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VOICES, STORIES AND EXPERIENCES OF BLACK WOMEN

Informing the Establishment of a Trenton-Based Maternal and Infant Health Innovation and Research Center

Prepared by:

KEAN UNIVERSITY

KEAN

John S. Watson Institute for URBAN POLICY & RESEARCH

Acknowledgments

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The John S. Watson Institute for Urban Policy and Research at Kean

The John S. Watson Institute for Urban Policy and Research at Kean University is dedicated to deepening the analysis around critical public policy challenges and broadening the range of policy ideas, perspectives and options. The Institute plays a critical role in researching issues affecting the state's urban centers and developing solutions to address them. Named in honor of the late N.J. Assemblyman John S. Watson, the nation's first African American chairperson of an appropriations committee, the Institute serves as a vital resource for New Jersey decision-makers through a practical, nonpartisan, hands-on approach informing public policy and linking people to policy.

Kean University

Kean University is a public cosmopolitan university serving undergraduate and graduate students in the liberal arts, the sciences, and the professions. Kean is the first and only urban-focused research university in New Jersey, dedicated to the important work of conducting research on issues that impact the state's urban centers. A member of the Hispanic Association of Colleges and Universities, Kean is a Hispanic-Serving Institution (HSI) of which first-generation college students comprise over a third of the student body. Kean's diverse students engage in research and creative projects that develop sustainable solutions to critical issues in communities across the state.

Stockton University

Stockton University's mission is to develop engaged and effective citizens with a commitment to life-long learning and the capacity to adapt to change in a multi-cultural, interdependent world. As a public university, Stockton provides an environment for excellence to a diverse student body, including those from underrepresented populations, through an interdisciplinary approach to liberal arts, sciences and professional education.

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Executive Summary

The establishment of a Maternal and Infant Health Innovation and Research Center is one of nine recommendations outlined by the 2021 Nurture NJ Strategic Plan to reduce maternal and infant mortality and morbidity and ensure equity in care and in outcomes for mothers and infants of all ethnic groups. The purpose of this environmental scan is to provide input for the design of a Maternal and Infant Health Innovation and Research Center within Trenton.

Building on the Nurture NJ Initiative, this project is a deeper dive in its focus on Black and Latina women living in Trenton and surrounding areas. Black and Latina women are the experts on their bodies and the environments that shape them. This study is a preliminary step in legitimizing Black women's rights to autonomy over their bodies, building on a long history of existing knowledge and networks that exist within Black and Brown families and communities. Furthermore, it represents a step toward the long-term goal of creating, supporting and sustaining fully built, equity-promoting community health ecosystems in Trenton.

Our work was grounded in addressing the social and structural determinants of health in Trenton, including sexism and racism. We paid special attention to safe and equitable housing, food stability, and economic security, and to working against discriminatory practices and policies embedded in social and health institutions statewide.

Furthermore, we sought to understand local needs, existing supports and networks from the perspectives of service providers within Trenton and surrounding areas. In addition to recruiting a diverse population of Black women who participated in focus groups, we interviewed a wide range of entities and agencies identified by key informants committed to the health and well-being of Trenton residents. Across all wards of Trenton, we conducted interviews with individuals such as health care system administrators, clinicians, local business leaders, city officials, social service providers, and grassroots community-based organizations led by Black women and doulas who have left and come back to Trenton. As a way to maintain the anonymity and confidentiality of participants, the names of individuals and organizations have been removed or altered for this report.

Several culturally inclusive frameworks were used to design the project, and a mixed methods approach was implemented to assess social and structural determinants of health (i.e., economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context) by focusing on the needs and challenges, as well as the resources and assets within Trenton identified by Black women and their service providers.

The framework articulated by The Black Mamas Matter Alliance Research Working Group (BMMA 2019) was utilized to make recommendations based on the voices and stories shared by women in this environmental scan. The BMMA approach centers the ways in which Black and Brown women make meaning of their experiences, and importantly addresses system-level and structural challenges to providing optimal care for Black women. The framework centers its approach to applied research, evaluation, and practice in Birth Justice, Reproductive Justice, Human Rights, Black

Feminism, Womanism and Research Justice. The authors assert that six domains comprise the best practices and guidelines for the conduct of research as well as implications for practice, that centers Black Mamas.

The MIH team based its recommendations for research and practice on findings from focus groups, interviews, and survey data and organized them using the BMMA's six domains as a framework.

1: Recognize and Respect the Rights of Black Mamas

Foundational to respecting the rights of Black women is centering the skills, expertise, voices, and strengths they bring to the care of their health and their infant's health as highlighted by a focus group participant:

> *"I don't feel like I've been listened to, like, I don't really get taken seriously when I say something's wrong. Like it's my body? How can you tell me when I'm not in pain? Or how can you tell me when I don't feel something like that? That Something's off? How can you tell me oh, it's just fine? It's my body. I know when something is wrong. So like, that's like, for me, that's the issue. Like I just get brushed off."*

Black women are the experts on their bodies and should be active participants in their own care.

Recommendations

- Make Black women's personal experiences and perspectives the starting place for defining and providing access and quality care
- Engage Black women's experiences/skills by hiring them on boards and steering committees
- Provide Black women, pregnant people and families care with dignity; giving them autonomy must become a standard of practice
- Include Black women's experiences/skills at the decision-making level and in research design/implementation for broader knowledge and awareness
- Involve Black women and their communities/designated spokespersons in community/systems-level shifts in health care services
- Support Black women in advocating for themselves with groups of legislators and engaging with universities affecting policy at the societal and personal levels

2: Understand the Historical, Sociocultural, Political and Economic Contexts in which Black Mamas Live their Lives

A clear understanding of the multiple and intersecting identities of Black women should inform the approach and practice of care. As one example shared by a service provider, Trenton's history as a

hub for industries including clinical care services has significantly shifted over the past decade. These changes influence where women seek out care and develop trusted relationships with providers.

"In 2010, when there was a great layoff in Trenton…so we now rely on [Healthcare Provider 1] a lot for their services. After that layoff…it's kind of hard to bring some of the programs back because we used to have [more] staff... …"

Black women want to be accurately reflected in the care they receive from the images, cultural approaches and compassionate styles of care. The social, economic, and health challenges and needs identified by Black women, particularly trauma, also exist for service providers that are on the ground providing care. There are unique needs for women of color in Trenton, who include Spanish-speaking women, homeless women, teenagers and trans women.

Recommendations

- Build culturally responsive practices and accountability into local care systems
- Increase the number of culturally competent providers to help buffer the insensitivity and inequitable norms experienced in the Black community
- Offer long-term family mental health support
- Sustain supports for both Black women living in Trenton and the (primarily) Black women on the ground leading community-based organizations often using their own resources
- Integrate opportunities for groups with distinct needs (youth-led, spiritual leaders, male-focused)
- Provide trauma-aware and responsive care (both historical and personal/direct trauma)
- Create a space for community conversations to address needs with stakeholders
- Require anti-racist and cultural training programs for clinical providers and administrators
- Hold providers and systems accountable for biased and racist care

3: Invest in Black Women as Researchers

This entails the inclusion and investment of skilled and compassionate Black women in the practice of care, and the implementation of programs and research to improve optimal care.

> *"…it's I don't think that it's just the issue of race. I think it's an issue with compassion. It's just not there and it's just not there anymore. They need to teach them compassion in the same way that they teach anatomy, but they don't."*

Black women want to be actively engaged in creating and implementing solutions. Respondents in our focus groups and surveys were happy to be asked for their input and to be provided with information about reproductive health and other resources. They would like to hear more and be heard. Both Black women and service providers described a lack of empathy and compassion, reflected in the quality of and access to care. The social and economic challenges and needs,

particularly trauma associated with economics and mental health, were expressed by both Black women and service providers.

Recommendations

- Engage Black women within the Trenton community in creating and implementing solutions
- Include youth and teens as advocates
- Ensure cultural representation of compassionate physicians and staff
- Include new technological approaches to communication through social media engagements
- Integrate community-based doulas and midwives to improve information access, advocacy and access to care as well as improve outcomes
- Include long-term involvement with trusted community-based providers in the advising, designing and implementing of locally responsive systems going forward

4: Fund and Conduct Ethical Research that Benefits Black Mamas

Sustainable infrastructures and processes are needed to fund and conduct ethical and asset-based research and practice of care. Residents are aware of inconsistencies in what service providers say and what residents see reflected in their community to support their health.

> *"I just don't think when you look at our world and look at all the structures that are in place, there's really a lack of consistency, right? You say you care about us, but you do something different. You say that you want things to be better for us or for our community. But there's not a lot around me that says that that matches what you're saying. So I think to me, that means it's not sincere it's not authentic."*

> *"It's like having all of these supports and having all these programs, and we don't have access to it, then what's the point?"*

Not all supports provided are accessible and affordable.

Recommendations

- Create transparent decision-making processes that require accountability and sustainability
- Ensure third-party reimbursement for services through insurance/Medicaid
- Provide access to affordable and quality healthcare services including prenatal care, delivery services and postnatal care
- Support services for families including parents, other caregivers (like grandparents), partners, and children
- Offer free and sliding scale services

- Respect the village mentality, in part by including programs and training for extended families
- Provide financial and personal assistance through training and micro loans to launch and sustain businesses started by Black women and women of color (for example, assisting them in cases with high-interest debt, opening a business, and alleviating medical expenses)
- Integrate non-hospital based maternal and infant health services
- Offer integrated multiservice care in a single location
- Improve access to services through better options (cost, accessibility, proximity, safety, cleanliness) for transportation
- Address economic determinants of health by offering financial training to help families budget and amass wealth
- Conduct job training to help diversify the workforce and help community residents gain the skills needed to be competitive (including careers in healthcare)
- Explore options for free birth centers

5: Honor and Commit to Community Engagements through the Entire Research Process

Community engagement should be integrated into the approach to care. Black women are not seeking care even when it is offered by trusted Black sources. Similar to many community and health care providers, it was challenging to obtain participation in our focus groups. The COVID pandemic may have contributed to hesitancy on the part of Black women to engage in health-care related community engagement efforts.

They are also not coming in for services and care, likely due to the many challenges and needs that exist involving food insecurity, housing, transportation, racial discrimination and inequality.

Recommendations

- Build community capacity by addressing social, economic needs through - STEM education, job training and safe homes
- Start with priorities of basic needs, safety and security identified by focus group respondents
- Ensure continuity of funding streams that ensure ease in qualifying for support
- Utilize community ambassadors to engage the community and build trust
- Normalize the inclusion of community residents in the process of planning and design of the MIH Center programs from the beginning and make it very easy for them to attend by providing childcare, dinner and other incentives
- Increase support of existing programs that have positive relationships with women
- Support sustainable lifelong practices of culturally responsive care in Trenton by those familiar with and trusted by Black women and their communities

- Increase sustainable, Community-based Doula and Midwifery Care
- Include CBOs/grassroots groups at the beginning and not after the decisions and system changes have occurred
- Engage and empower women through active participation in CBOs
- Provide healthy incentives for women, children and infant for food and transportation
- Ensure ongoing support for providers who offer on-the-ground support to Black women
- Commit to transforming planning and decision-making processes to require community leadership input
- Build on women's/communities' networks of trusted resources

Although the scope of this study did not permit hearing from all communities and service providers in the Trenton reproductive health landscape, those we did hear from made it clear that a wealth of experience and knowledge exists in the Trenton community regarding birth equity and care needs.

6: Include Health Equity and Social Justice as Key Themes in Research

"It's almost like they're not trying to save our lives."

Not all support provided is experienced as support. Service providers identify a wide range of services, resources, and supports throughout Trenton and surrounding areas, but Black women do not use or are unaware of them. This is at least in part due to a lack of continuity of care by trusted providers.

Recommendations

- Implement approaches and interventions that focus specifically on the experiences and challenges of Black women and women of color
- Provide communities with access to medically accurate reproductive health education, knowledge and information
- Support interactions that communicate trauma related to mental health and its stigma
- Increase access to mental health support through telehealth options and health visits by providers
- Provide continuity of funding for sustainable and integrated services
- Offer prenatal incentives and group practices to address postpartum depression

Introduction

The U.S. has the highest maternal mortality rate of all 36 OECD-member (Organization for Economic Co-operation and Development) countries. In this global context, New Jersey's maternal health outcomes and disparities are among the worst in the nation, with Black women faring worst among state residents. Recent 3-year averages indicate that Black women in New Jersey experience *seven times* the rate of pregnancy-associated death compared to their white counterparts, and 3.5 times the rate of infant death.

National estimates suggest that 66% of maternal deaths are preventable, yet trends in racial disparity, overall maternal and infant mortality and morbidity have worsened in recent decades. Women giving birth in New Jersey are more likely to die than almost anywhere else in the developed world. Infants who are born unhealthy, or whose mothers die, face lifetimes of potential deficits in health, learning, and economic security that compound over time.

In 2019, in response to longstanding racial health disparities, the Office of First Lady Tammy Murphy established the Nurture New Jersey initiative (NNJ) with secured funding and organizational partners dedicated to overhaul state agencies and public policy in support of maternal and infant health equity throughout New Jersey. As outlined in the NNJ Strategic Plan (NNJSP) and Year-1 Playbook (NNJ 2021), New Jersey is now initiating the establishment of a new statewide Center for Maternal and Infant Health (MIH) in Trenton, New Jersey.

As an initial step to establishing a Maternal and Infant Health Innovation and Research Center, the New Jersey Economic Development Authority (NJEDA) entered into a Memorandum of Understanding with The John S. Watson Institute for Urban Policy and Research at Kean University to conduct an environmental scan to identify the needs of, existing services and assets to support women, specifically Black women in Trenton, who disproportionately experience pregnancy-associated and infant death in New Jersey.

Social and economic factors including the conditions that impact how women grow, work, live and age are responsible for many of these disparities. These social determinants of maternal and infant health include such factors as economic instability, food insecurity, safety, housing and transportation. Other barriers to care which are magnified for Black women include limited access or lack of access to quality care, health and clinical needs, and in particular, mental health services.

This study focused on the state's capital city, Trenton (population 90,871). Trenton's population is 48.7% African American, of whom 54% are female. According to the NNJSP Companion Document (2021, using 2016 data), approximately 17% of females twenty-five or older had no high school diploma, and 8.1% of births were to teen mothers. The median household income was $32,615, 56% of households were led by women, and 12% were below the poverty line. Pregnancy data indicated 39.6% of birthing parents experienced late/no prenatal care, 6% had gestational diabetes, 8.4% had gestational high blood pressure, 69.6% were obese, and 9.2% smoked during pregnancy. Key mortality data show that 15.3% delivered prematurely, 13.9% delivered a baby of low birth weight,

and only 33.1% reported breastfeeding exclusively upon discharge (Black Infant Mortality Municipalities and Key Indicators, 2016; NNJSP 2021 p. 34).

Evidence suggests that, in order to improve health and wellness outcomes for Black women and their infants, additional attention must be placed on gendered stressors and racism as well as contexts, resources, practices, priorities and networks used by Black women. Several frameworks were used to ensure the environmental scan assessed Black women's experiences and the social and service providers who support them, including reproductive justice, social and structural determinants of health, ecological, cultural, human development and life course models.

Through a Memorandum of Agreement between The John S. Watson Institute for Urban Policy and Research at Kean University and Stockton University, a team of Stockton researchers and students collaborated with Kean University researchers and students to complete this environmental scan..

An environmental scan assesses the availability and use of resources and assets, as well as the needs of a particular community. The power of qualitative data using a community engagement approach is to provide in-depth, contextualized understanding of the experiences and perceptions of Black women to inform processes, outcomes, practices and policies affecting communities.

Building on the Nurture NJ Initiative, this project provides a deeper dive in its focus on Black and Latina women living in Trenton and surrounding areas. As Black and Latina women are the experts of their bodies and the environments that shape them, this study is a preliminary step in legitimizing Black and Latina women's rights to autonomy over their bodies, building on a long history of existing knowledge and networks within Black and Brown families and communities. Furthermore, it represents a step toward the long-term goal of creating, supporting and sustaining fully built, equity-promoting community health ecosystems in Trenton.

Such data helps to provide a platform to elevate the everyday experiences of Black and Brown women, to inform a process that addresses their needs, and to promote a paradigm shift that can improve Black maternal and infant health by building the first NJ Maternal and Infant Health Innovation and Research Center in Trenton.

Purpose

The investigative team designed an exploratory study, using a mixed-method community-based participatory research (CBPR) approach, to assess conditions leading to persistent disparities in maternal and infant health outcomes primarily affecting Black women and children in Trenton, New Jersey. We proposed the following objectives:

- Identify and examine the experiences and quality of networks of community and family assets, local resources and challenges perceived by Black women in navigating their health before, during, and after pregnancy and the health of their infants and children.
- Examine how service-providing organizations support the maternal and infant health needs of Black women.
- Determine potential supports and resources needed to offset specific stressors and challenges in order to optimize the health of Black women, infants and children through the establishment of a Trenton-based Maternal and Infant Health Innovation and Research Center.

Supported by NJEDA funding, community engagement, recruitment, implementation, data collection, and analysis were achieved through a partnership between Stockton University and The John S. Watson Institute at Kean University. The value of a large research team representing a range of disciplines (biobehavioral health, data analytics, public health and administration, social psychology, sociology, and gender and sexuality studies) assisted in leveraging outreach and engagement resources and implementing program activities in the Trenton community. Additionally, our team of researchers were primarily Black women, thus reflecting women participating in this initiative.

The research team designed and conducted a ''landscape analysis" of needs, assets, and life conditions perceived and experienced by Trenton-area Black women - both pregnant and non-pregnant individuals - to initiate sustainable conditions that facilitate their meaningful input in the creation of a new statewide entity in support of maternal and infant health equity.

Methods

Recruitment

The MIH Equity Team identified a wide range of stakeholders that provide services for residents including prenatal care throughout the four Wards of Trenton and surrounding areas (see Figure 1). Researchers attended a number of events to build trust, learn more about Trenton communities, share information regarding the MIH initiative, and recruit community members, advocates, organizers and service providers to participate in the study. Several members of our team participated in a driving tour of Trenton led by key informants who identified stakeholders throughout the city. Using a snowball approach, additional stakeholders assisted with the recruitment of participants for focus groups, interviews and surveys as a part of the MIH initiative.

Figure 1. Snapshot of Prenatal Care in Trenton

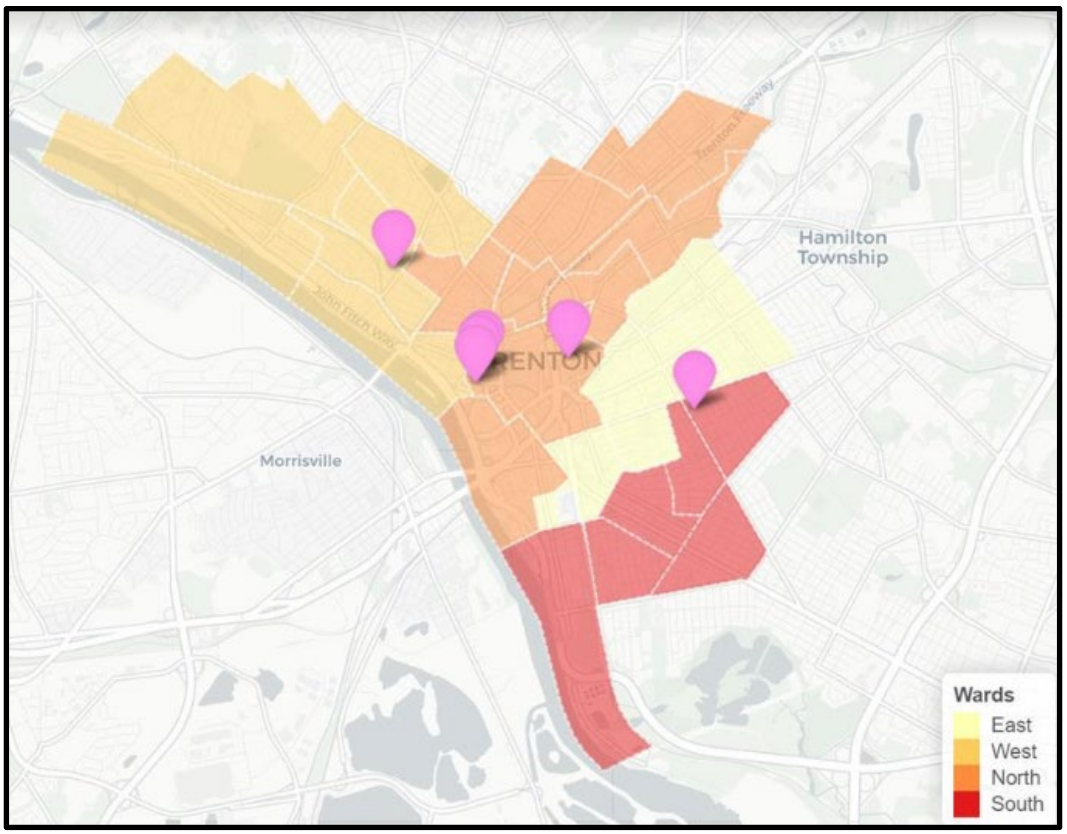
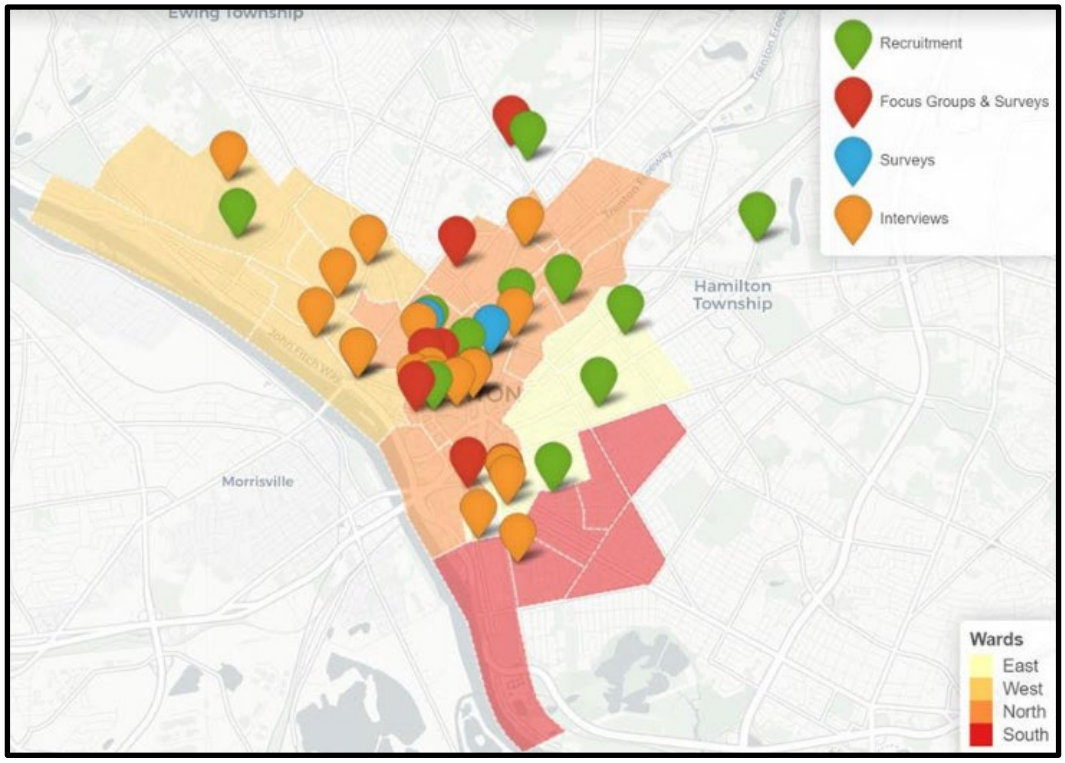


Figure 2. Snapshot of Recruitment and Data Collection Locations



Recruitment events included a Juneteenth and Capital City Farm event (6/19/22), Neighborhood Block Parties & National Night Out in several neighborhood locations (7/6 - 7/18), the Tufts Black Maternal Health Conference (4/8), the NJ Doula Conference (7/12) and the Trenton Economic Development Series: The Future of North Trenton (7/12). Key informant interviews with Trenton city officials, residents, and service providers began in April and continued throughout August as a way to continue to build relationships and assist with identifying individuals to later interview and partner with to host focus groups. Interns and all team members attended weekly meetings that included training on collecting field notes, organizing focus groups and conducting surveys, as well as on specific topics such as mapping, working with vulnerable populations, and on the history of Trenton.

In order to ensure the safety and protection of rights of all individuals participating in this research project, we submitted a proposal for approval to Kean University's institutional review board (IRB) in June. Following the receipt of IRB approval (ID #: #22-060105) on 7/19/22, the MIH Team canvassed and recruited specifically for MIH focus group participants on a near-daily basis for over two months at neighborhood block parties and at more than 60 community sites and businesses within the four wards of Trenton, including nail and hair salons, community centers, corner markets, faith-based institutions and schools. All recruitment and IRB data collection documents were translated from English to Spanish.

With IRB approval, the MIH team in August collected data via focus groups, interviews, and surveys in Trenton and Mercer County which focused on centering the experiences of Black and African

American women. An Interim Report included analysis of the majority of Key Informant Interviews (KII) as well as six focus groups. The current Final Report includes results from all key informant interviews, focus groups, structured interviews, and completed surveys (see Table 1). The study team was charged with holding 4 focus groups, 30 interviews, and 5 events. The results of this initiative have far exceeded that expectation in the three-month data collection period.

Focus Groups

As illustrated in Table 1, 11 focus groups were conducted (10 in person and 1 virtually). Of the 58 individuals who signed up to attend a focus group, 47 participants attended (79% attendance). With various collaborating partners, all focus group meetings were held in Trenton-area locations easily accessible to the participants. Transportation vouchers were provided to women who requested them. Recruitment of participants and the collection of surveys took place at the focus group sites (See Figure 2).

Approaches to recruitment varied depending upon the location of the focus group. Contact information including phone numbers and email addresses was collected in most cases by asking interested community members to scan a QR code and provide the information. If the individual did not have a cell phone the research team collected contact information by hand. All potential participants were asked to complete two consent forms (either on their phone using a specific QR code or by reading and signing the consent form in hard copy). The first form asked for their consent to participate in a focus group. The second form requested consent to be recorded (audio only) during the focus group. Participants who signed affirmatively to both consent forms were provided with a list of dates and locations for upcoming focus groups. Based on their selection, a student research assistant would remind them of the upcoming focus group meeting via text, email message or phone call at least two days in advance and on the day of the focus group. The sessions were recorded using two iPads positioned in the middle of the focus group table. At least one graduate/undergraduate research assistant or researcher took field notes.

Each focus group was provided a dinner prepared by a local Trenton restaurant (many participants were able to take home food after the meeting as well) and child care was provided. Once participants had time to eat, an introduction to the project was given. Questions were designed l to elicit discussion in the following areas: a) beliefs and assumptions about maternal and infant mortality, as well as a review of definitions, b) positive and negative reproductive health care experiences within families and communities utilizing a photovoice approach, and c) recommendations for a maternal and infant health center in Trenton. Before the focus groups started, participants were asked to put dots on a board of pictures of Trenton landmarks identifying assets and challenges throughout the community to elicit a discussion..

All participants had a chance to win a raffle for a small gift basket, and they all received a journal and pen as a small token of appreciation for their participation. Additionally, all participants were given information to join the MIH Facebook Group – *Every Mother Matters* - as an opportunity for them to continue to stay connected and share resources with one another. In adhering to IRB protocol to

reduce possible coercion for participation, we were unable to provide more incentives for women to attend the focus groups, so participation may have been more limited than desired. We found that attending a focus group may have proven difficult given the various compounded challenges of being low-income with limited transportation among other issues facing Black women in Trenton. We believe that providing a small monetary incentive would have made it more likely that women could attend. Additionally, service providers have reported that engaging Black women and families has been particularly challenging during and after the COVID pandemic, which may have exacerbated concerns of trust of medical/health systems as well as actual health conditions and physical needs.

Interviews

With recommendations from NJEDA, stakeholders, and key informants from the community, potential participants were contacted in person, by phone and online to help identify key representatives in organizations that provide services and support to Black women and pregnant individuals in greater Trenton. Following IRB approval, the research team obtained consent and conducted 45-60 minute semi-structured interviews with community organizers, advocates, service providers, and representatives of local agencies and government offices. These interviews took place online, by telephone, or in-person (See Figure 2).

Data from these interviews provided contextual information regarding existing supports, current activities to address needs of Black women, and efforts to reduce maternal/infant health disparities in Trenton. These data also informed understanding of efforts to implement self/family-care management by clinicians, primary caregivers, service providers, and pregnant individuals themselves as needed to support their health.

Survey

With IRB approval and participants' informed consent, we conducted a brief electronic survey of participants on socio-demographics, social determinants and stressors related to health including racism, medical conditions, trust/distrust, and general health status. These data were collected by our team using Qualtrics on electronic devices (cell phones, iPad, laptop computers). Data collection took place during events throughout the summer in Trenton, prior to the focus groups, and over several days at two clinic sites within Trenton. The surveys were also offered in hard copy, and if needed in Spanish taking approximately 10 minutes to complete.

Findings: A Deeper Dive

Overview

The survey was used to supplement the qualitative data collected from focus groups and interviews, and provide a snapshot of participants. The focus groups and interviews yielded more than 700 pages of transcripts. A coding spreadsheet was developed by the PI that consisted of four sheets including 1) Challenges, 2) Assets, 3) Location, and 4) Recommendations. The research team reviewed the codes within the four sheets and modifications were made after reviewing a subsample of transcripts. Following the analysis of the transcripts by the team and discussions, a second process of identifying subthemes was completed. The results converged into eight key subthemes within the Challenges theme: 1) Food Insecurity, 2) Housing, 3) Transportation, 4) Access to Care, 5) Quality of Care and Services, 6) Mental Health, 7) Trauma, and 8) Knowledge & Information Sharing. Assets converged into two themes: 1) People and 2) Places. Recommendations were identified by participants and fell into five categories: 1) Location, 2) Long-term Parent and Family Support, 3) Staffing, 4) Flexibility and Inclusivity and 5) System Transformation.

Table 1. Summary of Data Collection

Focus groups conducted	11
Women who participated in focus groups*	47
Interviews conducted with organizations/service agencies	34
Individuals who participated in advocate/provider interviews**	50
Women who completed a survey***	62
Key informant interviews conducted	12
Identified stakeholders	142

*95 consent forms completed for focus groups
**52 consent forms completed for interviews with service-providers
***95 consent forms completed for surveys

Demographics

Race and ethnicity, age, education and income data were obtained from survey participants. The majority of survey respondents were Black, younger than 45 years of age, have received a degree or had some college, and earning $40K or less annually. Thirty-one percent speak a language other than English. And when asked how much decision making power they feel they have in the state and local political system over issues regarding the city on a scale of 1 to 5 (1 equal to little power, 5 equal to a lot of power), 71% answered 2 or below.

Figure 3: Race and Ethnicity Breakdown of Survey Participants

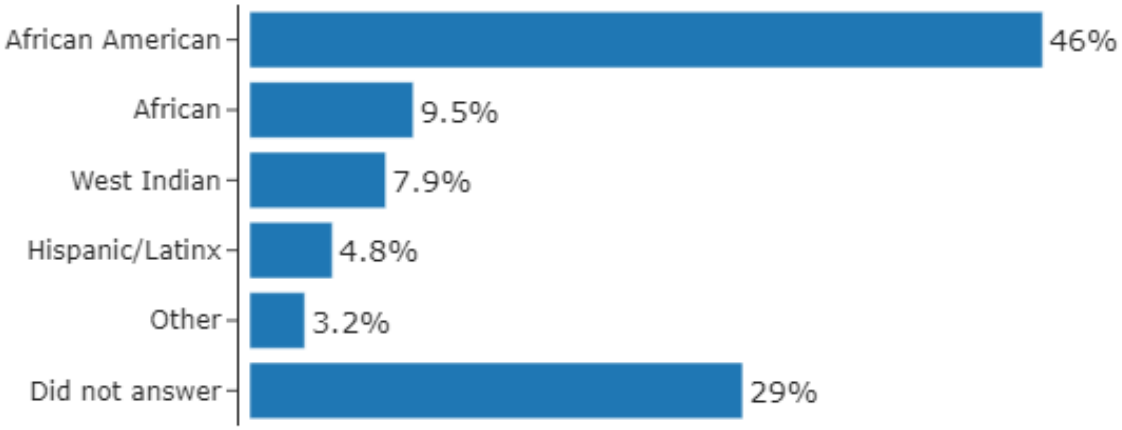


Figure 4: Age of Survey Participants

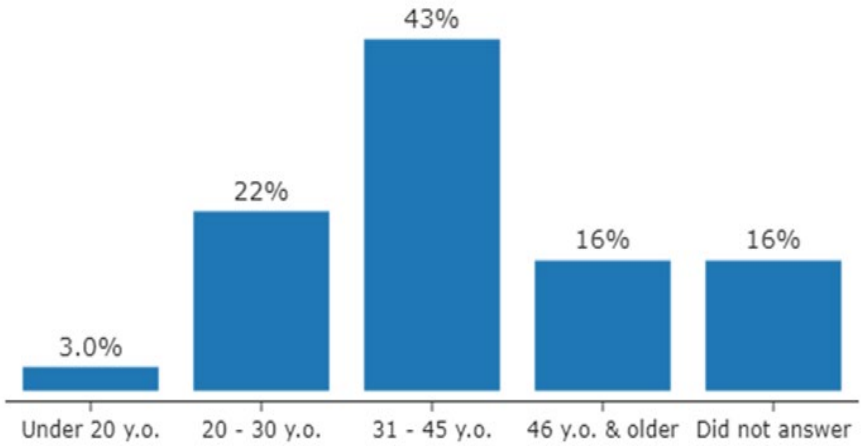


Figure 5: Income of Survey Participants

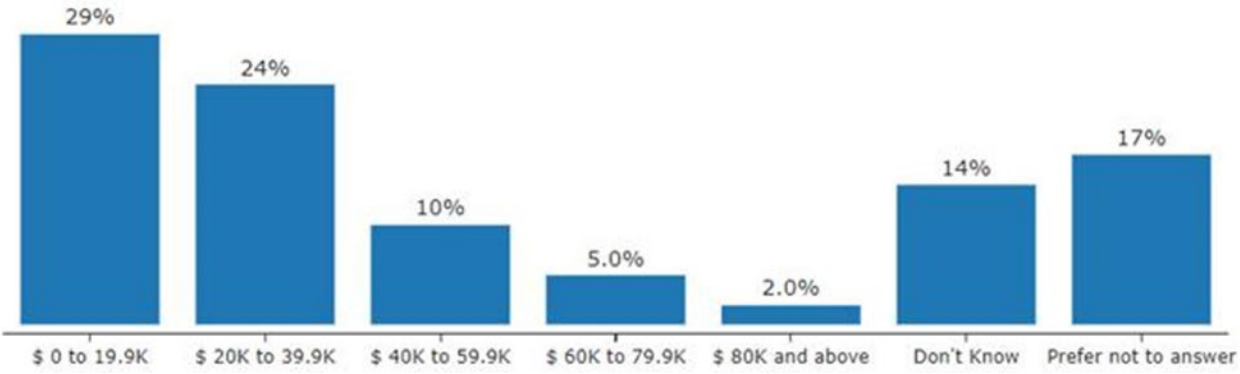
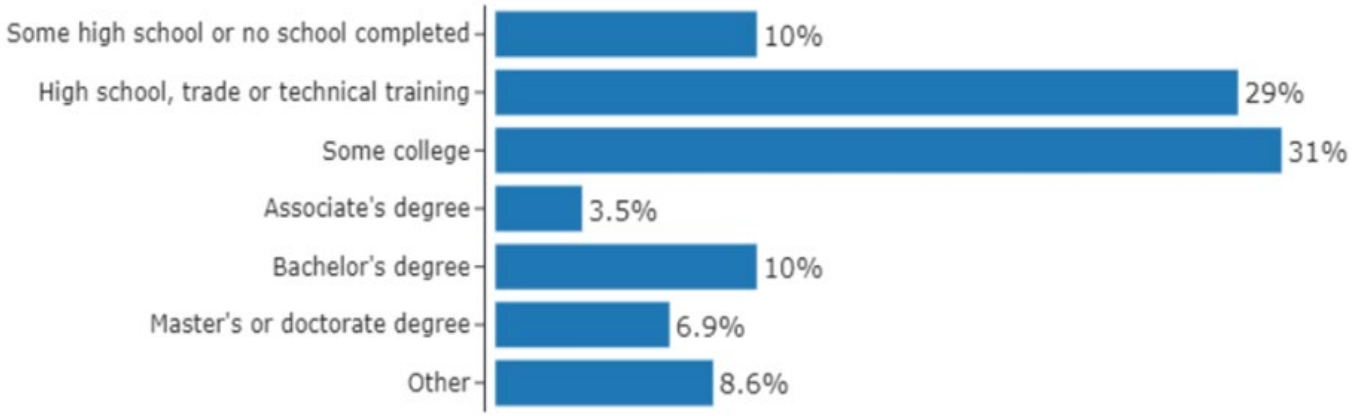


Figure 6: Education of Survey Participants



Findings 1: Perceptions of Needs and Challenges

Food Insecurity

According to the Nurture NJ report, the city of Trenton is still considered a food desert, which contributes to food insecurity for Black families. Food insecurity can be defined as decreased availability of food due to cost, proximity and access. Across the state, the NNJ Report finds that 10.6% of Black families in New Jersey are food insecure.

Among our survey respondents, 48% indicated there were times the food they bought didn't last, and they didn't have money to buy more. Fifty-seven percent of respondents worried their food would run out before they had money to buy more. One focus group participant said, *"I had to pick and choose who's gonna eat, me or my kids, one piece [of] bread, what we're gonna do."*

Even with families who have WIC, the combined issues of inadequate transportation and proximity to healthy food causes Black women to endure challenges which limit their ability to be food secure.

> *"My income is not enough…welfare won't give me food stamps. I gotta cover food."*
>
> *"Especially because we don't have transportation. So it's like we have no choice but to go to corner stores. We have no choice but to go to places where I can catch the bus, pick up the kids, you know what I mean, they hike up the prices at the corner stores."*
>
> *"A lot of wards or places in the city may not have food, like you gotta walk, you got to go 10 to 15 miles to go way across the world to get quality food…WIC has changed, you get bread and vegetables, but I got to travel forever to get it."*

According to our service providers, food insecurity is difficult to address due to additional challenges and concerns of women and their families. Food insecurity and its connection to other social determinants impedes a woman's ability to support both her and her infant's nutritional needs during pregnancy as well as pre- and post-pregnancy.

> *"We're trying to promote breastfeeding and some of these great initiatives [but] we cannot get the full attention of folks because they're grappling with so many other issues like…housing, childcare, employment and food security."*
>
> *"There's family violence and addiction in the homes, because they're hungry and kids are hungry…they've gone to school hungry. They're having behavioral problems because they're hungry…they're selling drugs, right? Because they just want to eat."*

While service providers are hired to address specific maternal and infant health needs, they are routinely challenged by families trying to find solutions for multiple concerns and needs at one time. Our findings reaffirm the continued importance of food security as a stable foundation for infants and families, which in turn, affects the maternal and infant mortality rate. If a Black mom is concerned

about putting food on the table or arriving on time due to transportation, there is less time to attend breastfeeding support groups or regular check-ups, thereby causing increased stress. According to providers, addressing food security at the root helps reduce gaps in education, behavioral problems and drug addiction within the larger community of the mother.

Housing

Many Black families in Trenton endure significant challenges with housing including affordability and deteriorating living conditions. Like food insecurity, housing is a social determinant of health as it shapes the life of pregnant people and families, working in tandem with other stressors in the lives of Black women. Additional limitations with accessing housing support resources impact providers' ability to provide maternal and infant health care.

Survey results indicated 43% of respondents have one adult at home and another 35% have three or more adults. A large percentage of families are single-headed or have extended families living together. Eighty-eight percent of respondents have one or more children staying at home, with 24% having three or more children at home. Some families struggled with obtaining safe and secure housing and keeping up with utility bills.

> *"We have a case right now where the mom's like living hotel-to-hotel because of violence in the neighborhood, [and she's] trying to get the kids away from it, right? If I can get them into a home, I know there's a chance for them. Besides us, there's really not anyone doing that kind of work."*

Among survey respondents, 10% of respondents or their child have stayed in a shelter, with others, in a hotel, or outside for one night in the past 12 months. Twenty-two percent have had a utility company shut off their service because they were unable to pay a bill. Additionally, 48% of respondents currently have two or more problems in the place they live including pests, water leaks, oven or stove not working, smoke detectors missing or not working, other repair issues, mold, lead paint, lead pipes, or lack of air conditioning. Similar to food security, with moms having to address these additional housing concerns to maintain a safe environment for their families, they encounter increased stressors.

> *"For now my newborn is living in this house breathing in smoke. And my daughter that's five years old is living in this house. Breathing in this mold."*

> *"They were supposed to give me temporary housing until the issue was fixed. They didn't provide me housing because they said that they didn't have enough funding in order to fix it."*

Service providers reported that moms in high school have additional struggles finding stable housing and finishing their education.

> *"I think just being transient, and like when you're not, when you don't have that level of stability, and I'm just thinking of students just recently, that they're just moving all the time. So*

then it's okay, I can't make it to school today. Or I lost this paperwork, because now I'm over here, and I left that over there. I lost my Chromebook. Because now that was at the other house. And now I'm over here. So just those like the level of being able to be organized, time management, stability, like all of that is out of the window, because their goal is where am I going next? Where am I staying? And [are] me and my child going to be okay."

"But housing is my first priority. And this is what I have to focus on. I'm sorry, I'm not going to graduate. I can't do it right now."

Service providers are also constrained in their abilities to provide resources for mothers. Moms report that they have to be evicted or extremely economically disadvantaged in order to receive financial help. They state that eligibility for state and federal resources effectively requires you to be in the worst possible scenario in order to receive aid.

"I went to [Agency A]…and I'm like well this is how much I owe in rent and then she's like, well, because you haven't gotten an eviction notice whatever this would be. We can't help you. But why isn't that the point of me coming to you?"

"…[Agency B] is limited in what they can do [regarding housing needs]. They have parameters for who they can help. So if you don't fit in that box, you're done. You're screwed. And then [Agency C] they're not really helping with housing….if your issue is housing, you're on your own….women are looking for what's safe, it's whoever they feel they can trust…."

Transportation

Transportation was an unexpectedly severe stressor in the lives of Black moms and pregnant people in Trenton. We heard from key informants that one of the most important concerns of Black women is how far it takes to drive to give birth. One mom noted, *"Most people who are going to have a baby, they have to go to [Healthcare Provider 2], to [Healthcare Provider 3], or they may go to [Healthcare Provider 4]. So there's nothing really here in Trenton that they, you know, may feel that it's close to them."* Another mom remarked, *"you talked about pressure, that's pressure. How am I gonna get to [Healthcare Provider 2]? Which they are 20 to 30 minutes away from me? And I had a car. Yeah. So there's no, there's nowhere for you to give birth."* One service provider noted that for teen moms, transportation is the biggest challenge for them. It repeatedly came up in focus groups with older women and service providers, and additionally impacted their ability to participate in our research study as well.

Given the dearth of places for moms to give birth along with limited availability of public parking in Trenton, many rely on public transportation or other services like Lyft or Uber to make appointments and give birth. One mom said *"First off, I have a car. And I was upset that I had to drive like 20 to 30 minutes to get to [Healthcare Provider 2]…and my blood pressure was high."* Thirty-eight percent of survey respondents said they do not have someone they can call when they need help with their child, such as with transportation or childcare. Many women are on their own in getting to and from places in Trenton. Twenty-two percent of respondents indicated that in the past 12 months they or their

child went without medicine or missed a medical appointment because they did not have a way to get to the pharmacy or doctor. Some moms believe that transportation needs are generally not considered in the stability of families and securing a safe pregnancy.

> *"When you take the services from Trenton and put them in Hamilton, how are we gonna get there? I mean, we're not in Jamaica, we can't ride horses and donkeys to get there. How do they expect us to get there, or was it intentionally moved?"*

> *"Transportation is an issue. I do know certain places, some medical providers in the area. They do provide Uber Health. I know [Healthcare Provider 5]is one, [Healthcare Provider 1] is one. I'm not sure if any other place will do that. [Healthcare Provider 3] really should do it..."*

Conversations with leadership within healthcare organizations in Trenton highlighted existing approaches to address the transportation needs of women taking into account distance, cost and eligibility.

> *"Specifically in the Trenton office, in addition to the nurse case managers, there's dedicated social service resources that are there to help patients. We have the Charity Care and the Medicaid enrolling people so that they don't have to travel in order to, you know, obtain the financial assistance that they need."*

> *"We do we do have like an ultrasonographer [at] that location so that they don't have to travel to the hospital to get their routine ultrasounds. We also provide a phlebotomist at that location so that they can get their lab work drawn while they're there for their prenatal visit. We know it's difficult for them to get to a third location."*

Improving public transportation in Trenton and providing more vouchers and alternative ways to access services would increase options for moms. Some moms state that Trenton's borders impact the places in which women can receive care. One respondent noted that Trenton is a city of boundaries, and most stay within those boundaries for services unless there is accessible transportation offered. Moms note that access to transportation should be considered more seriously when providers are engaging them to make appointments. This contributes to the quality of care that healthcare organizations and institutions can provide as discussed in the next section.

Access to Care

In addition to challenges due to food insecurity, housing and transportation, accessing care is a challenge for Black women and their families in Trenton. They, along with service providers, described challenges in accessing care due to the lack of certain health care services such as doula care or lactation support. These challenges were exacerbated by insurance coverage limitations and failures in sustainability and continuity of service embedded in a history of distrust of Trenton's healthcare institutions. Survey results indicated that because many women struggle financially, they are limited in their ability to pay for services and appointments; 32 percent of respondents in the

past 12 months have had trouble paying for a doctor, dentist, or medicine for themselves or their child.

Shortage and Lack of Health Care Services

Women described difficulty securing appointments before, during and after pregnancy for a wide range of services including contraceptives, mental health care due to postpartum depression, stress and trauma. In the examples below, one mom and several service providers share their challenges with accessing care and providing care.

> *"I've had some experience with doctors in the area. They're over, like they're overbooked. A lot of times, it's hard to get to them. They may be nice, but they're like, you can't, like they're not accessible. So, I know for me, I look outside of you know, Trenton to be honest, hoping for a better experience. And a lot of times, they still treat you just as bad if not worse."*

> *"I've had some moms that have tried to get an appointment …. And that's delayed and then their first appointment is normally virtual. They don't even get to be seen in the office until a later date."*

> *"I don't think there are enough OB/GYN midwives, pediatricians, for example, a woman may not get seen for their first prenatal visit, until like December, like right now they're making appointments for December. So that woman if she has other risks, and challenges going on, high blood pressure, blood disorders, anything like that, she's not being seen until three months in, four months into her pregnancy, which could be detrimental to herself as well as her baby…it's not enough services in Trenton for Black and Brown women at all."*

> *"Like say, for instance, if the mom has experienced, like infant loss, or loss of a child, there's not many resources in the area that can, you know, provide those services at least, you know, free or low cost. Or at least you know, I don't really know of any. I don't know if anybody else can speak to this. But you know, we really don't have a lot of services that handle that or just even just therapy in general surrounding, you know, birth, the birthing process, and, you know, any other type of traumatic events that they may have been through is very hard to access at least quality services, for our moms some ours, there's definitely a barrier."*

When numerous offices are booked, we have found that women described looking outside of Trenton for care.

Limitations on Insurance Coverage

Shortcomings in insurance coverage, including Medicaid acceptance, was given as a major barrier to access to care for those who have some form of coverage. Moms and service providers describe very strict and rigid eligibility standards. Medicaid-eligible moms indicated a difference in their access to services. Moms who were Medicaid recipients indicated that local providers do not always accept Medicaid reimbursement.

"I have attempted to get a therapist. However, I do also have Medicaid insurance. Don't cover it. Like they want to send you to a focus group where you can sit in front of women and you could talk but I feel like at that point in time, I don't want to hear another woman's problem, I want to know how you can help me. So again, like I said, I do still go into depression."

Many focus group participants described being overwhelmed by trying to keep up with which providers take which insurance and which services are covered. This reality becomes magnified with Spanish-speaking women who lack documentation. There are specific challenges for Latina and Spanish-speaking women due to racism, language, citizenship and fear of deportation. Many only qualify for a specific type of payment assistance called the New Jersey Hospital Care Payment Assistance Program (or Charity Care Assistance), a free or reduced aid to small hospitals for some necessary care. One focus group participant said, *"I think the health issue is very important, because if we don't have…papers, health insurance is difficult to apply. I was at the doctor and the specialist doesn't cover them with Charity Care."* Some women described that if they had more comprehensive health insurance, they would receive check-ups more often. According to service providers, it becomes challenging when Spanish-speaking pregnant moms often balance the fear of being deported and the process of obtaining a green card with maintaining a healthy pregnancy.

"A lot of times they [our clients] fear getting deported. So making sure that they know, getting help throughout their pregnancy is not going to be a hindrance on their process of getting a green card."

Another challenging aspect of insurance is strict eligibility for families. Service providers note that you need to be very low-income or homeless to receive increased support. Additionally, there is a heavy reliance on pay stubs for determining aid. For some Spanish-speaking families, the determinations do not take into account other bills, or financial responsibilities in their home country.

"…it depends on if you have a job, I would say, or like, depends on how much you're getting paid at your job. Because at times, you could be getting a good paycheck, but depends on your bills, even though you have like a small family size, but if you have like, a lot of bills, or your bills are high, sometimes you're not able to get help because they just look at your pay stubs and stuff like that. And they just base it on, you know, you have pay stubs, you don't need extra help. But in reality, you do need help because all that money goes to bills, or like you have other people that you're supporting as well, you know, from different countries or from different, you know, sides and stuff like that."

Similar to the experience of Medicaid recipients, there were some moms who noted different interactions with healthcare providers based on the type of insurance they possessed. One mom noted:

"When I finally changed, when I got private insurance and I had went to [Healthcare Provider 3], and I had another situation like that. So that situation, they really coached me through it. I could tell a total difference in care."

Limited Access to Doula Care and Lactation Support

When taking a deeper dive into access to care, we found that women and service providers were concerned about the limited access to doula care, lactation services and breastfeeding resources in Trenton. Additionally, job status influenced their ability to be able to access these resources, if they are available, to support their pregnancy. One service provider described how low-wage service sector jobs can prevent Black women from taking advantage of these resources, citing *"no paid leave, no guaranteed paid leave, no adequate places to pump…inconsistent cultural acceptance of breastfeeding in public. And, all of these factors are exacerbated for African American women who are disproportionately represented in low-wage service sector jobs, where there's even less leave and there's less support."* These jobs are less likely to provide moms with flexibility or support to take maternity leave or breastfeed and/or pump while on the job. We also find that there is a need to view postpartum care in a more holistic way up to a year post-pregnancy.

> *"I feel like it's a bigger problem than just like, you know, just pregnancy and birth. Because, you know, even when you are pregnant, you have all these prenatal visits and specialists, if you have extra issues, and you know, that you had the birth, and then after that, you had that one postpartum visit, and then that's it. It's like, they say, 'You're healed.' And it's just so much that goes on after that. And I feel like maybe up to a year postpartum, women need to be followed by their OB, or whoever delivered their child or whoever. There just needs to be more support, I feel like postpartum, so that women aren't falling through the cracks."*

Additionally, focus group feedback from moms and interviews with service providers described challenges in access to care (even when in the hospital after giving birth) due to limited available appointment hours, as well as quick return-to-work policies after giving birth.

> *"A lot of times lactation coverage is during the day, 7am to 3pm in hospitals and once that 3pm shift is over, if it's six o'clock in the evening that you need lactation support it's left up to the nurse. Sometimes nurses know a little about lactation, sometimes they don't. So families don't get that support.*

> *"Returning to work is a big challenge, a big challenge [for] a lot of the families…, some of them have to go back to work within three weeks, within, you know, six weeks, and it's just not enough time to establish that bond."*

Doula Care

One type of service that stood out as an example of a missing service was doula care. Within a care system that historically perpetuates gendered racism, respondents and providers reported that doulas advocate for Black moms and their vision for their birth process. One mom referred to her doula as her 'mouthpiece' at the hospital; she helped this mom understand her rights, desires and spoke up for her. One service provider said, *"We see a system that was not built for this [doula care]. It was actually built for physicians, you know, men, people who could afford to get grant writers and billers and enrollers…."* Several respondents indicated a fear of being expelled from service-providing spaces if they advocated for themselves. Doula programs help give them a voice and confidence in

navigating services. One service provider said, "*…they're thinking that they're going to get thrown out of the hospital space."*

Those who access doula services tend to be middle to upper class moms, but an increasing number of Black women find these resources very valuable. Many grassroots service providers advocated for a more doula-friendly environment across all health care facilities.

> *"Yeah, sometimes it was an issue with the nurses and how they wanted to tell the client how they should labor. And the client already had an idea of how they wanted to labor."*

> *"I do want to say that, yes, a lot of times the providers that cover them [doulas], sometimes they're just not as friendly, or they're just not as open. I know, a lot of times…we have issues with the nurses that are there, because it's like, we're not respected or they see us as trying to do their job or, you know, speak for the client. And then, you know, I've even been kicked out of the delivery room one time. So sometimes there's a big clash between, like, you know, the people, you know, the doctors and midwives and nurses and the doulas when we all should be working together because, you know, for our client's best interest."*

> *"When we look at the 17 years that I've been a doula I have been helping upper middle-class people. Because they're the ones who are reaching out to me because they don't qualify for anything. And they need to again, the phone calls I'm getting are ' I need your help, because I don't want to die. I don't want to be a statistic.' So we're missing that critical piece with all the programs that we're doing. Because I'm not saying that low-income families don't need this support. For sure they do. Absolutely. But we cannot just say we're only focusing on this group and that's it."*

> *"There was resistance with that [doula care]. Sometimes there was resistance, whereas it almost felt like the nurses, I can't really say the doctors, I want to say the nurses, it felt like the nurses felt like we were, I don't know, infringing on their territory, so to speak. And so they didn't care for that too much."*

Doulas are critically important according to service providers and moms. They not only teach moms about how to take care of themselves and their bodies during this vulnerable time, but also teach new parents about advocacy and self-care within health care institutions.

Sustainability and Continuity of Services

Service providers pointed out that doula care and other program initiatives that are supportive for Black women tend to be temporary, losing insurance coverage or funding after a period of time. The lack of continuity and sustainability of insurance coverage or funding arose as a major challenge for women and service providers.

> *"You know, the spirit of racism, knowing that the system is a problem, we can come up with some really great initiatives. But our initiatives seem to like start and stop quick and instant,*

because we don't have the resources. It's great that we have these great ideas, but sustaining them and maintaining them has been a real…issue."

"[There's a] need for more resources, but also a need for accessible resources, not just a community agency getting a grant, and then they create a program, and then they only have two to three years for the program. And then the grant is taken away. And the program no longer exists. I think consistency, I think continuity of care"

Women reiterated the importance of balancing appointments with other family issues while taking care of themselves. Self-care and advocacy is challenging when there are competing priorities. Flexibility in the system is critical and there is a need for additional support which may be provided by Doulas to address this dilemma.

"Competing priorities is a big problem, that when you have a sick kid…you have to get your kids to school, you're not going to keep your nine o'clock, prenatal visit appointment or postpartum visit."

Generally, service providers agree that better coordination and advocacy of care is important for Black moms accessing care.

"I see people coming in and then coming in again, and you're like, 'Well, what's going on?' And they're like, 'Well, I don't know where to go.' You don't know where to get help. So it's about that care coordination. And we do need the legislators to assist us in that."

"And for the last few years, me and another community partner realized that there's nothing really standing for that prenatal, postnatal and 0–5 population. So that's where we come in with, you know, piloting [a program] in Mercer County, because the goal is to get that also connected with the children's system of care in all of the 21 counties."

Quality of Care and Services

Black women's experiences vary not only with their access to care, but also with the quality of care when they can access it. Historically, gendered racism within health care systems has made it difficult for women to obtain quality care, taking into account race, culture, education, class and language. Quality calls into question traditional measures of care, and includes the perspectives and experiences of Black women to optimally support their care.

Currently, many Black moms feel lost in translation when interfacing with health care providers, which impacts their ability to feel knowledgeable and to be understood. According to our survey, 17% of respondents had a hard time understanding what their doctor or nurse was telling them about their health or the health of their child. An additional 21% had a hard time understanding their doctor's instructions and medications.

"My first experience with [Agency B] was horrible, it was horrible, I was pregnant with my son and they gave me seventeen dollars a month in food stamps…seven-teen, one- seven. A month. In food stamps, and then I had one of the ladies like, "I'm tired of all the young people having these babies coming down here thinking that we going to support you." And just she was coming real crazy and I'm like, "First I'm not here because I want to be here, I'm here because I need to be here. I've worked since I was thirteen…I'm not here to abuse the system. I'm here because I genuinely wholeheartedly need the systems to put me on the right track. I don't know what I'm doing" like this, my, it was my first time being past three months pregnant. So I'm like, this is all new to me. And they gave me the hardest time…my first experience was horrible."

Quantity of Time with Providers

When women are seen by providers, the short duration of appointments detracts from the quality of care. Service providers also agreed that the short duration of appointments was an issue.

"The time is 15 minutes and when the 15 minutes are up, you could have a million questions, but your 15 minutes are up and you're out the door."

"So, by the time you see the patient, you have about five minutes to measure her belly, check the heartbeat, make sure she's okay, because then you have someone else waiting next door for you. And it just continues. So, it's like you're on a treadmill so to speak, just trying to keep up."

It is additionally difficult to have longer appointments in places that are a one-stop health provider with several appointments. One provider said:

"But sometimes it's kind of like a revolving door in the waiting room. You know, they go to see the nurse, and then they go to see the dietician, and then they see the provider. And so it's hard to get time to talk with women themselves sometimes."

Lengthening the appointment time will contribute to improving the quality of care for Black women. It provides time for listening, feedback and questions between a woman and her health care provider during a very vulnerable time in her life.

Overcrowded, Unstable and Disconnected Environments

While the interactions between women and their health care professionals is important, the environments within health care offices provide an important context in making important health decisions about the lives of themselves and their baby. Excerpts below offer perspectives by service providers who describe the environments of their offices.

"So right now, in Trenton, it's just this office [for prenatal care], which is overpopulated, very crowded. And you don't get the quality care that the patients deserve, just because it's so high volume."

"Like we don't provide contraception, birth control. I feel like it's so many pieces, everybody does their part, but we don't talk to each other, we don't really connect with each other."

"There was a lot of mixed communications between doctors and nurses. And it was just a lot of things that happened that led up to me delivering a stillborn."

"We all kind of take care of pregnant women, and then they have the baby and we never see them again, because they go somewhere else."

In some cases, moms do not return to their prenatal/OB office and choose another location for continued postpartum care. The increased volume, long wait times, time constraints with appointments, intake back-ups, and the lack of continuity and communication causes some health care facilities to be unstable environments for moms. Staff and health care professionals do the best they can to keep up with the large number of programs starting and stopping and procedures growing and changing, all of which make it difficult to focus on the quality of care for women.

A History of Institutional Distrust: Culture, Scarcity, Stigma

The lack of continuity of services perpetuates distrust within the healthcare system on the part of Black women. For both English- and Spanish-speaking Black moms, there is also a fear that maternal and infant health resources will be scarce. Given the history of distrust of medical systems and the discontinuity of programs that benefit them most, they often fear that they will not be able to access resources in the future, as in the past. Additionally, many mothers fear a nurse, doctor or social worker may take their baby, which stems from past experiences and intergenerational distrust of a system that has given them inadequate and sub-par care.

Also, service providers did note that it was more difficult to reach Black women, compared to Latina, Asian and White women. Still, many communities of color have intergenerational histories of creating familial-community networks of resources as a response to racism and isolation and find it difficult to trust and rely on the traditional health care system. Scarcity of accessible services produces some feelings of competition among different racial and ethnic groups in Trenton.

"There's a large Latinx community in Trenton now and they are very community oriented and centered, whereas our history, cultural history is very different, right? We were just disbanded and not you know, our cultural roots don't support that type of, you know, we were separated from mothers, fathers, you know, so there's a different cultural history there. So, practices are different. And they share a lot of information together with our community, sometimes not so much. We're afraid that there's not going to be enough resources for me."

Given the history of gendered racism within health care institutions, Black women's distrust of medical practitioners and of medical systems is warranted. However, when we asked women if they trust medical professionals to provide quality reproductive care pre- and post-pregnancy, on a scale of 1 to 5 (1= cannot be trusted at all, 5 = can be trusted a lot), 76% of Black women responded 3 (neutral) to a lot of trust in medical professionals to provide quality care. This finding is in contrast

to the stories and detailed examples of negative experiences with health care professionals. It is possible that women have trust in individual providers yet little trust in health systems.

The challenges Black women have experienced from providers and structural systems have eroded the trust they put in these resources. One service provider noted:

> *"I think there's still a huge mistrust of the healthcare system. People want to be supported by people that they feel understand them, that they feel are from their own culture."*

A Black woman respondent commented about challenges in her effort to find institutional support:

> *"I just don't think when you look at our world and look at all the structures that are in place, there's really a lack of consistency, right? You say you care about us, but you do something different. You say that you want things to be better for us or for our community. But there's not a lot around me that says that that matches what you're saying. So I think to me, that means it's not sincere, it's not authentic."*

Additionally, due to the history and maintenance of gendered racism, there are so-called negative images that stereotype Black women as not serious in trying to access resources; some service providers blame them for not seeking out care, information and resources.

> *"I think these women need to take it a little bit more serious and really try to get this information because this is too many resources out here, it is way too many resources out here. So, I'm not personally, I'm not into the — I'm past the sad story thing…I'm not dismissing it, I'm just past it because I've been hearing stories forever…"*

It is especially critical that Black women find a supportive and flexible health care system. Providers who are culturally responsive to this history can more effectively persuade Black women to take advantage of services when they are available. Our findings do suggest that hiring Black practitioners and staff will address some of the discomfort.

Traumatic and Challenging Experiences

Many English- and Spanish-speaking Black women have tough and traumatic experiences obtaining quality care in Trenton and perceive themselves as being treated differently than White women.

> *"…you walk in, there's no one that looks like you and a lot of times don't understand where you're coming from."*

> *"…when a Latina arrived, a Latino person, they helped me and a Latino doctor arrived and helped me. But the other doctors here, gringos didn't want me, they didn't want to help me, they didn't want to help me."*

> *"One of the clients I had, she had an issue, too, with a lot of retention. And she was to the point where she could barely walk. And they were like, Oh, it's okay, [Maria], and she's like, 'No,*

something really, really is wrong. I can barely walk. I can't breathe like I should.' Something's wrong and she was like 'I'm going to the Emergency Room.' And I'm not, I'm not listening to what you're saying anymore. And of course, the doctor was a little annoyed. But she did go to the emergency room. And they found out that, you know, there was something going on with her kidneys and that type of thing. So she stood her ground, and they found out that there was an issue. And then from that point on, they started working on her and helping her, but had she not said, there's something wrong, then they wouldn't have done that, they just would have sent her back home, and who knows what would have happened to her."

"They're undocumented so they [providers] treat you any way they want. They know you're not gonna go complain to anyone. So they just continue to do it."

"Also, this isn't comfortable. They're like super-racist over there [at Healthcare Provider 3]. I remember being there with a Black sexual assault victim and I was like, I'm pretty sure if I [as a White woman] came in here I would not be treated this way."

Patients described not being taken seriously, encountering disrespect, and practitioners and staff lacking empathy. Women described these interactions as a lack of cultural connection with their provider.

"[Healthcare Provider 6] was the first episode with my son. I was in labor for 16 hours. And I'm a cry for the doctor and he just brushed me off kept telling me to shut up, they're gonna give me more medicine. Like it was a horrible experience."

"Whereas I feel that the health care that I choose to go after needs to reflect my values, it needs to look like me. I mean, because I feel so unsafe."

"…feel safer with a Black reproductive health physician. I feel safer with taking my child to a Black doctor."

"Miss [Davis] is, she's white. Like she was not very nice, first of all, and like when she saw his head like she just yanked him out. And I'm like, I'm glad you didn't injure anything when you yanked him out of there, because he was only like six pounds two ounces. But it tore me…they're supposed to ask you, do you want to stop pushing, and then they're supposed to like, make a little cut so it won't be zigzag? Because the zigzag is, it's harder to stitch."

While progress has been made toward cultural sensitivity and equity in our health care system, historically entrenched racism continues to impede quality of and access to care. Many Black families and communities harbor long held deep suspicions when engaging with medical systems, since doctors and other health professionals often reflect the racist society in which they live and are trained. The negative experiences of Black women due to the racism and sexism within medical systems are passed down generation to generation, between Black mothers and women as they interface with health systems and professionals. Images of Black women as being 'angry,' 'loud' or 'on drugs,' serve as dangerous assumptions placed on them as they try to seek care.

"She went to [Healthcare Provider 3 after] having a miscarriage. And she went a few different times for bleeding. And she said a White nurse looked at her and said, 'Honey, I don't know why you keep coming back. We can't do anything about this. And it's probably because you're smoking weed."

"What we saw in the Black community is, unfortunately, children are being taken from their parents. And we asked ourselves, why is that happening? And what a lot of people did not take into account is, a lot of these moms are dealing with postpartum depression. They're not angry moms."

"When I was having my son, it didn't seem like the doctors were — first of all, they were kind of rude. They wouldn't even, like when I was giving birth, I screamed like once and they were like, oh, you can't scream. It'll disturb everyone else. But I can hear the ladies down the hall screaming and no one ever said anything to them. And like the one lady, I think next door to me might have been White, she was able to just walk through the hall screaming, like, it's already bad enough, it's my first kid. So it was like, okay, she's allowed to walk through the hallway and disturb everybody, but I scream when I'm pushing [and] it's like, a problem."

Many of the providers described detailed accounts of the "subpar" conditions in Trenton facilities.

"[Healthcare Provider 7] it's filthy, right? …You should not be going to a hospital that's that dirty…I would much rather see us put energy into [Healthcare Provider 3]. The problem in Trenton is that Trenton does not like change and they're gonna fight for [a place] that's sub — I mean have you been in there? It's disgusting and nobody should be in there."

The experiences shared by the women in the focus groups illustrate that even before Black women engage with providers, there are negative mental and structural images that dictate the quality of their care. They are forced to create strategies to try and avoid being treated with disrespect.

Our findings support that the quality of care greatly influences Black maternal mortality and Black women's relationships to the health care system. Women feel supported when they are listened to and when there are authentic interactions between them and their healthcare providers. Black women fully understand the multitude of issues and the complexities surrounding their life condition, and the effect of pregnancy on their condition; therefore, a supportive, flexible, and nurturing environment is an important aspect to decreasing maternal mortality.

Mental Health

"I accidentally almost got my baby taken from me because I had postpartum depression with my son….Depression, the whole pregnancy with my daughter gained not an ounce of weight, cried the whole pregnancy. That baby popped out. My mom said, Oh, ain't she cute? I said get that baby the hell away from me. I wanted nothing to do with her. And I said it about five times….I couldn't bond with her. It was horrible, dealing with mental health and trying to deal

with a one-year-old and a newborn, then got medical issues, it was just too much I was only what 25."

The importance of mental health was another important finding that contributed to maternal and infant care, and the ability of infants and children to thrive. Women often shoulder the burden of family responsibilities, which can include taking care of their families, friends, earning money and maintaining a household. These responsibilities magnify when a person is pregnant, causing stress to increase and their mental health to suffer. One service provider said:

"So I saw a lot more of those women falling into depression, or becoming homeless, because now I'm not working. So the little income I had coming in, now it's gone. Or now I have multiple children and children get sick, so I lose my job for that reason. It's so many different things. And so the level of stress, you kind of feel like, okay, I pushed out a baby, now I gotta get back to life. So you're physically not healing properly, there's so many different dangers and risks."

The stress of pregnancy often exacerbates everyday normal stressors. Within Trenton, according to service providers and women, there is not enough access to mental health resources. As noted in focus group sessions, it was routinely brought up as a recommendation for the Maternal and Infant Health Innovation and Research Center. We also learned that Black women's mental health is equally dependent on the mental health of her partner and children.

In many of our focus groups, Black women shared that they either tend to take on other people's responsibilities or tasks are defaulted to them. By doing so, this can quickly lead to a cycle of depression which can then lead to job loss, and then homelessness. *Gendered racism* adds an additional layer to their mental health challenges as they combat negative stereotypes and images and demand adequate care. Forty-three percent of respondents indicated that during the past 12 months, they were emotionally upset - angry, sad or frustrated - as a result of how they were treated based on their race, ethnicity or culture. Twenty-two percent of respondents indicated they need mental health support and are currently looking for it. Thirty-three percent indicated they experienced postpartum depression.

Lack of Mental Health Services

Many respondents and service providers indicated that there are not enough mental health services in Trenton. There are high incidences of maternal mental health needs, yet the few services and providers available are underfunded, understaffed or eliminated.

"It's a huge lack of mental health services in Trenton. We see a lot of women with anxiety, depression, addiction. Currently, there's nowhere for us to refer them to for treatment, other than [Agency A], which is a long way."

Mental Health for the Whole Family

Addressing maternal mortality is not solely about addressing a mother's mental health, but that of the whole family. There were many instances where moms expressed frustration at having to address the depression of their partners or extended family members in addition to their own. When Black women shoulder everyone else's responsibility, there is less time for their own self-care before, during and after their pregnancy.

> *"But the men in our community need their mental health addressed. That's one of the reasons that the woman in the community are suffering because they have mental health issues, too. But those mental health issues are not addressed. You know what I mean? So I mean, this center if they could provide mental health counseling for not only the women, not and to children, because children need it, too. I mean, I'm a firm believer, three years old, [Sarah] started me counseling. I think they need mental health, counseling for women, for children, for me."*

> *"My daughter's father has mental illness so he's incapable of paying child support. But he still wants to help out. He you know, he wants to be there certain things he can't do. But a lot of things he can do, where's the services to help him? Because just because he have a mental illness, don't mean he's a bad person."*

> *"Most of our women are single, so we don't have our men supporting us. And that's a huge, not just sadness, emotionally, but it's the sadness for the children too. We kind of need all of those, you know, typically, in communities, whereas collective, there's multiple adults to one child. So now you have multiple children to one adult…a space where they feel safe, where they feel wanted, they feel heard. And yes, we can give you the resources, maybe for some of them, that's the thing that gets them in the door. But over time, they see that it's much bigger than that. And it's really the relationship with the women in the room that's going to bring that healing that they need."*

However, even when mental health care is provided, due to a historical lack of trust, there is less openness and communication with a provider.

> *"And even yeah, and even if you say your information is confidential, I mean, if your husband has beaten you at home, in the back of your head, you're thinking oh, I don't trust you that my information is confidential. So, then they shut down."*

> *"How do they address the stress? Black people in general don't believe in telling their business to anybody. It's something you know, that we inherited. And I think you know, all the way way back during times of slavery days. You know, we just we didn't talk about our problems."*

Teens and Specific Mental Health Challenges

Teen parents in Trenton experience additional mental health challenges as they are still in school. Service providers expressed that the amount of violence, trauma and loss in Trenton weigh on teen moms. According to providers, it is also difficult to accept the need for mental health resources.

> *"I think sometimes they're [teens] even pondering their own mortality, you know, especially in a city where there's been a lot of violence, there's been a lot of death, there's been a lot of grief. So, it's how do you get that message within even that context? I think."*

> *"But once again, as soon as I start talking to them about it is I don't need it, I don't want it. And some of them don't even recognize it as I don't want to call it an issue, but some of them don't see the need for it. They don't know that they're having some challenges. But when you start talking about, I think you should talk to them in such a such this would be a good connection for me. So, I don't need that. And you know, so they don't even realize that the way that they're operating or their, some of their behaviors can fall under maybe some diagnosis that they don't want."*

> *"And so then when you start talking to them about some of their behaviors, I had a student that I was just talking to this summer and they ended a school year. And it sounds like you know, maybe it was some postpartum depression. And so when I asked so many of them, I'll say, so when you went to your checkup, your six week visit, what happened is her postpartum. Oh, I lie. I didn't say because I'm afraid that they'll take my baby. So then it's those fears of not wanting to be truthful with people that they think will take their children from them."*

Our findings confirm the need for more accessible mental health services in Trenton. Maternal mental health is dependent on the mental health of the entire family, as Black women very often are the anchor of their familial networks. Mental health care for their partners and children would decrease moms' stress levels.

Trauma

The Nurture NJ Year One Playbook references SAMHSA's definition of trauma as an "event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being." The Nurture NJ Report cites historical trauma, including adverse childhood experiences, as major factors in negative hospital experiences. Educating healthcare providers on trauma-informed care practices helps promote a safe and caring environment.

In our research, 60% of respondents indicated they have concerns about safety or gun violence in their neighborhood. Additionally, 50% of respondents indicated they experienced discrimination, harassment, or were made to feel inferior because of their race, ethnicity or culture.

In our focus group results, Black women in the community identified needing a specific type of mental health support as a way of coping with trauma within Trenton neighborhoods and within families, both of which are related to the accessibility and quality of health care. Many women appreciated the space to share their stories of physical and psychological trauma as a way to cope positively. Within focus groups, women described experiences of sexual abuse as children, and others found themselves being abused by the father of their child/children. For some women, domestic violence extended to all family members, such as siblings. Some Black women felt they could not rely on protection from local police who they perceived to be racist and not serious about their responsibilities to the public.

> *"That's what made me want to be a lawyer because my father molested me. So, when I have went through the whole experience of the police, and I realized how I just had no type of support, like I just felt alone, even with my mom being there, so ever since then…to make sure that to let women know that's not okay, to talk to somebody because that for some reason sexual abuse - not that I'm shying away other abuses, it does twist your mind."*

> *"The most difficult place for me is [Agency B]. But the reason that [it] is difficult for me is because first off to backtrack, I didn't have any sexual experiences that they have had, I had never had that opportunity to have somebody sit and talk to me about what this is what's going on with sex, I was raped from seven years old, all the way up to fourth grade."*

> *"At the beginning of my pregnancy, I wanted to terminate it. Me and my children's father was going through with domestic violence. So I felt like I still hold on to everything that happened with my pregnancy, my son, my son is three years old. And I don't even know what else to say. But I see tell him, because it's like, sometimes I'd be sitting in a house, and I don't even want to be a mom."*

> *"A lot of times people think that domestic violence is just for intimate partners. No, you can have a toxic family member who's abusive, who, you know, it can be two sisters that fight all the time and domestic violence."*

> *"The police in here is horrible, the most despicable. They do not take their job serious. I feel tension. If I was in dire need and about to die, would I call Trenton police? Honey, I don't think that would be a good idea. They're very racist, very bigot. It's just like with that it scares me and you know, it's, I don't care. It's just a mess."*

Both service providers and women from Trenton highlighted the need for support for trauma specific to men in the lives of women. The quotes below highlight first the need for Black men who have been through birth trauma with the mothers of their children to support each other, and second the need to support Black men and boys who have been raised to exist in a world that expects the worst from them.

> *"Because, you know, I mean, you can look at historically men weren't even allowed in this space, right? So for men to want to participate, and then also with the mortality and*

morbidity, men seeing women after they've gone through the process, like bleeding out or like, you know, coding or having all these traumatic things happen."

"'I'm standing there. In my head. I want to say all these things, but I'm worried about they're gonna view me as the Angry Black Man, and then tell me I can't be here. So speaking to other fathers, like there are a bunch of different fatherhood groups around the state. But like speaking to fathers about that, that specific like, feeling, it's way too common. And it's like, they have the voice. They have the presence, right?

"The way that we have parented, traditionally, it was to protect our children. So we're a little bit harder on them, a little bit more detached, because the world is a scary place, and they're not going to care. So we have to kind of toughen you up, that that makes sense. So while I understand the reason, and I was raised that way too. I see the damage that's done to our children. I've seen the damage, especially to our boys, because you have to be tough, or else you are going to become preyed upon, which is why I moved out of Trenton."

Our service providers also described traumatic experiences specific to certain populations such as immigrants and teens in Trenton. For Spanish-speaking immigrants, there is an additional fear of local authorities' treatment of their children. Immigrant children do not receive necessary healthcare, especially for mental health challenges. And for teens in Trenton, there is a need to numb themselves from multiple losses and living in an unsafe environment, often with the use of substances.

"PTSD, we've heard moms give us stories about you know, the baby was hurt because they pulled her so hard her arm came out, you know…in the immigration center…or I couldn't get my baby until two weeks later, and they were separated."

"I got a call the other day for a four-year-old who was having mental issues and the school was rejecting her has no insurance for her. She wasn't born here. So again, we're a sanctuary state but there's a lot of services that are not giving to these folks, you know, so why be a sanctuary state if we can't provide that. For the undocumented, psychiatrists and psychologists was not an option. That is not something that they're receiving."

Coping with Trauma among Teens

"…in this community, there's a lot of trauma, there's a lot of violence, there's a lot of losses that they experienced, too, like there's girls that are constantly coming in, where they've had another loss, you know…something happened. And there's fears, there's constant fears that they have, but then it's kind of like they have to feel like they just have to go through the motions. And now they bounce back and I have to keep moving. So they don't even they don't even take the time, I think to really fully grieve, a loss. They acknowledge it in that moment at that time, and then they just keep going until another loss occurs. And this is what I see all the time."

"And then obviously, with this population, there's a lot of self-medicating. Right, you know, so then it can be, I mean, I'm talking to things all the time, and I'm saying, 'What do you mean, a

drink? You're not even 16, let alone 21.' No, so there's the self-medication piece too. So, if they feel like they can have a drink, where they feel like they can smoke some marijuana."

"Ms. [Angie]] said I, you know, I have to tell my kids to duck down you know, when they hear a sound. You shouldn't have to do that. And she said, 'This is not…what they should be experiencing.' I'm just thinking about the women that are there that have grown up under that and this is their norm."

Knowledge and Information Sharing

"A lot of different resources that helped me not knowing, because I didn't tell nobody that I was pregnant, I was terrified. So, for me to handle that on my own, they offer a lot and it was right around the corner from my house, so it all worked out perfectly. That's a good place, [Agency D]."

Black women in Trenton desire more accessible information and education about their reproductive journeys. Many rely on Google searches and documentaries for information, and few receive accurate information from their extended families (grandparents, aunts, uncles). Many women expressed not understanding information about their bodies, as practitioners may use words/ phrases unfamiliar to them. The Nurture New Jersey Strategic Plan described "long standing acts of human disregard and oppression that have perpetuated deeply ingrained dynamics of racial inequities that continue to be encoded in American health systems. These inequitable and often inhumane practices have shaped structures and influenced knowledge, values, and attitudes." Trenton-based Black women in our focus groups provided examples of how these very same inequitable practices have influenced their lack of knowledge. Some women had no idea they could advocate for themselves for a vaginal delivery after having a C-section and others were never informed about the stark realities of Black maternal health inequities nationwide, in New Jersey, and in Trenton specifically.

Some women and service providers describe the education system in Trenton as poor, as they come across many women who struggle with illiteracy and comprehension. One service provider said:

"The education system is broken. And I think, you know, our job is to communicate to people in language and in reading level that they understand, right. And I, we learned this lesson ourselves, … we used a word in our application that people didn't understand. And some people didn't apply. Because they didn't understand the word we used. It was like three months before we figured it out. Right? It was a 12th grade reading level word. And we needed to use a sixth-grade reading level."

"But in clinics it's whoever's there the day you come in. These are the kinds of things that, how are you going to be my practitioner? And then I think we need to communicate with people in a way that they understand and understand where they come from. Right? That they don't, they're probably ashamed to tell you what they have and what they don't have. Right? When you say to them, you know, 'Hey, your cervix is incompetent.' Incompetent, what does that

mean? They might not know. They might be like, Oh, okay. And then you're like, Yeah, you have to go to the hospital. Like they're like, I don't understand what that means."

Our findings support the need for more accessible and culturally relatable information that families can comprehend so that they are able to access available resources. There are some helpful services in the community that aid families. For example, the library offers help in signing up for utility assistance programs that are needed and useful. Additionally, using safe and trusted places like libraries could be a hub to access valuable information and tech support to access state programs. According to our findings, strengthening our education system and increasing more care coordination can improve the translation of information to better serve women.

Accessible Information on Maternal and Family Health

Many women know from intergenerational histories about the process of birthing in their families, but some did not know about their own history of pregnancy or birth complications, or the high mortality rate and wanted to learn more. They wanted to learn more about the structural foundation for such high inequalities among Black women. They described challenges in obtaining information related to such services as breastfeeding and support for postpartum depression.

"Postpartum depression, and it lasted for a long time. And it took me a while to get connected to my children and have, you know, some type of normalcy…I didn't know how, I didn't know how to touch him. I didn't know how to breastfeed, and they don't tell me they didn't teach you that. They just bought a book in a few nipples to go over in here, figure it out."

"I had no idea. We're more prone to like cesarean sections, C sections, more African American women and Latino women get, are getting cesarean sections than having natural births. Like I didn't even know that I had the option to have a natural birth after having a cesarean because they kept saying like my little cousin, like, oh, you can only have a cesarean you only have a cesarean. But then like I started reading about it, and I was like, Oh, wait, I can actually try for a vaginal birth after cesarean. So, a lot of information is not provided to us."

"We think this is a system that isn't really meant to protect us when there was another shocking statistic to kind of go along with the Black women in New Jersey experiencing death rate from pregnancy related complications seven times more. Well, they say that a Black woman with a graduate degree is three times more likely to die than a white woman with no high school diploma living in a trailer park. So make it make sense about That made me very scared."

"I need them to provide some parenting classes for dads…dads either need to be pregnant for like 24 hours or they need to take a parenting class."

"I think this is this is the first time I've heard a conversation is even attempting to be had about Black mortality in women. When it comes to giving birth. I've seen like so I just recently finished a prenatal and postnatal yoga teacher training and one of our final assignments was to look within our community and in our state for different resources that we would give out

to parents, and I saw something that was more statewide. Right, but then it was like, Oh, I didn't even know this exists, right? Like, how come like that, like the statewide things are so hidden, it's like, well, nobody is going to know that they exist. Because if you if I have to, like, really dig in deep search for it, it's not there. But as far as like, I'm a sacred community, and really like something there. And this, this might be the first that I've heard, like an intentional conversation, trying to be had about it that is going to plant a seed for something to grow and to create change."

Advocacy and Patients' Rights Education

Women and service providers additionally mentioned the importance of the topic of patients' rights and learning how to advocate for themselves. Some women with Medicaid coverage may work with a doula who can advocate and translate much of the needed information, but the large majority of women feel unsupported and lack knowledge and understanding of how to advocate for themselves. Self-advocacy in the healthcare environment requires support, time, focus, patience, and cultural sensitivity to help build baseline knowledge and skills.

"They they're accepting what the doctors are telling them. Like I said, that agency that knowledge of knowing how the knowledge to assess what they are being told, in evaluate what they're being told. It's just not the it's not there. You know, it's not there's not an abundance of that. So yeah, they may not get their surgery or you know. Yeah. They're just not very good advocates all the time self-advocates. They don't have what it takes to be the best self-advocates I would say."

Findings 2: Perceptions of Assets and Supports

For this project, our team conceptualized assets as people and places that create supportive networks for them in Trenton. One of the first questions all focus group participants were asked was, "*What do you love about Trenton?*" Additionally, participants were asked to identify where they would like to receive specific reproductive health support, and also general family and community support and services within a map of Trenton.

People: Family, Neighbors, Community, Providers

Focus group participants primarily identified first, family members and community residents, and second, supportive Black and non-Black doctors, nurses and staff as assets.

> *"She's Dr. [Moses] my MVP, I love her…She asks questions and she listen[s]…She's a Black queen who understands what difference you're in, she knows our voices don't be heard. And she just instantly…she asks you, how do you feel? You know, she don't say, Hey, I think this is your diagnosis, and you need to go get this, that and the third. She breaks everything down where you can understand it, because I don't understand the medical terms. Well, most of it now because I'm a coder, so I have to deal with it. But with her it's like, you go in, and she instantly, tell me what's the problem? Tell me where it hurts, tell me, you know your issues. And we go from there. And she listens and she doesn't just brush you off and say hey, like when I told her about you know how I felt about the vaccine and things with my weight and stuff like that. She said, Okay, well, are you okay with us doing X, Y and Z and seeing this doctor and this doctor. Now I see a therapist every week, now I see a nutritionist, you know, on a regular to make sure you know I maintain certain things to help me better my situation.…She's really, really good…"*

Many service providers described going above and beyond to support women. The majority of the grassroots community-based organizations, churches, doulas, midwives and lactation coaches were women of color often using their money, additional time and personal resources to support Black and Brown women's health.

> *"A lot of times, you know, just even at the beginning…I would accompany them to their doctor visits. sometimes a lot of the practitioners will, you know, use terminology that they may not understand or may partially understand so sometimes it helps for us doulas to be there."*

> *"For the mothers, I try to, everything I do is either free or is low cost. Like I had summer camp this past summer. I want to charge…$80 a week and that's very cheap. But what I provided, we went on trips, it was free, it was free breakfast, free lunch."*

> *"I'll also add to just making sure we have the resources available for our clients. And I know oftentimes for my clients, they would want, like, English-speaking classes, so I would make sure that I'm abreast to when those are, where they are."*

Places: Existing Health and Social Service Assets

Participants described a great deal of Trenton pride when identifying a wide range of organizations as assets throughout the city across health, education, and not-for-profit sectors. Examples include Baby Please Birthing Center, Catholic Charities nurses, Change Church, Children's Home Society, Children's Futures, Homefront, Perry Street Emergency Shelter, Princeton House for Postpartum Pregnancy, Tracy Martin House, Trenton Area Soup Kitchen, and Women's Space.

> *"… she really saved my life…. I would call her at seven, eight o'clock at night. And I don't mean to get emotional….I told her my story. And, you know, she listened. She understood. Rather, she went through it and she just got it. … my mom she around, but she's very negative. So, having my daughter, and trying to, you know, figure things out for yourself and instantly become a single mom, you know, unexpectedly and life just happening. You know, you come in, you've gone into shelter, trying to process everything then coming out of shelter. And so it was just a lot. And she, you know, she made sure I had all the resources I needed, down to housing, down to, you know, making sure my daughter had her milk and her Pampers and, you know, whatever I needed for her, she had it, and when, up until she was probably like, I'm gonna say, like, the written when you look at the preschools together, like, you know, it was just all the information, anything that was going on… if she was not able to help me, she will point me in the right direction to people that can help me and will help me…And it was just like, I will call her and she was just, you know, hear me cry and just listen. And that just meant a lot to me. Because I got to be a real mom, you know?"*

> *"If you're not maybe super religious church, like I found out, there were a church program, how to sign up [at an agency] and all the programs that they offer. Not even my own church, like a different church. So different churches offer a lot of information.*

Many service providing organizations throughout Trenton represent large health systems or complex and diverse for-profit and nonprofit organizations. Given this level of diversity, it is not surprising that several organizations came up in discussion as both an asset and a challenge for Black women including [Healthcare Provider 3], [Agency B], and [Healthcare Provider 1].

> *"[Agency B], just recognizing how it's much of a hub of being able to connect with those different resources, all in one setting, you know, versus you trying to do that research independently…but it just helps you to organize yourself. Like these are the resources you know, if you're looking for this, etc, you know, to set that tone or whatnot. So after the fact learning that I've seen that as a positive aspect…*

> *"[Healthcare Provider 1]. My son was…really small. I was, I started taking him there first before I found the first pediatrician. But they gave me a lot of resources. Like they told me to go to a WIC and you know, like, where to go for assistance."*

Many providers also identified services, programs, and activities that support maternal and infant health available to women across Trenton.

"We have a whole array of comprehensive services. We have nurses and doulas and nutrition and all of that, but it's really about the rapport and you know…They would rather speak to Miss [Charlotte] though because she's been with them from the beginning and connecting…"

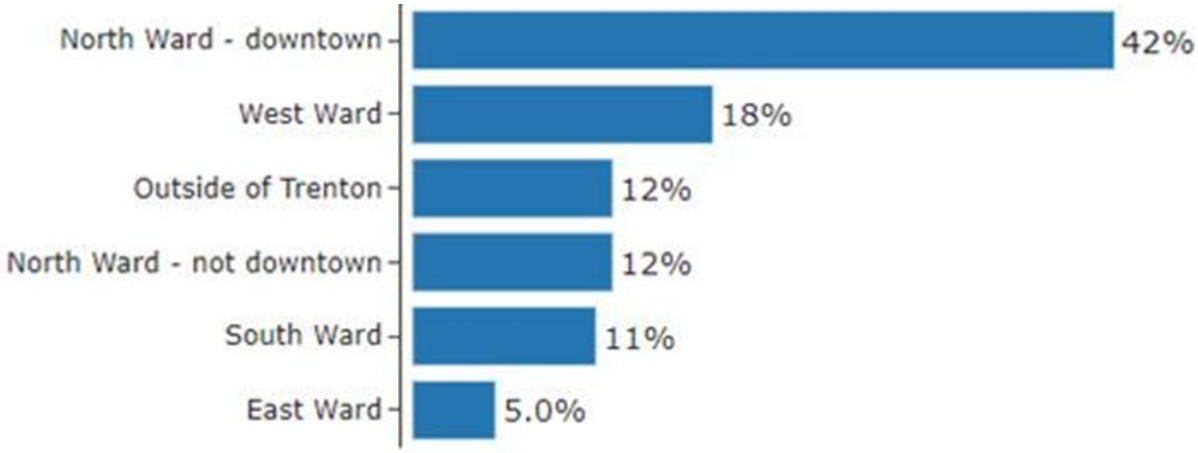
"We kind of link them with whether it's [Agency E]…, , or whether it is [Agency D], and…whether it's WIC enrollment, their prenatal care, any of those services or things that I'm always, you know, talk to the students about and trying to get them enrolled in that…then…we do…education and prenatal classes, not classes, but more education, you know, groups sessions, we on a weekly basis. And then I do individual case management…."

Findings 3: Participants' Suggestions for a MIHIRC

Location

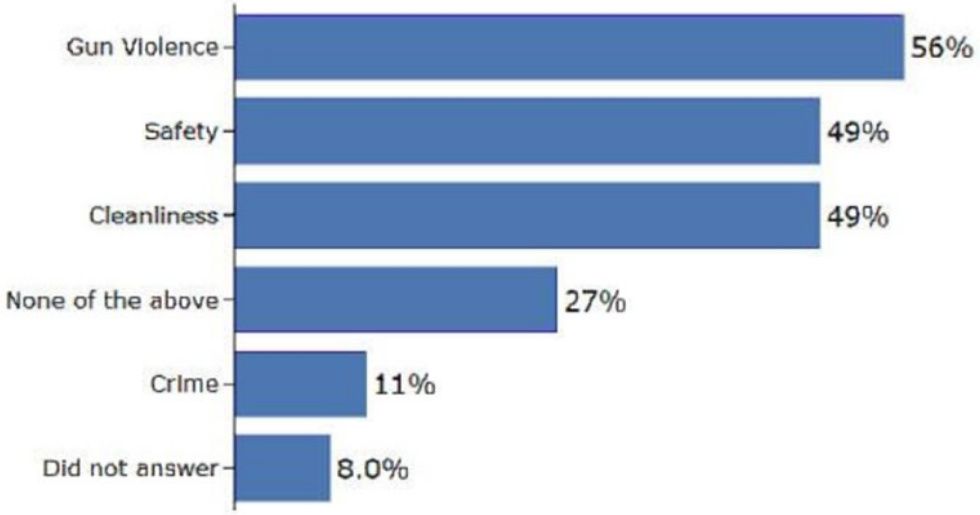
Focus group participants readily offered recommendations when asked where the upcoming MIH Innovation and Research Center should be located. Forty-two percent of women participating in focus groups indicated that they preferred the MIH Center to be located in the Downtown area of Trenton, within the North Ward, with adequate parking (Refer to Figure 7).

Figure 7. Recommendation of Location by Survey Participants



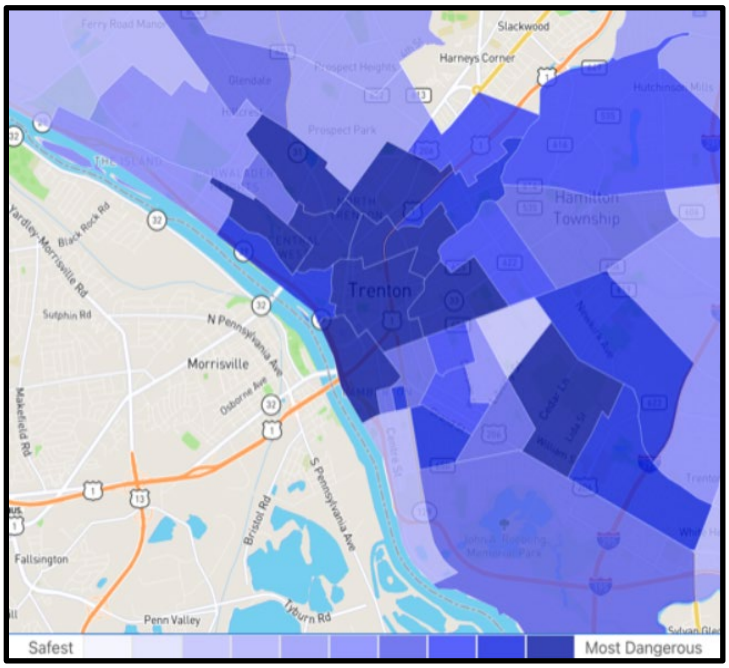
Key factors by participants in identifying recommended sites for the Center's location were safety and security. The majority of survey respondents identified gun violence as a major concern within their neighborhood, consistent with crime rates for Trenton (see Figures 8 and 9).

Figure 8. Safety Concerns



These findings are consistent with reports that Trenton is one of the most dangerous cities in the country, with a crime rate that is higher than 92% of the state's cities and towns.

Figure 9. Trenton, New Jersey: Safety
(FBI, 2020 data from neighborhoodscout.com)



In conversations with women and service providers, both groups emphasized the importance of identifying a location for the center that was safe and accessible.

> *"We need people to feel safe. That's why I was like, downtown."*

> *"I would just say that wherever it is, obviously, it has to be a safe place, a safe destination. And it has to be a place where it's easily accessible. I mean, just think about how women have to have their babies. They live in Trenton, but yet, and still, they gotta go to [Healthcare Provider 2]or to [Healthcare Provider 4], to have their babies. That makes absolutely no sense. So the, the facility or wherever you know, what you guys put together, it definitely needs to be an area that is safe. And that might take some work to make sure that you know, the area is, you know, a safe location, but also to make sure that the people will come because they're not going to go if it's far away, or is outside of the community…that's just going to, there's going to be a fail from the start."*

Accessibility, specifically transportation access both by bus and by car, including convenient parking were identified as important factors to be considered for the site location.

There were also multiple recommendations to renovate the "Old [Mercer County] Hospital Space." Several suggested offering multiple locations throughout the city that are accessible by public transportation, due to the perceived large size of Trenton.

"Centralize it. All the buses go there. Also remember, some people in West Trenton can't go to this train because they have a little rivalry going on. So you can't do that. But you're back to that, the criminality of stuff that you can't ignore. Some folks may not be able to go to West or East to get the service, so centralization."

"But I do believe that one center probably just won't work. I think that because Trenton is so big."

A downtown site would be close to North Trenton, which could address issues of safety and transportation especially for people who live in North Trenton where many Black residents live. North Trenton's Battle Monument neighborhood is to be redeveloped in a project integrating affordable and accessible housing with safe, walkable streets, connected parks and other improvements intended to build and strengthen the community, which could complement the MIH Innovation and Research Center.

Long-term Parent and Family Support

Based on existing assets within families and communities, both focus group participants and service providers recommended a more holistic and integrated approach to care, which encompasses care before, during and after pregnancy and birth, including multigenerational and extended family services reflective of the community's cultural diversity.

Women in our focus groups recommended specific types of services and resources that address much of the cumulative experience of their challenges including mental health, parent support, maternal and family information, workforce development and primary care for routine medical check-ups, as well as support completing forms and state paperwork to obtain other services.

To prevent and respond to daily stressors driven by race, class and gender inequities, the majority of focus group and interview respondents described the need for responsive services well before and after birth takes place - all times that profoundly affect children, families and women in their experiences as parents.

"…sometimes they always talk about, you know, how you feel throughout the pregnancy, but like, postpartum there is not much places that offers help. So moms still needs help after they give birth to their babies."

"Parent support at the top of the list. Real parent support, somebody that's, you know, gonna be honest with you … not sugarcoating what's going on and to make you feel more, to make you feel comfortable to open up and not feel attacked. And not feel like what you're saying is the worst thing in the world. It's okay to talk it out. And sometimes that overwhelms [you] with depression and anxiety and just speaking on what you're going through, so that they, so that way it will help you."

"Maybe they could do like a raffle and their mom could like moms could win, um, maybe diapers or stuff for kids or stuff like that. To give them encouragement to continue to come and getting good information that would support that would help them and their kids at the same time because you know, good mothers make good babies if they have the help."

Staffing

As a way of improving quality of care, a service provider recommended *"definitely hire staff that looks like the community you want to serve,"* joining numerous women interviewed who spoke to the importance of access to doctors and health care staff who look like them and understand their communities and traditions.

"I do feel as though as far as who's running it, to be honest, I feel as though as far as who runs it should be someone from our community. And the reason why I say someone from our community because when a person can relate to you, they can help you better, versus a person that even though they have degrees, they don't know what you've been through…so it should be someone that can either relate to me, relate to my children, or they can relate to my situation at that moment."

"I think, and just anything not non-judgmental…non-judgmental attitudes is like very, very key with being able to pull them in and keep them connected."

Additionally, we heard the benefits of increased support of doulas and midwives to deliver care reflected by women who were familiar to them.

"Because a doula is like a mother. Church person is like a mother. Your mother is a mother. So like, especially with those kinds of people, everybody, y'all all understand like what to do, where we're coming from. So that support, it takes a village. And then plus you have someone to talk to. It's always the older Black, Black grandmas [who] do it."

Flexibility and Inclusivity

As a way of promoting the accessibility of the center and communicating on behalf of it, women recommended in-person and hybrid options for care. They emphasized care that considered understanding women's circumstances, which meant incorporating patience and sensitivity to cultural norms as women access care. Women also suggested multiple ways to reach them including advertising through social media, texting, and other non-judgmental approaches to reach them—specifically the WhatsApp platform, particularly for staying in touch with teens and providing support.

"…flexible pediatricians. Yeah, like that. You want to go on WhatsApp, if you want to talk to me at night or you want to go on the weekend. Okay, but the outside sources are not going to be flexible."

"Me personally, I rather be seen in person, that's just me I feel as though you can see more, you got to understand more about my body being seen in person versus virtual."

"Keeping an open mind and actually be willing, these mothers and them knowing that they can come back and get the support, that we are important factors for them to access so really, to get the health, that so as long as they feel supported, as they need to consider taking care of themselves. Like that turned away or they don't find what it is that they're seeking. They're gonna seek it somewhere else or not do anything at all."

Both women from the focus groups and service providers highlighted the need to support specific populations, in particular men, teens, and those who are without consistent and safe places to live.

"*Creating space for fathers and men to take part in conversations happening…This is, this is something that I want to make sure I'm including in my demographic of people that I serve. So having space for fathers as well."*

"And the men also feel like they don't know what their place is like, they're like, 'Well, where do I go? What do I do? How do I, how do I exist as a parent outside of my financial obligation?' Because there are so many that only think that, 'Well, I'm a father because I pay child support,' or 'I'm a father because I bought diapers.' Like no, I need you to actually be mentally and physically and emotionally present. And this is what you can do as a man to support you know, your partner, or your child's mom or your wife, whatever, you know. But then also hearing each other and saying, like, you know, from this lens, it's really difficult for me to do that as a man, but I'm looking for insight on how to be a part of the process, especially during birth."

Providers stressed the importance of considering the specific needs of teens when providing services and designing programs. An example was given by a service provider of the specific challenges of teen mothers living with other family members:

"Do you want me to tell my aunt that I can't take her children to school anymore, and then I'm pulled out of the house. So, it's either I'm going to take her children to school because she say if I don't want them, I can't go to work and earn the money that she needs to because now she doesn't have anyone to take her children. So then this is like a trickle-down effect. If I say no, my aunt can't go to work, we don't have any money. And then I'm put out on the streets. So, either I'm going to take them to school and deal with it. And I come to school late, that was her only option."

"When I think of what we did with the young women, you know, that were prostitutes, and so forth, I think they really just wanted a safe space, and clean space, with no judgment."

"These girls [teens] barely know how to make the phone calls. We're doing role plays in my office before I even let them use the phone to call. I say now you make pretend like I'm the doctor. Now what do you want to say? So, we do this to prep before they even make the call. So that they can feel more comfortable doing it."

System Transformation

Service providers and community advocates identified recommendations needed to support parents and families across the lifespan within Trenton and to improve the access and quality of maternal and infant health services. Recurring themes included building transparent and accountable systems that are inclusive of community partners and sustainable over time.

> *"I think, for this center that they're talking about, if they're gonna bring in community members, which I feel like that was definitely a good thing to do. Because you need to work with the people who live in the heart of it, or who are among the people, you definitely need to do that. But there was no equality there, there wasn't any equity. In this. It was, again, in a systematic kind of hierarchy way, where those community leaders who were present who were doing the work who were on the front lines. We weren't respected in what we were bringing in, and then the community was [just] left."*

Both women living in Trenton and service providers identified recommendations of ways to make structural/systemic improvements to health systems. Suggestions included extending hours and including within the Center and/or healthcare sites physical fitness and nutrition services, a community multi-purpose room, and lounges as safe and quiet spaces where families can spend time together.

> *"So [if] there were evening hours and Saturday hours, yeah, that's a big thing. Sure, if you're trying to work to do the right thing and take care of your kids, you can't come in between eight and 4:30."*

Conclusion

This project identified existing needs, assets, and recommendations to support a Maternal and Infant Innovation and Research Center focused on the needs of Black women throughout the Trenton area. Improving our understanding of Black women's health and reproductive challenges—including how they perceive and use neighborhood assets and resources—should inform the methods, systems, structures, and policies of care in communities dedicated to improving maternal and infant health equity. Similarly, identifying assets as perceived by Black women and their service providers offers an opportunity to build on the many existing supports throughout the city. An important criterion of efficacy is the realization that all supports may not be recognized as such by those for whom they are intended.

The success of a Trenton-based Maternal and Infant Health Innovation and Research Center in addressing the socio-cultural and economic factors driving the high maternal and infant mortality rates will depend on the equitable partnership and participation of Black women and the existing service providers from the area. Funders, practitioners, and providers must be accountable for ensuring that the support and services they are offering are actually experienced as support by women, especially by the Black women they are serving. This approach puts Black women at the center of contributing to conversations about and design of care systems and puts them in control of their own health and the well-being of their infants, children, and community.