staff, and the transcriptions will be utilized to implement an in-depth qualitative analyses process using inductive and deductive coding methodologies. This process and results will be written up in manuscript format and submitted for publication in a peer-reviewed journal.
After the listening sessions were complete, Design Impact worked with the notes to identify initial themes from the research and hosted a collaborative session with the peer researchers, CelebrateOne, and Nationwide Childrens to build on and refine these themes.

The research identified two very broad areas of concern from the mothers in the listening sessions: **Access to Resources and Bias in Services.**

Both of these areas were supported by several distinct themes outlined in the following pages.

**ACCESS TO RESOURCES**

1. Supporting Good Mental Health
2. Moving Beyond Self-Advocacy
3. Connecting With My Child

**BIAS IN SERVICES**

1. Bipoc Women Feel Unheard
2. Marital Status Changes the Quality of Care
3. Representation Matters
4. Caring for People on Public Insurance
Access To Resources

Moms want to be informed about the critical resources available to them before, during, and after pregnancy. When moms have the resources they need to feel safe and supported, they can better care for themselves and their families. However, they often feel as though important resources they need aren’t shared with them.

“When it came to having knowledge about premature babies, I just didn’t know; It made me feel so bad and inadequate as a mother.”
Access To Resources Themes

1 SUPPORTING GOOD MENTAL HEALTH

SUMMARY
The medical community often talks about the importance of good mental health but when it comes to BIPOC (Black, Indigenous, People of Color) women, it can be deprioritized or missed. Pregnant BIPOC women and new mothers need to receive express and focused support because they face bias and mental stressors — often from medical staff — such as racism, sexism, and other ‘isms’ that weigh on their mental health. They want supported mental health pre, during, and post-pregnancy.

CALL TO ACTION
How might we provide pregnant BIPOC women and new mothers with support systems to safeguard and preserve their mental health, as they struggle with personal and domestic issues, global crisis, and postpartum depression?

MOM WHO HAD A PREVIOUS MENTAL HEALTH DIAGNOSIS SHARED:
“[During the] first 3 – 4 weeks I cried hysterically questioning am I good enough mother, am I doing this right? Certain words would trigger crying. [During weeks] 5 – 6, after getting to know my daughter and having positive interactions, [I knew] ‘I love her so much’.”

“[Poor] mental health [often] removes the enjoyment of the experience [of pregnancy, becoming a mother].”

“Postpartum is not a joke; it is hard on women and it is real.”
MOVING BEYOND SELF-ADVOCACY

SUMMARY
BIPOC (Black, Indigenous, People of Color) pregnant women and new mothers do not feel that pertinent medical resources and information are readily provided to them by healthcare providers. They often have to be proactive in seeking out the information that they need and then have to be actively vocal about advocating for their needs. They want to feel that their needs are being anticipated and immediately addressed by healthcare professionals.

CALL TO ACTION
How might we empower healthcare professionals to better anticipate the needs of BIPOC pregnant women and new mothers to more immediately and directly provide the information and services that they need for themselves and their children?

MANY MOTHER’S FEEL UNSUPPORTED BY MEDICAL STAFF:
“I felt like if I was a white woman I would have been treated differently. They wanted to drug [my son] up in the hospital (fentanyl for just crying, opioids, etc.) — I told the doctor that my son is a black boy and this is what you all are doing to our children. Six months in hospital. Before they put anything in his IV, I made sure to be contacted by the nurse first.”

“I never used resources — not because I didn’t have them. I wasn’t in a financial bind, or anything mentally. I had my family, prayer, and God and that’s what kept me going. But none of the resources were ever put in front of me either. He is a little person and we don’t have many resources for that in Columbus so I have to go to Cincinnati (Little People of America). I looked up everything and came upon this resource personally. None of the hospitals gave me any information at all for dwarfism, etc. I didn’t get any resources at all except for clinics to terminate my son.”

When asked what might they share with health care providers or others about how they could make your experience better, a mom commented that [she wants to let] the doctor know that she knows her body better than they do.

“[My] doctors suggested bed rest — [but] how am I supposed to do that and take care of a five-year-old and work full-time? I didn’t know about short-term disability; I didn’t have education for resources; [and I wasn’t able to] follow doctor’s orders [bedrest]. [That] was not a realistic thing for me. I felt very in the dark [because bed rest] was an unrealistic expectation.”
CONNECTING WITH MY CHILD

SUMMARY
BIPOC (Black, Indigenous, People of Color) mothers crave more time to spend with their newborn babies so they [the mothers] can recover from childbirth and bond with their babies, but maternity leave and/or under-resourced or inadequate FMLA allotments often leave them feeling as if they haven’t had enough time to do either. When women face complications during pregnancy or childbirth this further impacts their ability to access leave time.

“Eight weeks maternity leave is not enough; women need more time to spend with their babies; rushing back to work is depressing; [the] time frame is too short.”

A mother shared that eight weeks off from work for maternity leave is not enough time [to bond with her baby]. “They need to give more time for mothers and baby.”

“They gave paid maternity leave. I stayed off for 4 months and was told I could do FMLA but they don’t pay you for it so there aren’t any other options. You are out of luck.”

“Six to eight weeks is not enough time for maternity leave. [It is] inhumane.”

CALL TO ACTION
How might we support BIPOC mothers in a way that provides them with adequate time and space to heal and bond with their newborn children?
Bias In Services

When compared to white women, pregnant BIPOC (Black, Indigenous, People of Color) women experience the healthcare system differently, and often negatively, due to the unequal and disparate treatment that they receive. Additionally, the intersectionality of race, gender, and class creates further barriers for mothers navigating a system based in white supremacist culture.

“*If birth equity was achieved, we wouldn’t feel like we have to put up with [the mistreatment].*”
Bias In Services Themes

1. BIPOC WOMEN FEEL UNHEARD

SUMMARY
When BIPOC (Black, Indigenous, People of Color) women are treated with respect and dignity, they can live into their full humanity. They have wisdom, gifts, and experiences that can strengthen and connect to their roles as caregivers. Their lived experiences make them experts in their own lives, but their concerns and voices are often ignored, not respected, and they often receive pushback on the choices they make. This is not about feelings. It is about how being unheard leads to being untreated. Being untreated leads to chronic conditions, disabilities, and, unfortunately, even death.

CALL TO ACTION
How might we listen to and respect BIPOC women in a way that validates their lived experiences and humanity and leads to improved health outcomes?

“If you are a woman of color, it’s as if you don’t have a voice. There are preconceived notions from others.”

Several women shared instances of health care staff ignoring their [the womens’] pain:
“I was in active labor [but] I was told it was ligament pain.”

A mother shared that her second pregnancy was high risk so her doctor pushed [for her to receive] a progesterone shot—this mother didn’t understand the long-term effects (and asked about those effects):
“When women of color question what the doctor suggests, the doctors push back on the curiosity.”
SUMMARY

Institutional support structures like healthcare are supposed to lift us up but often treat single mothers differently and make them feel judged. Mothers want to be seen as a whole person, not as someone who has failed to meet supposed white, christian, middle-class sensibilities of doctors and staff. This incredibly vulnerable time in a woman’s life requires a trauma-informed, healing approach to care.

CALL TO ACTION

How might we identify our biases and learn to treat every mother with the care required to make her feel at ease?

There is a stigma on marriage and what kind of care you get (state resources aren’t just for single mothers, but we assume that’s the only people who need them).

Feeling judged [from doctor] around not being married to father of child.
REPRESENTATION MATTERS

SUMMARY
Rising diversity in the medical field has positive effects on BIPOC (Black, Indigenous, People of Color) in general and BIPOC mothers in particular. Black mothers appreciate when their medical team reflects them and understands their unique needs – they often feel as if medical staff who look like them treat them with greater care and support.

CALL TO ACTION
How might we ensure Black mothers have more opportunities to be treated by medical staff that look like them?

MOMS SAY IT MAKES A DIFFERENCE TO HAVE A POC (PERSON OF COLOR) ON STAFF PROVIDING CARE:
“I want someone who looks like me to be in the room when it’s life or death.”

“There was an old black woman on staff who actually supported me, saying: ‘I believe you can do it; I got you.’ She listened and heard me while other staff ignored me. She went out of her way to advocate for me and my baby even after she was born.”
CARING FOR PEOPLE ON PUBLIC INSURANCE

SUMMARY
BIPOC mothers reported receiving less quality healthcare services after switching their insurance coverage plans. These women often started with private providers and compared their experiences to the level of care they received when using public government insurances, like medicare. They reported shorter visits with doctors, the inability to afford uniquely helpful services like doulas, and more dismissive interactions from healthcare workers. BIPOC pregnant women and new mother’s, using public insurance, want the same level of care and service that their counterparts, with private coverage, have.

CALL TO ACTION
How might we elevate the quality of healthcare service that BIPOC, pregnant women, and new mothers receive when using public government health insurance and ensure that it matches the kind of care one receives from private insurance providers?

A mother shared a story of needing to relocate due to her husband’s job (she was 8 ½ months pregnant at the time). She was referred to a new doctor and says she “had a horrible experience [that was] blatantly racist. ” She called corporate and wrote a letter and once she shared that she had private insurance, she says the experience changed. She says she wanted time to be able to ask questions and have a positive birthing experience, but these other issues got in the way.

Stories shared illuminated a difference in treatment between private healthcare versus medicaid.

Had to switch to government insurance and her visits got shorter after that; just dismissed her concerns.
Emerging Strategies

The themes from the research were presented to the CelebrateOne Lead Entities group. This group represents a wide variety of healthcare and community organizations that work on the issues surrounding maternal health, and are primary stakeholders in Celebrate One’s strategies and initiatives. This group worked with the themes to identify key actions and strategies to pursue. Their work generated a set of high-level strategies and supportive actions for each of the major thematic areas — Access to Resources and Bias in Service.
Access To Resources Strategies

1. **INCREASE ACCESS TO ALTERNATIVE SUPPORT FOR PATIENTS**
   - Link families with prenatal supports such as: doulas, partners, community health workers or home visitors.
   - Include the advocate or support person in care discussions.
   - Engage in clear communication that allows for advocates to ask the questions.
   - Expand the prenatal team to become a “dynamic care team” in order to help connect with resources and better engage with mental health and other services.
   - Support legislation for sustainability of perinatal supports (doulas, home visiting, etc.)

2. **RESPOND TO SPECIFIC FAMILY NEEDS IN REAL TIME**
   - Incorporate qualitative inputs on the family’s experience of birth into specific approaches based on family’s needs.
   - Use technology (EMR) to incorporate action and connect across systems.
   - Create feedback loops between providers and clients that allow for timely input or critique to be delivered.
   - Create spaces for mediated dialogue between patients and providers.

3. **INCREASE ACCESS TO MENTAL HEALTH SUPPORT**
   - Prioritize screening for mental health in prenatal care and warmly link to appropriate resources.
   - Modify EPIC/EMR to allow for mental health inputs, including factors such as homelessness and interpersonal violence.
   - Share mental health information with the healthcare team prenatally and during labor/delivery.

4. **INCREASE THE TRANSPARENCY OF DATA BETWEEN HEALTHCARE AND CBOS**
   - Conduct research to determine how funding challenges or other limitations impact the quality of care that mothers are receiving based on location.
   - Share research to generate transparent records on locations for families—potentially connect to resource allocation.
   - Create digital Information sharing platforms that link with EMR and community-based organizations.
Bias In Healthcare Strategies

1. **INCREASE ACCOUNTABILITY OF HEALTHCARE PROVIDERS**
   - Create space for families to provide meaningful feedback on their experience to providers.
   - Conduct audits and collect data on patient experience that is tied to provider and/or location and disaggregated by race of provider and patient.
   - Publicize the results of these activities (a+b).
   - Connect the results of these activities to funding.

2. **INCREASE BIPOC REPRESENTATION IN HEALTHCARE**
   - Collect data on BIPOC representation and patient outcomes based on racial alignment.
   - Connect families to resources that center Blackness, including providers of color, birthing classes, and affinity groups.
   - Provide more scholarships and incentives for BIPOC students in the healthcare fields.

3. **INCREASE AWARENESS OF BIAS IN HEALTHCARE**
   - Assess and update organizational policies to reduce barriers to inclusion (ie. fees for tardiness, asking about marital status, etc.)
   - Incorporate bias, structural racism, and cultural competency into education and training programs for new and experienced healthcare providers.
   - Create feedback systems that allow providers to learn from patient experience and tie this feedback system to payment/finances.
Closing

Celebrate One plans to apply the assets from this work, including the research findings, strategies and relationships with community members to our programmatic and strategic initiatives moving forward. This includes how this work will influence our strategic planning process, services and engagements with the Lead Entities group. We appreciate the opportunity that the support from Ohio Department of Health provided us and look forward to our ongoing collaboration.

For more information about the work of CelebrateOne, including our strategic plan, please visit our website at:

www.columbus.gov/celebrate-one/
This report was made possible with the support of the Ohio Department of Health.
## LOGIC MODEL

### INPUTS
- Individuals with lived experiences of maternal morbidity and mortality including pregnant and post-partum women, especially non-Hispanic Black women who have experienced maternal morbidity its risk factors and families and friends of women who have experienced maternal mortality
- Providers and public health professionals providing direct service to women experiencing or at risk for maternal morbidity and mortality
- Human-centered design consultants
- Leadership buy-in
- CelebrateOne and partners: OHIO, NCH, etc.
- Funding, guidance and support from Ohio Department of Health

### ACTIVITIES
- Recruit 100 participants including 60 women impacted by maternal morbidity and mortality and 40 public health professionals and providers by February 28th
- Train 4-6 peer researchers by January 15th
- Co-design a structured question guide for listening sessions by February 15th
- Conduct four listening sessions with participants by June 30th
- Collaborate with partners and peer researchers to identify lessons learned and action steps from listening sessions by September 14th

### OUTPUTS
- Recorded and transcribed information from listening sessions by June 30th
- Identified central themes and ideas from listening sessions by August 31st
- Concrete lessons learned and recommendations for improvements published in a listening session report by August 31st
- Information from listening sessions will be considered in CelebrateOne 2.0 planning process
- Increased awareness of challenges and underlying causes of maternal morbidity and mortality
- Increased awareness of racism, racial bias, and racial inequities experienced by Black women and BIPOC

### SHORT-TERM OUTCOMES
- Partner agencies and CelebrateOne take action steps to produce change based off lessons learned in listening sessions by September 29th

### INTERMEDIATE-TERM OUTCOME
- New programs, policies, research questions, or interventions are proposed as a result of listening sessions
- New investments are targeted towards solutions for maternal morbidity and mortality
- Adoption of recommendations in final report and policy changes by health systems
- Adoption of the CelebrateOne 2.0 strategic plan

### LONG-TERM OUTCOMES
- Changes to local, state, or federal policy resulting from lessons learned and additional research
- Changes in healthcare practice resulting from lessons learned and additional research
- Decrease in pregnancy related deaths and injuries
- Reduction in racial disparities in maternal mortality and morbidity

### ASSUMPTIONS:
- Pregnant and post-partum women, especially non-Hispanic Black women who have experienced maternal morbidity its risk factors and families and friends of women who have experienced maternal mortality are well positioned to share relevant information about their experiences to inform meaningful change.
- Stakeholders value the input of the community they serve and will follow their lead to create change in policies and practices.

### CONTEXT:
- Women of color are disproportionately impacted by maternal morbidity and mortality through systemic racism and implicit and explicit biases held by healthcare providers.