

## **Saving Our Babies**

Low Birthweight Engagement Final Report



Advancing Black Maternal, Child & Family Well-Being in Dane County to Improve Birth Outcomes

Submitted to the Dane County Health Council February 28, 2019









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## **Executive Summary**

In March 2018, the Dane County Health Council initiated a community engagement campaign around the African American low birthweight crisis in our community. The Council contracted with The Foundation for Black Women's Wellness and its project partner EQT By Design, LLC. to execute this effort with the explicit goal of gathering the insights, perspective, and feedback of members of Dane County's African American community. More specifically, the project's aim was to bring the voice of the community most impacted by the issue to the table as an active partner in identifying and informing root causes and solutions.

The initiation of the project is an extension of the Council's efforts over the past 20 years to implement and support health system and community-driven efforts that work to address and improve the quality of maternal and child health in the African American community, and specifically to address and eliminate disparities in the birth outcomes of Black women and their babies. The effort comes at a time when achieving significant gains in improving Black maternal and child health in our county has never been more urgent.

Presently, we know that babies born to Black mothers in Dane County are 2 times more likely to be born at low birth weight than babies born to white mothers, placing them at increased risk of significant health and developmental challenges, and of dying within the first year of life. These gaps in birth outcomes occur alongside a troubling track record of stubborn health disparities in Dane County where African American residents comprise roughly 5% of the total population, but are over-represented in all major categories of disease and illness, including hypertension, heart disease, diabetes, cancer, stroke, obesity and reproductive disorders. Black women and men are more likely than their peers to live with and die from treatable and preventable illnesses, and at younger ages. And despite greater access to healthcare in Dane County and Wisconsin than in many other states, African Americans still experience the worst overall health and mental health outcomes than any other group. Furthermore, Wisconsin was recently cited (2014) as the only state in the U.S. where the life expectancy gap between black women and white women had widened.[1]

A recent analysis of Dane County public health data revealed a Black infant mortality rate as high as 15.4 infant deaths per 1,000 live births during the period of 2015-2017. [2] A most sobering illustration of this crisis in one of our many engagement sessions was the testimony of a local church pastor who shared that within her church congregation, 8 babies have died at or shortly after birth in the past 7 years to seven families. Two died from sudden infant death syndrome (SIDS); the others from complications related to premature birth or unknown causes. The families are still struggling with the immense grief and loss of these unspeakable casualties.

These harsh realities reflect a larger troubling trend and reality in our state where we carry the unfortunate designation of first in the nation for Black infant mortality, and where Black women's health and that of their communities is colored by an overarching theme of disparity.

<sup>[1]</sup> Trends In The Black-White Life Expectancy Gap Among US States, 1990–2009, Published Aug 2014

<sup>[2] 2015-2017</sup> Dane County Infant Mortality Rate, Public Health Madison Dane - reference for page 5





A <u>2017 report</u> named Wisconsin a national leader in racial inequality. Similarly, a <u>2018 report</u> published by the Centers for Disease Control (CDC) found that Wisconsin, comparatively, had the highest state infant mortality rate among non-Hispanic Black women during the period of 2013-2015. The rate, 14.28 infant deaths per 1,000 live births, was 1.7 times higher than the corresponding rate in the state with the lowest mortality rate for infants born to Black women (MA). This present state of Black maternal and child health in our county and State is one of the MOST significant and urgent health challenges we face, and one for which this engagement effort was designed to uncover viable, sustainable and community-driven solutions that will turn the tide towards healthier birth outcomes for Black women and their babies.

Our engagement strategy centered on the design, development and implementation of a series of community conversations which targeted local Black women as the primary audience, and included Black men and Black youth as critical members and extensions of Black women's lives and families; as well as the inclusion of at-large members of the Dane County health and social services community who serve Black women and families. We were not tasked with carrying out a rigorous research study in order to identify a specific truth, but rather to facilitate the stories and experiences of African American women in Dane County. The outcome we achieved was a space for many different truths to come forth while taking careful record to share what we learned about their experiences with local healthcare and community systems, their perceptions of and vision for their overall health and wellbeing, and their identification of factors that both promote and hinder the realization of well-being.

Our work over the past nine months has been unprecedented in that we were able to engage the voices of nearly 300 Black women, men, youth and community members in a process that has been as rewarding as it has been challenging. Participants gave generously of their time, their stories, their experiences, and their truths. While our African American participants did not constitute a random or fully representative sample of Dane County's Black residents, the individuals we engaged did reflect a significant cross-section of the diversity existing among African American residents in ethnicity, age, education, family composition, income and location.

Like the Dane County Health Council, we believe there is no one better equipped to inform our community's understanding of the drivers of adverse Black maternal and infant health outcomes than our County's Black mothers and families. We have listened deeply and captured the voices, challenges, ideas, needs, and hopes of a subset of Black women, men and youth in our community, and have been inspired by their strength, resilience, perseverance, loving commitment to their families and community, and their desire and willingness to be a part of the solution.

While we are aware of many past local community engagement efforts, we are unaware of any that have engaged as many Black women as this campaign, or around the specific issue of maternal and child health. We cannot understate the significance of this accomplishment, as it is a strength of this outreach and of this report. The information we collected provides a rich perspective and body of work that can and should inform critical steps, sustainable strategies, and effective solutions that reduce and eliminate Dane County's Black low birthweight and infant mortality gap. We are fully committed to this work for the long haul, and offer this summary report as a first step in a powerful direction of collaboration towards saving our babies.





### **Big Messages We Heard**

#### At the root of poor birth outcomes rests:

- Stressed Black family systems.
- Generational struggle for economic security and stability.
- Institutional racism and bias and its looming impact on Black life and progress.

#### **Furthermore:**

- Though African Americans see Dane County as a place of opportunity, that
  opportunity does not translate consistently into success or stability for them
  and their families despite their best efforts.
- Although there are instances of individual stability and "success" to point to, participants overwhelmingly cite a persistent pattern of racial inequality and opportunity imbalance across all domains of community life (education, employment, income, social capital) that relegates Dane County's African American community as a whole to a second-class status. This makes them susceptible to the poor health outcomes and pattern of disparity that persists in our region.
- Root causes of Black low infant birthweight stem from this backdrop of racial and economic inequality in Dane County that goes unchanged.
- The dual impact of economic insecurity and racial inequality on the Black family system, past and present, has created a toxic cycle of stress and pressure that is driving Black infant low birthweight and other health disparities.
- Black mothers and families, though hopeful, resilient and persevering, are in far too many cases, living under a state of duress and chronic stress in Dane County. This toxic cycle of stress impacts Black women and families of all education and income levels.
- Solutions that eliminate Black birth disparities and improve mother and baby health must be broad and cross-sector, within and beyond healthcare, to address both improved maternal and child health, and whole-family and community well-being.

#### Our Recommendations and Why

Our recommendations, outlined on pages 39-41, are written in response to the rich feedback offered by participants, and shaped around ten (10) subsequent and consistent themes that emerged across the twenty-two (22) target population sessions we hosted and one (1) additional session with healthcare and social service providers. Key factors cited by Black women (and men) that heavily impact their quality of life and health in Dane County, including the quality of their pregnancies and the health of their babies can be best understood through the table below.





#### 10 Critical and Consistent Themes

The following themes capture our assessment of what we identified as the drivers of low birthweight births and maternal and child health disparities in Dane County's African American community based on participant feedback and our analysis:

- Racism, discrimination and institutional bias
- Bias and cultural disconnect in healthcare delivery experiences
- Economic insecurity
- Housing insecurity and high cost of living
- Poor access to health-supporting assets

- Inadequate social supports
- Gaps in health literacy, education and support
- Disconnected and hard-to-navigate community resources
- Systemic barriers to individual and family advancement
- Chronic stress

We expand on these themes on pages 25 - 37, providing participant insights and select data sets. In response to these themes, our recommendations (pages 39-41) are necessarily broad and systemic in nature, calling for actions and investments within healthcare systems, community, and in cross-sector systems and policy level change. This multi-pronged approach allows for the deployment of readily available resources and assets for immediate and short-term impact, while building capacities and collaborations needed to achieve long-term transformational change that stabilizes Black family systems and improve Black birth outcomes.

#### The Opportunity at Hand

It is often said that the health of a community is best measured by the well-being of its children. By this measure and in the case of Black babies, we have urgent and considerable work to do. Yet, despite the challenges we face and the barriers outlined in this report, there is a significant opportunity before us to make unprecedented change in elevating the health of Black mothers, babies and their families in Dane County. The timing of this engagement effort and the completion of this report and recommendations are happening at a time where our state leadership has made promising commitments signaling a willingness to confront health disparities in ways it hasn't before, and to prioritize maternal and child health and infant mortality specifically as policy imperatives. In this climate, and with proper investments and collaborations at the local level, we are poised to move from a position of "worst to best" for African American maternal and child health, and for Black families overall.

#### The time to be bold and courageous together is now!

The findings of this engagement effort and the subsequent recommendations we propose provide a roadmap to a bold new path that confronts racial inequity, leads with a social determinants of health lens, and aims to dismantle systemic roadblocks that have compromised the stability of Black families in Dane County for far too long. We know that the path to healthier mothers and babies begins with strong families and community systems that support them. Our greatest opportunity lies ahead to lead, invest and partner in powerful ways that secure the health and future of Black babies.





### **Acknowledgements**

We would like to thank the many organizations and individuals who assisted us in making this engagement effort a success. Their partnership was instrumental in helping us organize, recruit, and/or co-host sessions and to reach our goal of engaging a broad and diverse audience of participants within our target group of African American women, men, and young adults. Without their support and involvement, we could not have completed this undertaking.

- ♦ Aaron Perry, African American Men's Health Center of Dane County
- Allied Wellness Center, Gloria Farr
- Badger Rock Community Center, Marcia Caton Campbell and Hedi LaMarr Rudd
- Brandi Grayson, Community Advocate
- Dane County Human Services, Martha Stacker and team
- Delta Sigma Theta Sorority, Inc., Terri Strong
- ❖ Diane Mitchell, Bridge Lakepoint-Waunona Community Member
- Kennedy Heights Community Center, Patrina White and staff
- Lussier Community Center, Nikki Conklin and Paul Terranova
- Madison Metropolitan School District, Sally Zirbel Donisch
- Michelle Robinson, Kids Forward
- Capital High School Principal Karyn Stocks Glover
  - East High School, Principal Mike Hernandez and Ebrahim Amara
  - LaFollette High School, Principal Sean Storch and Johnnie Milton
  - Memorial High School, Principal Matt Hendrickson and Suzanne Blackamore
  - West High School, Principal Dr. Karen Boran and Sean Gray
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- Meadowood Health Partnership, Sheray Wallace
- Mentoring Positives, Will Green
- Mothers in the Neighborhood, Sina Davis
- Mt Zion Baptist Church, Carola Gaines and Health Ministry
- Northport Community Center, Pat Wongkit
- Oleka Parker, Stoughton Community Member
- One City Schools, Marilyn Peebles-Ruffin
- The Foundation for Black Women's Wellness Board and Advisory Team
- Theodora Hodge, Sun Prairie Community Member
- Urban League of Greater Madison
- Zion City Church, Myra McNair

We also sincerely thank the Dane County Health Council and its member organizations for the opportunity to undertake this project, and for their support and assistance throughout this process. --





## I. Overview of Engagement Effort

### What We Completed

We designed a community engagement process that would achieve the goal of centering the voices of Black women and men in informing our understanding of their concerns, experiences, and ideas around improving the birth outcomes of Black Mothers and babies in Dane County. We specifically set out to hear from the population most impacted, their ideas of the root causes and solutions for addressing and resolving low birthweight births and the subsequent infant mortality disparity burden that local African American families face.

Since Black women residing in Dane County were the core constituency for this engagement process, we centered our recruitment strategy around wielding the reach of the Foundation for Black Women's Wellness, complemented by EQT By Design, in connecting with some of the hundreds of local Black women who engage with our programming each year. The vast majority of our participants were Black women (232 of our 256 African American/African descent participants, or 90%).

Additionally, we developed a list of local organizations, community/neighborhood based partners and institutions where Black women are well represented for additional targeted recruitment. Per the parameters and requirements of the engagement effort, we included:

- Large/established/mainstream non-profit organizations
- Grasstops organizations: organizations that address African American women's social and/or health care needs and programs and services that focus on and engage with African American women in a social and/or health context
- <u>Grassroots:</u> African American women who have experienced low birth weight births, infant mortality, and other maternal child health disparities, and others who have had close relationships with these women -10-12 neighborhood, faith- and school-based gatherings

We were diligent and intentional in our outreach to partners, organizations, neighborhoods, and individuals who represent and serve persons along the full spectrum of income, educational, and family composition characteristics to ensure adequate representation of all members of the African American community. Beyond our targeted recruitment within the Foundation's network and connected local institutions, we also relied on a snowballing strategy where we encouraged participants to connect us with other Black women and men in their own personal/family, community, neighborhood, and professional networks. These efforts helped up to engage a diverse set of Black women and men who reflect a variety of socioeconomic, geographic and demographic characteristics mirroring those of segments of the broader population of African Americans in Dane County (see Demographic Snapshot of Black Women Engaged on pages 13-14 and Participant Data Profile in Appendix G, Page 61).





It is important to note that the residents we engaged represent a sample of convenience, not a representative sample of Dane County's Black female and male residents. Engaging a representative sample was not the goal of this engagement process and goes beyond the scope of this initiative. We must also note that participation was entirely voluntary, and participants self-selected themselves. As such, it is likely that the participants in this initial engagement effort reflect a greater representation of individuals who are better connected to local, Black resident-serving community institutions and networks and better positioned to navigate challenges they may face while living here--though our outreach was certainly inclusive of those who are less well positioned. Despite participants' socio-economic standing, family dynamics, or zip codes, we heard and observed general alignment in the themes and experiences they shared.

#### Our Engagement Process

The work of EQT By Design ensured that the engagement process would support open and authentic conversation and communal dialog among participants in a safe and trusted setting. This required that we be considerate of where the engagement sessions were hosted, and that we provide additional supports as needed to make attending the sessions accessible. We hosted sessions in familiar and trusted community spaces—community centers, local service provider spaces (i.e. Urban League of Greater Madison, One City Schools), churches; and other spaces based on proximity to public transportation or walkability within one's neighborhood. In the case of high school students, we organized and hosted sessions in school buildings during or immediately after the school day with the assistance of school staff.

Childcare and transportation support were provided when needed, and a meal was provided in each session. Participants were offered stipends in the form of \$25 gift cards upon completing a session. Each session was two hours in duration, with an occasional session running over to accommodate persons who arrived late from work or who needed extra help completing forms due to challenges with literacy or physical impairment.

We also developed a set of tools and strategies to use in our participant engagement process designed to capture information that was comprehensive and multi-layered. Our tools included a participant survey and a participant questionnaire developed by our team with weigh-in and feedback from members of the Dane County Health Council work group. The work group's suggestions were incorporated in the final versions of each instrument, and all material was reviewed and approved prior to our use with participants. Following is a brief description of each instrument, and copies of each is included in the Appendix:

**Participant Survey** – 50 questions completed by each participant to capture consistent data on personal demographics, health history, health care experiences, family planning and pregnancy, well-being, race, and social determinants of health (see Appendix Apg. 44 - 46).





**Participant Questionnaire** – 20 questions completed individually and followed up with facilitated group discussion. Participants wrote notes (both written and post-it notes) to share their feedback. The questionnaire was designed to help us understand qualitatively how participants viewed their life and lifestyle in Dane County, health and wellness issues and needs around low birthweight and infant mortality, experiences with healthcare and healthcare providers, and relationships and social emotional support (see Appendix B pg. 47 - 50).

**Scribed Engagement Session Notes** - for each session, scribed notes were recorded as an added tool to capture information from the facilitated discussions derived from the participant questionnaire. This design allowed us to hear and refer to "context" and clarity behind comments, to capture participants verbal sharing of their experiences, and to ensure our understanding of participants' insights on challenges and solutions beyond the survey (see sample set of scribed notes in Appendix C pg. 51 - 52. Notes were too extensive to include all in the report).

Our strategy was to collect responses to our quantitative survey and qualitative questionnaire during our engagement sessions. We drew on multiple techniques that allowed us to allocate time for individualized reflection and response, as well as group dialog and processing. An additional benefit of our approach is that it supported information triangulation – a strategy of verifying information which allowed us to use our collected data to inform itself. This process added clarity and/or clarification/correction and expanded on the level of detail shared by participants.

Ultimately, our engagement process made the information we collected much richer and strengthens our confidence in our interpretations and the conclusions we have drawn.





## II. Participant Profile and Characteristics

## Target Audience engagement (22 sessions):

256 participants of Black/African American/African descent/of color/multiracial participants:

- 232 women (60 were highschool age)
- 23 men (3 were highschool age)
- 1 no gender indicated

## Non-Target Data not included:

15 Attendees

- Did not complete their documents
- Not member of the target audience



- 1 session hosted to engage this audience (for total of 23 sessions)
- See questions from this session on page 55, Appendix E)

## **Our Key Partners and Community Reach**

A total of 22 Engagement sessions were held:

- Community Centers (5)
- Neighborhood Leaders and Programs (3)
- Black Civic Leaders and Organizations (6)
- Churches (2)
- Sororities (1)
- MMSD High Schools (5)



<sup>\*</sup>Refer to Appendix G, Tables 1-4 for Participant Demographic Data.

<sup>\*</sup>See Appendix G, Table 7, pg 64 for outreach map and session sites.





### **Demographic Snapshot of Black Women Engaged**

The table below describes the African American women participants in our engagement sessions and provides a snapshot of how they compare based on similar measures from the most current population estimates of Dane County. The data presented in this table suggests that the Black women we engaged reported higher incomes and higher educational attainment when compared with population estimates. However, it was clear in the sessions that the vast majority of women engaged shared more in common in life experiences and cultural congruence than income or education differences could shadow.

Likewise, it was generally observed that despite demographic differences in education and income among the women we did engage, Black women overwhelmingly expressed and identified the same underlying concerns and experiences within healthcare specifically, and in navigating life as women of color confronting racialized experiences individually and in the context of the broader community and society in which they and their families live. This observation is consistent with what we know in the case of Black maternal and child health outcomes -- that higher education and income do not guarantee better birth outcomes for Black women, and that Black women with a college degree are still 3 times more likely to give birth to a low birthweight baby or to die in childbirth than their white counterparts with similar or lower socio-economic status.

# Dane County Demographic Characteristics, Low-Infant Birth-weight (LIB) Sample and American Community Survey (ACS) Estimates

	2018 LIB Engagement Sample		2013-2017 ACS Estimates	
	African American*	Proportion	African American	Proportion
Total	246	96.0%	26,167	
Total Female	224	87.5%	13,142	
Median Age/Age Range	35-44+	51.0%	26.2	
Median Age/Age Range -Female	35-44+	49.5%	26.5	
Educational Attainment (Female, 25-years and over)	150	67.0%	6852	52.1%





Less than H.S. diploma	14	9.3%	673	9.8%
High School Graduate/ GED	19	12.7%	1457	21.3%
Some College or Associate's Degree	60	40.0%	3091	45.1%
Bachelor's or Higher	57	38.0%	1631	23.8%

African American*	Proportion	African American	Proportion
\$50,000 - \$74,999+	58.0%	\$32,328	
213		9,748	
111	52.1%	6024	61.8%
21	9.9%		
44	20.7%	1993	20.4%
1	0.5%	402	4.1%
6	2.8%	363	3.7%
30	14.1%	966	9.9%
	\$50,000 - \$74,999+ 213 211 21 44 1 6	\$50,000 - \$58.0% \$74,999+ \$213 \$213 \$214 \$2.1% \$21 \$9.9% \$44 \$20.7% \$1 \$0.5% \$6 \$2.8%	American*       American         \$50,000 - \$74,999+       58.0%       \$32,328         213       9,748         111       52.1%       6024         21       9.9%         44       20.7%       1993         1       0.5%       402         6       2.8%       363

<sup>\*</sup>In the LIB sample, the category African American consists of all individuals who identified as African American including those who were mixed race and identify as African American. The ACS sample does not include individuals who identify as multiracial, or as Hispanic and/or Latino/Latina/Latinx.





# III. Key Insights - Black Women, Men, Teens and Healthcare & Social Service Providers

The following section provides insights and key data on the feedback of our target population--Black Women, on their overall health status, perceptions of their healthcare experiences, and interactions with healthcare providers. Also included are summarized observations and insights collected by or about men, their experiences and/or their role as members of Black family systems and as partners and/or fathers. Additionally, we include insights collected from teen sessions hosted at five (5) local high schools with young women of childbearing age.

It is important to note that the Black women comprised 90% of participants in this outreach effort, and it is their perspective that we hear most loudly. The insights of Black men, however, as members and extensions of Black family systems were critical to us, and despite their smaller numbers, their voices are illuminated here. Future engagement efforts should allow for additional engagement of adult and youth Black males.

Finally, we close this section with insights from a group of 31 healthcare and social service providers who work closely with Black women and families on a daily basis, and whose feedback was considered valuable to this effort.

#### A. Black Women - Perceptions of Health Status and Healthcare Interactions

Data below is summarized from the 50 item Participant Survey (see Questionnaire results Appendix A pg. 44-46) we administered to focus group attendees, and specifically from questions Q12 - Q48 which aimed to gather participant health history, perceptions of their current health status, and experiences within healthcare systems with healthcare providers.

We are encouraged by the 75% of Black female participants who described their current health status as good or excellent, and with the 64% who are satisfied overall with the care they are receiving. An overwhelming 92% indicated access to public or private health insurance, a testament to Dane County's and Wisconsin's higher rates of healthcare access for Black women than many other states or regions. Eighty-percent (80%) of participants described their interactions with health professionals in Dane County as fairly or very positive, and more than half expressed feeling welcomed (68.5%), treated with respect and dignity (66%), and listened to (61%).

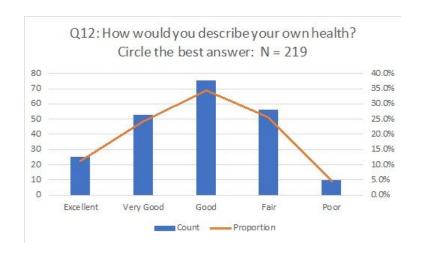
It is critical, however, to interpret this data independently and separately from the responses collected by participants in the Participant Questionnaire and in the facilitated whole-group discussion. What we observed across all of the 22 target audience sessions we hosted, is that Black women and men generally reported mostly positive perception of their current primary care provider in their survey responses, but upon further exploration in their written responses to the participant questionnaire and facilitated group discussion, they overwhelmingly and consistently cited experiences with racial bias at some point in their healthcare journey in Dane County. Many cited





the urgent need for greater cultural competence among healthcare professionals from the front desk to the operating room, for greater staff diversity within health systems that reflect the community and diverse populations served; and practitioners who understand the unique health conditions, risks, and concerns of Black women, families, and communities of color.

This implies that in most cases, Black men and women feel positive about the physicians they choose as their primary care providers. However, the range of other professionals they encounter in their healthcare interactions and over whose presence in their healthcare delivery process they possess less control or choice, do or have at times presented experiences that involve real or perceived racial bias or insensitivity.



#### The Health Status of African American Female Participants (Questions Q13-15,47)

- Ninety-two percent (92%) of Black female participants reported having access to public or private health insurance for themselves (Q15, N = 211).
- Approximately 70% described their health as ranging good to excellent.
- 1 of every 5 African American female survey respondents reported their primary health and wellness concern being related to their weight (Q13, N = 163).
- Thirty-seven percent (37%) of Black female survey respondents reported being diagnosed with a health condition or illness within the last 5 years (Q14, N = 212).
- 1 of every 3 participants reported stressed often, almost always.
   (Q47, N = 211).

#### Maternal and Child Outcomes (Questions Q24-25, 27, 33)

- Sixty-seven percent (65%) of respondents reported either being pregnant before, or currently (Q24, N = 224).
- Among African American female respondents with a prior pregnancy:
  - 83% reported receiving prenatal care for the full length of their pregnancy (Q25, N = 150).





- Approximately forty-four percent (42%) of respondents reporting a prior pregnancy also reported experiencing complications (Q27, N = 158).
- Seventy-one percent (71%) of Black female respondents reported that their healthcare provider did not talk with them about improving their health before pregnancy, or spacing between pregnancies. (Q33, N = 192)

#### Interactions with Healthcare Providers Survey (Questions Q18 - Q22)

- A majority of the African American women in our sample reported positive views of their healthcare provider:
  - $\Box$  64% reporting being satisfied with the care they receive (Q18, N = 216), and;
  - □ Nearly 80% described their interaction with health professionals in Dane County as being either fairly or very positive (Q22, N = 216).
- Black female participants also reported feeling:
  - $\Box$  treated with respect and dignity (66% -- Q19, N = 216), welcomed (68.5% -- Q20, N = 216) and listened to (61% -- Q21, N = 216).
- Q43 is the question in our survey that asks most directly about the role racism may play in healthcare services and treatment. It is also the question that was skipped the most by participants (N = 56 out of 224). We believe this suggests that while many of our county's Black women are encountering racialized and biased experiences in their healthcare interactions as evidenced by their written questionnaire responses and facilitated discussion comments, many of them did not feel comfortable acknowledging that experience as a generalization given other positive healthcare experiences. Furthered exploration is required.

#### B. Insights On Men, Family and Health

Though men were limited among the participants who self-selected to engage in this effort, their feedback was vital. It is also critical to note that the men expressed surprise and gratitude that we reached out to them as part of the engagement effort. Many communicated an observance or experience of feeling excluded or ignored in discussions and local efforts to address and improve Black maternal and child health outcomes, as if men are not a part of the process. These sentiments confirmed for us the critical need for initiatives and solutions to address and improve Black birth outcomes to expand beyond a singular focus on women and babies, and to intentionally include men and fathers as partners and recipients of support.

#### Key insights on men include:

- Black men, though in small number in this engagement (N=23), communicated a strong sense of commitment to their current or future role as fathers.
- Most men in this engagement were presently fathers and some were grandfathers.
   Sixty five percent (65%, N=15) were married or in a committed relationship; 26% (N=6) were single/never married, and 2 (9%) were divorced. Two were high school aged males without children. Sixty-five percent (65%, N=15) were 35 and older, 22% (5) were ages 24-35 and married or with a committed partner with the exception of





1 single male; 9% (N=2) were 18-24 and one male was 17. Ten men (43%) possessed a Bachelor's Degree or higher, 5 had completed some college (22%), 6 completed a high school diploma/GED only thus far (26%), and 2 were in high school (9%).

- Black women and men agree that men are vital, important, significant, and necessary in the life of their families. However, it is clear that their role is inequitable in support, attention, accountability, and in how systems include, "allow" or factor them into policies and practices.
- Black men communicated awareness of the negative stereotypes often attached to Black men as fathers by the broader community and systems, and want to see this narrative changed to acknowledge the presence of engaged Black fathers regardless of marital status.
- Discussion ensued about the dynamics of absentee fathers which came up throughout the engagement session as a stressor for some Black women during and after pregnancy, factors that drive this phenomenon when it is at play; and how systemic, historic racism and inequality and faulty social policies have created or contributed to these dynamics over time in Dane County and beyond.
- Men cited financial stress and insecurity, unemployment and/or under-employment, poor mental health, or lack of family and community support or role models as factors that keep some fathers from being more supportive and available to their child/ren and their mother.
- In citing challenges or barriers to a mother's health before, during and after pregnancy, men cited factors such as lack of prenatal care, lack of health insurance, poor prenatal education and nutrition, lack of support from the baby's father or an inadequate family support system, financial struggles, social isolation, and relationship problems.
- Black men noted that expectant and new fathers are often excluded from pre-and
  post-natal education and support programs and that this needs to change. They
  also noted that young men are not provided an adequate level of pre-parenting or
  fatherhood education/preparation which can present challenges in knowing how
  to support their children's mothers as partners and co-parents. For men who grew
  up without fathers present, such education is all the more vital.
- Black men, like women, cited factors like financial and housing instability, unemployment and under-employment, over-incarceration, under-education and the achievement gap, over-policing/racial profiling and a hostile community culture towards Black men and male youth as stressors impacting Black men, women and their families that require system change. \*See Insights and Needs of Teens and Young Adults pg. 19
- Thirty-two percent (32%) of participants in the survey indicated that they had a relationship and that it was either committed or married.
- In terms of parenting, we heard accounts from women in the facilitated discussion that spoke to highly engaged and supportive fathers; as well as marginally involved or disengaged fathers. Thirty-one percent (31%) of women indicated that the biological father of their child/ren was "very present and active in their lives, or





"somewhat active and present" (12%). Twenty-five percent (25%) of women stated that the biological father was "not active or present, or rarely present."

- In terms of sources of support/core support system, men in the engagement indicated that they rely on themselves primarily, or on the women (partner/significant other) in their life (65%). If not their partner/significant other, men cited other women in their family (sister, daughter or mother) as their primary source of support.
- The data about men's healthcare experience with providers differed slightly compared to women. For example, men responded more positively about their experience with healthcare providers when it came to being "welcomed," and "listened to." (Q20 and Q21). Men and women's responses were similar in that scores went down when asked if they felt listened to by providers (Q21). Men indicated feeling respected and welcomed by healthcare providers (Q19 and Q20) at a higher rate than women.
- Ultimately, due to the small participant size, and given the responses provided by women about the role of men in their life, and the men's own responses--a larger participant sample of men is vital and critical to understanding their perspectives about their roles and needs as partners in efforts to improve Black maternal and child health outcomes.

#### C. Insights and Needs of Teens & Young Adults

Sixty (60) female high school students participated in our structured high school engagement sessions and all were African American or bi-racial youth identifying in whole or part as African American. The participant survey presented some limitations for the teens we engaged given their age, and in most cases, their non-parenting status. However, we did gather important demographic information about their families, their sense of personal and family well-being, and a glimpse of their experience around sexual and reproductive health education and planning as potential future parents.

The open-ended questions and facilitated discussion were most effective in illuminating teens' awareness, perception, and understanding of the issues surrounding the African American low birthweight crisis, and the broader issues impacting their parent(s)/caretakers, families and community. Additionally, they had their own set of unique experiences and insights to share, and were eager to participate, asking in most cases when we would return for more discussions, something they conveyed to be rare and much needed as they navigate their own lives and choices. It was through this process that we gleaned our recommendations around teens offered in this report (see recommendations, Section 7, Community Investments, #6 - 7 on page 39. Also see high school session presentation to MMSD, Appendix F, pgs. 56 - 60).

We do believe that it would be important to engage and reach out to more African American students and to increase the number of male participants to ensure and affirm that the emerging findings presented in this report are representative of a broader student body.





It was clear in our time with the students that they are observing and absorbing the dynamics and pressures faced by adults in their family, and that the impact is just as significant on them personally as it is to the adults and caregivers in their lives. This is particularly important to understand the connections of their growth and development—reproductively, socially-emotionally, and academically—and how they are impacted by social determinants as they grow into adulthood and potential future parenting roles.

It was very apparent that many of the high school participants in the engagement effort were:

- Aware of persons in their family, community or school (including peers) impacted by low birthweight babies and infant mortality, with examples shared.
- Affected by struggling or stressed families.
- Living with stressed parents who are juggling work, financial pressures, and in a few cases, housing insecurity and active homelessness.
- Directly impacted by criminal justice system engagement among their male siblings, fathers, family members, and peers--and for which they expressed great emotion and distress.
- Feeling their school was not socially supportive, in particular-- limited number of consistent, caring, available adults onsite to steward their needs or issues on the topic of reproductive health and related issues that touch family and community. Many, however, cited individual counselors, minority service coordinators or teachers/administrators who were very supportive and instrumental to them.
- Noticing and experiencing what they perceived as racial bias and racialized experiences in school and in community settings. Most communicated high aspirations and plans for college and career after high school, but few felt supported by their school at-large in planning and preparing for these goals.
- Communicating a desire for culturally competent and more diverse teachers and school staff who actively care, intervene, and steward a healthy, inclusive culture for students; and more representation of diversity in curriculum.
- Demonstrating the urgent need for stronger and more effective sexual and reproductive health education that goes beyond basic biology and sexually transmitted disease education to include emotional and relational aspects.
- Actively seeking sexual and reproductive health information from multiple sources including Google, Youtube, peers, family members (sometimes but not usually parents), Planned Parenthood, but needing more education at school.
- Communicating that teens/peers are having sex, often times risky and unsafe, and that more education is needed to prevent STI's and unwanted pregnancies.
   Proper understanding of birth control methods and use was cited by some as a need, illustrated by an example of some young women's overuse of the day after pill/emergency contraception.
- Expressing that current gender roles and expectations heavily emphasize the responsibility of young women in making decisions around sex, pregnancy, and parenting but de-emphasize and require little of young men which they believe contributes to an observed pattern of young men being less ready or willing to take on fatherhood responsibility in the event of an unexpected pregnancy.





• In the case of young women and men who become parents before graduation, participants indicated that the needs of such parents are not adequately met, and in many cases, young parents are left to "figure it out". Connection for young parents, particularly young fathers to school is weak, and preparation for their role as parents/caregivers/providers lacks a connection to concrete post-secondary education and workforce/career readiness and training. A need for stronger programming and education that tangibly helps young parents prepare for a stable future for themselves and their child is needed, in addition to improved sexual and reproductive health education to prevent unplanned pregnancies.

#### D. Key Messages from Healthcare and Social Service Providers

To further explore root causes and solutions for addressing the birth outcomes of Black mothers, babies, and families, we engaged a diverse group of local health care providers, social service workers, and community health advocates in a special session on November 5, 2018. The session was held at the UW Madison South Madison Campus Partnership space. Out of thirty-seven persons who signed up, 31 health professionals, providers and advocates were present. This group of professionals were racially and ethnically diverse in composition with the vast majority presenting as White/European, or of non-African descent--in contrast to the target engagement population.

Attendees represented a host of organizations including local hospitals and clinics, human service agencies, a large healthcare tech company, and local non-profit organizations serving Black women and families among their clients. Attendees indicated their places of employment to include those listed on the table below.

## Agencies (or Professions) Represented in November 5th, 2018 Healthcare & Social Service Provider Session

- 1. Unity Point Health
- 2. Dane County Public Health
- 3. Dane County Nutrition
- 4. Dean Health
- 5. Pediatrician
- Well Badger Resource Center /WI Dept of Health
- 7. UW Health and Hospital
- 8. EPIC Systems
- 9. SAPAR/MMSD

- 10. Home Visiting program
- 11. UW Population Health
- 12. UW Madison
- 13. Center for Well Being
- 14. OBGYN
- 15. Kids Forward
- 16. UW/Meriter
- 17. Planned Parenthood
- 18. Children's Hospital
- 19. WI Women Health Foundation

The feedback from this session was informative, eye opening and a second layer of reinforcement of the messages shared by the target audience. The discussion was shaped around a set of eleven (11) key questions which attendees had the opportunity to answer on their own in written form, and which were further explored in a facilitated whole group discussion. See the list of healthcare provider session questions on page 55, Appendix E.





The following sub-set of questions were prioritized in our full group discussion:

- 1. What factors impact Black Maternal Health the most before, during, and after pregnancy?
- 2. What particular challenges do you hear about in Dane County that have impact on Black Maternal Health?
- 3. What community assets help positively support the health and well-being of Black Maternal health?
- 4. What do you see as the root cause of low-birth weight babies?

Key themes from the discussion expressed by this group around challenges, root causes and solutions included:

- Stress (on women and families)
- Family lack of finances
- Systemic inequity
- Health/service system perceptions of Black Women
- High cost of housing and affordable childcare
- Lack of transportation

- Heavy burden on the woman
- Physical and emotional burdens
- Need more diversity reflected in healthcare and social services staff
- Need more culturally competent health care
- Lack of transportation

#### Specific quotes from the session with the providers:

- "Inequity how Black Mothers are treated in the hospital; perception of them being less ... how they are perceived, treated, the information they get (less and less complete); as a result, Black Mothers have a lack of faith in healthcare system."
- "Health systems perception of "non-compliance" and not aware of all the pressures mom is experiencing."
- "Systems that families need to navigate often hurt families more than they help; aren't set-up to assist them".
- "Transportation lack of it to get where they need to go --- limits their perception of access to services they need."
- "Barriers exist in accessing the resources (they need) or (they) think that it is not for them / lack of knowledge of resources and services."
- "The load is resting on the woman's shoulders -- been systematized over decades and so a vicious cycle continues."
- "Stress impacts high income family members -- because they [are expected to] raise the station of the whole family and carry the burden -- physical, emotional cost."
- "History of trauma and how that plays out in assessing services or growth."





- "Racism and the experience of it itself and the impact [is a root cause] of it. Slavery for example."
- "Employers who pay a living wage can impact health / need to boost up the wages and ensure they know their role."
- "Get people within large systems to be ambassadors of change then can help be a voice to challenge systems -- Institutional change agents."
- "Need culturally competent staff in spaces where they are working with community partners...seeking Black Leadership -- [must address] distrust with health care systems ... who is approaching who!"
- "Increase diversity in the health care system."





## IV. Summarizing Themes

In reviewing participant responses as a whole through the three triangulated feedback channels we used (participant survey, open ended participant questionnaire, and facilitated group discussion), and layering on the feedback from healthcare professionals and social service providers, a clear message and set of themes emerged. What we heard definitively from Black women and men is that the poor birth outcomes of Black families are, in their eyes, driven by larger social and economic forces at play that exert pressure and persistent stress on their lives as individuals and family units.

Their responses confirm what we know and what is best illustrated by the **County Health Rankings Model** graphic (below) developed by the University of Wisconsin Population Health Institute (2014)— that larger social, economic, and environmental factors commonly referred to as **social determinants of health**, play a significant role in the health outcomes of a population or community. We reference this model given its relevance in conveying what we have heard from participants in this outreach effort, and due to its adoption as a guiding framework for the work of the Dane County Health Council. Subsequently, it is our assertion that solutions that effectively disrupt and eliminate disparities, including but not limited to the poor maternal and child health outcomes of Black women and their partners, must address the systemic inequities that impact family well-being and security.

Further, it is essential that the following five assertions drive efforts to address root causes of overlapping disparities. These assertions and the subsequent themes we heard throughout the 23 engagement sessions hosted shape the comprehensive set of recommendations we propose at the end of this report:

- 1. The UWSMPH County health rankings model identifies the single largest contributor to health outcomes to be social and economic factors. The messages and experiences we heard in this engagement confirm that Black women view socio-structural factors as core elements in shaping their health and the health of their families and communities.
- 2. There is a critical need to center black women's health and wellbeing not only in relation to their being mothers or potential mothers, but also on their identity and positioning as one central part of a whole of Black family systems, communities, and as community members at-large. Black women's maternal and child health outcomes will improve as Black family and community well-being improves.
- 3. The engagement process also reflects that the other contributing 60% of factors in the County Health Rankings model (Health behaviors, Clinical care, and Physical Environment) cannot and should not be viewed separately or apart from the core driver of social and economic factors, as each is impacted and shaped by social and economic inequities that disproportionately impact Black families in Dane County.
- 4. Missing from the UWSMPH model are systemic and cultural drivers such as racism, bias, institutional discrimination, prejudice, stereotyping, and marginalization, which based on participant feedback, play a central and persistent role in shaping the quality of their lives, health, and access to opportunities.

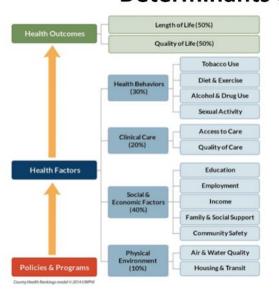




5. To truly make progress on improving the birth outcomes of Black women and babies, we must move upstream to intentionally address root causes (social, economic and cultural factors). If we don't, we will continue to swim against the current and recycle the same patterns of disparity at the ultimate cost of losing the lives of Black babies.

## The County Health Rankings Model

## Root Causes Rest in Social Determinants of Health



Effective and sustainable solutions to improving Black maternal and child health must address these key drivers with emphasis on social & economic security.

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**OUR CONCLUSION:** Solutions are needed that address the whole life well-being of Black families, **in addition to specific healthcare initiatives to address maternal/child health.** 

#### A. Critical and Consistent Themes

Based on the aforementioned information gathered from participants in the surveys, open-ended questionnaires, and facilitated group discussions, we crystallized **10 core themes** that emerged consistently and persistently across all sessions--and most notably raised and expounded upon by participants in the facilitated discussions.

These 10 key factors cited by Black women (and men) that heavily impact their quality of life and health in Dane County, including the quality of their pregnancies and the health of their babies can be summarized by the following, culminating in the final theme of chronic stress:





## 10 Critical and Consistent Themes: Drivers of Low Birthweight Babies and Maternal and Child Health Disparities in Dane County's African American Community

- Racism, discrimination and institutional bias
- Bias and cultural disconnect in healthcare delivery experiences
- Economic insecurity
- Housing insecurity and high cost of living
- Poor access to health-supporting assets

- Inadequate social supports
- Gaps in health literacy, education and support
- Disconnected and hard-to-navigate community resources
- Systemic barriers to individual and family advancement
- Chronic stress

In the pages that follow, we provide a summary of each key theme supported by participant quotes and related survey data where relevant and applicable.





#### 1. Racism, Discrimination and Institutional Bias

In the open-ended questionnaires and facilitated group discussion, participants clearly identified racism, discrimination, bias, racialized experiences and subsequent stress and trauma as key drivers of the poor birth outcomes impacting Black women and their babies, born and unborn. Black women communicated an experience of carrying the stress of the entire family unit or extended family unit on their shoulders and in their bodies given their central role, not only as mothers and caretakers, but as equal and often sole breadwinners and stabilizing forces in families that have been historically undermined by systemic racism and subsequent economic inequities. This stress on Black family systems, imposed by-and-large by outside forces--and resulting often in African American men's/fathers' compromised social and economic position as providers and partners--increases the burden of stress, responsibility, and economic insecurity endured by women and families. This in turn strains the physical and mental health of Black women, pre-and-post pregnancy, impacting the health of babies. Participants conveyed these dynamics irrespective of income, education, or

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relationship status, and spoke to this reality in their own words as the core threat to Black family and community health and well-being.

Understanding this framing and the systemic cycle it illustrates, as best conveyed by participants in this engagement, is critical and essential to unpacking and addressing the root causes of Dane County's Black low birthweight crisis and disparate Black maternal and child health outcomes. The persistent and unmitigated impact of structural racism, inequality, and the resulting dynamic of racial disparity in Dane County, past and present, on Black families and on Black women and their babies as extensions of the Black family unit, cannot be understated, ignored, or minimized. Further, participant feedback indicated that:

- Racism, discrimination and bias impact and shape the daily lives and experiences of Black women, men and youth as individuals and as families.
  - They experience racism, discrimination and/or bias in all systems that they and their families interact with (i.e. employment, workplace, housing, education, social services, healthcare, law enforcement).
- Participants cite an overall negative perception of Black women, men, and families in Dane County which poses barriers to their well-being and advancement. Examples of common assumptions/perceptions/behaviors by systems and community, communicated by participants in discussion:
  - o that African Americans don't value family, marriage, or education
  - o that all Black women are unmarried and on welfare
  - systems value married women/"intact" families over single women; judging single Black mothers differently and more harshly; yet social service policies often hinder intact families through penalizing women for the father's presence.
  - that Black men are disengaged and absent in their children's lives
  - that Black youth, males particularly, are dangerous and criminal-minded
  - that Black children are not learners
  - that low income status means you're ignorant, uneducated or lazy
  - that Black professionals earned their way through affirmative action, not personal competence and hard work
  - that Blacks are financially irresponsible
  - o condescending tone and behavior during process of service delivery as if one is illiterate or cannot comprehend
- Young people recognize, observe, and experience these realities in their daily lives, indicating how racialized experiences are passed on generationally and at an early age. Intervening early to disrupt this transfer is crucial.

#### Participant Post-It Note Responses

"Stigma that everybody is the same (based on race) ... and it (being Black) is negatively perceived"

"In general -- everything is given or not given based on bias --cherry pick who gets the info --- race, info, and who you know".





"Organizations are run by white people and biases are attached to it as are the policies. Not used to seeing professional people of color."

"Doctor assumes other things (family or lifestyle) about myself or my children."

"Nurse assumed I was a single mother without asking, though I am married to the father of my children and indicated this on intake forms."

#### Participant Survey Responses

Q43: Do you feel that your race/ethnicity has ever impacted your healthcare services or treatment?				
<ul> <li>194 out of 256 responded</li> <li>75% response rate</li> </ul>	<ul><li>Yes 39%</li><li>Not Sure 27%</li><li>No 35%</li></ul>			

#### 2. Bias and Cultural Disconnect in Healthcare Delivery

- Even with positive healthcare experiences, most overwhelmingly express the presence of bias at some point in their interactions with healthcare professionals.
- Their voices are often not being heard or taken seriously when expressing their health concerns, needs or ailments.
- Many feel race, gender, income and the negative stereotypes attached to these can and have harmful impact on the quality of care they receive.
- Many expressed feeling that those with BadgerCare or Medicaid versus private insurance receive lower quality care and are treated w/less respect.
- Historical distrust of the medical establishment does not help.
- Most cite the need for professionals of color at every level, and cultural competence/anti-bias training for providers.

#### Participant Post-It Note Responses

"Black women have to trust provider regardless of provider, more black healthcare providers, trusted credible navigators to help trust providers"

"I feel that healthcare providers thought I could "tolerate" pain more than I wanted them to."

"Going to a healthcare provider makes me uncomfortable."

"No Black health care providers in healthcare in any area that they searched."





#### **Participant Survey Responses**

Q19: Do you feel that you are treated with respect and dignity by your healthcare provider	<b>Q20:</b> Do you feel welcomed by staff when you visit your healthcare provider's office?
<ul><li>1 out of 3 said "No/Sometimes"</li><li>250 out 256 responded</li></ul>	<ul><li>1 out of 3 said</li><li>"No/Sometimes"</li><li>248 out of 256 responded</li></ul>

#### 3. Economic Insecurity

Financial stress and economic uncertainty were noted among the top sources of stress impacting Black women and families as they navigate daily life, pregnancy, and parenting. Participant discussion centered around the following:

- Money stress and financial insecurity is a significant factor in quality of life for Black women and families in Dane County.
- Stressors related to employment (unemployment, under-employment, work/workplace culture, making a living or securing a "good job") are high for individuals and within extended family systems.
- The experience of working several jobs to make ends meet is too common—yet, still not getting ahead. Many Black women communicated working 2-3 jobs even when pregnant.
- Financial pressure exerts stress on expectant mothers, their partners, and the entire family system.
- Black men and male youth in Dane County face higher unemployment rates than others, impacting their potential to achieve stability and act as breadwinners.
- Persons with college degrees point to workplace discrimination and bias that impacts their mobility/promotion potential at work despite experience and tenure.
- Feeling of being stuck and in constant chronic survival mode.
- Individuals who do well financially feel pressure and responsibility to support relatives
  and extended family who are not doing well; participants communicated this as a
  key facet and expectation of Black life (i.e. the "Talented tenth) that adds an
  additional layer of stress, especially to Black women who are often heads of
  household and primary breadwinners.

#### Participant Post-It Note Responses

"[We need] economic support amongst and between ourselves to help build financial capacity ... we need to support each other as Black people."





"Racial and economic disparities and how it trickles into other areas of life (knowledge, who is listened to, who is respected, who counseled well, and who gets opportunity)."

#### **Participant Survey Responses**

#### Q41: Services accessed in Dane County. (Circle all that apply)

- ✓ 152 respondents\* -- > 80% response rate
- ✓ 57% at some time received WIC/Foodshare
- ✓ 47% at some time were under Badgercare/Medicaid
- ✓ 28% at some time received SNAP/TANF

## Q45: How would you describe your current financial situation. (Circle all that apply)

- 234 out 256 responded
- 91% response rate

66% said "living paycheck to paycheck" or that "money was a major stressor"

Length of time living in Dane County 18 years (average)

#### 4. Housing Insecurity and High Cost of Living

Most in this engagement were stable in housing (81%) and those who were not were lower income, though many among each group communicated a present or past experience of housing insecurity or homelessness for themselves of family members. Nearly all referenced the high cost of living and housing as a major concern and as a hurdle for their families and families in general. Persons of lower income cited housing insecurity as a major stressor and barrier to stability and well-being. Seven percent (7%) of participants were actively homeless and 9% indicated having housing presently but fearing they may lose that housing. Other insights shared included:

#### Rising rents make securing and keeping stable housing difficult for many

- Gentrification, unemployment and underemployment contributes to the problem
- Concerns expressed about Black residents being priced out of neighborhoods even in communities where they have historically lived like Park Street/Southside, East Washington/Darbo, and others.
- o Sense that new development is not meant for them.
- Great need exists for more low to moderate income housing across area
- Some observe Black families being priced and pushed outside of Greater
   Madison to suburbs due to high cost of housing where there is even less

<sup>\*</sup> did not include high school aged respondents or those who did not respond





racial/ethnic diversity, reliable transportation, or readily accessible services (heard this from women in Stoughton and Sun Prairie)

#### • Discriminatory housing policies and practices:

- Perpetuated by property owners, landlords, and neighborhoods and upheld by city and county laws/policies.
- Landlord intimidation is high, and particularly in higher need.
   neighborhoods like Allied, Lussier/Wexford, Darbo, and others; very little support to address this issue and little accountability for property owners.
- "Slumlord" conditions exist in many Madison neighborhoods though landlords not held accountable.
- Communities and neighborhoods are segregated though no one wants to acknowledge it or why.
- This is correlated with significant housing insecurity which impacts homelessness or risk of eviction.
- Often mentioned was greater financial empowerment and literacy for Black families to build the capacity to become homeowners versus renters.

#### Participant Post-It Note Responses

"That's a good question, education, biases, lack of access (Housing, food, support, transportation)"

"Jobs and housing - male partner not accepted on the lease and so not able to keep housing"

"Unfair housing practices - the landlord - able to deny you for too many reasons."

"Living in hotels due to seeking housing - private owners, the big companies - they blackball you and won't give you an apartment."

"Have to 'luck up and pray.' Especially if have been blackballed -- housing insecurity -- no forgiveness especially if have been here a long time.

#### Participant Survey Responses

- 16% of participants "housing insecure" or "no housing"
- 40% of participants income less than \$25,000





#### 5. Limited access to health-supporting assets

- Dane County is a safe, clean, and family friendly place to live overall
- Yet many areas lack access to health-supporting assets like:
  - Quality food/grocery stores, describing some neighborhoods particularly where large numbers of low income people of color live as "food deserts", or lacking reliable transportation to reach food outlets easily especially for those who do not have cars.
  - Quality and affordable childcare
    - Childcare costs are a major financial burden
    - Many women/families are traveling far from where they live to take young children to daycare; especially difficult if using public transportation
    - Many who don't qualify for childcare assistance are relying on family, friends or significant others to care for young children
  - Well-maintained parks and green spaces often neglected and not kept up by City Parks Department
  - Robust public transportation
    - Needed to easily access living wage employment opportunities especially those that are further out from where they live
    - Want transportation planning and routes that benefit all residents and neighborhoods, not just the most privileged or young professionals living downtown

#### Participant Post-It Note Responses - Challenges and Needs

"Lack of healthy food or knowing what is healthy or access to it."

"A strong support group and eating healthy."

"It is cheaper to live out there...but does cause transportation issues...and it does create isolation"

#### **Participant Survey Responses**

Q41: Services accessed in Dane County. (Circle all that apply)				
✓ Less than 22% of respondents had ever accessed  ☐ Breastfeeding help ☐ Prenatal ed/classes ☐ Postpartum visits ☐ Childcare Assistance/ Head Start ☐ Section 8  * did not include high school aged respondents or those who did not respond				





#### 6. <u>Inadequate Social Supports and Isolation - and Domestic Violence</u>

- Women frequently conveyed a lack of adequate support systems and overwhelm.
- Feelings of isolation before, during and after pregnancy are prevalent.
- Many are living in Dane County without extended family systems; many moved here for a better life, but did not bring support system along.
- Relatives and natural family support system who are near are stressed, as many
  are trying to survive and stay afloat, and therefore limited in their capacity to
  help mothers.
- This is compounded by quietly hostile environment where they are perceived in a negative way by the majority community and the systems/agencies with whom they interact, including healthcare and social service systems.
- Additionally, and critically, 17% of Black women (N=29 of 172) with prior
  pregnancies completing the Participant Survey reported a previous experience
  with domestic violence during pregnancy. Given the prevalence of domestic
  violence during pregnancy and multiple family stressors, this prompts a need for
  stronger screening methods at time of patient intake, connection to community
  protections and supports, mental health services, and promotion of efforts to
  break the silence and stigma in the Black community around reporting and
  discussing domestic violence and its deleterious impact on Black women.

#### Participant Post-It Note Responses

"I like the beauty and nature, activities for kids, safe in the same ways...[don't like] silent racism and silent approach of its impact including social isolation."

"Black women living in isolation; both young and older women"

#### **Participant Survey Responses**

- 1/3rd of participants felt "sometimes or rarely" supported
- 44% of participants were from Wisconsin
- 33% were from Illinois
- 22 % outside of WI and Illinois

Q21: Do you feel listened to by your healthcare provider or doctor?				
<ul><li>246 out of 256 responded</li><li>97% response rate</li></ul>	Sometimes 30% No 9% Yes 59%			

Q31: Have you experienced domestic violence during a pregnancy?





<ul> <li>172 of 256 responded</li> </ul>	Yes	17%	
<ul> <li>67% response rate</li> </ul>	No	81%	
	Prefer not to c	inswer 2%	

#### 7. <u>Health Literacy</u>, <u>Education and Pre/Post Pregnancy Support</u>

The need for greater health literacy and education was clear, and support for expectant mothers, fathers and families pre-and-post pregnancy. There was limited knowledge about existing pregnancy support initiatives and programs like Centering Pregnancy, and many women communicated little interaction or guidance from healthcare providers about pregnancy planning.

- Need for more pre/post pregnancy support and education is clear, especially with 44% of mothers reporting prior pregnancy complications (Q27); 9 women (5%) having given birth previously to a stillborn baby (Q29), 10 women (6%) having lost a child within the first year of the child's life (Q30), and 25% (43) reporting previous miscarriages.
- General health literacy and promotion on healthy behaviors and habits needed, i.e. how to eat, keeping regular appointments, prepping for healthy pregnancy). Seventy-one percent (71%) of women reported not being talked to by their doctor about preparing for a healthy pregnancy (Q33); (70%) of mothers say they did not plan their previous pregnancies (Q32).
- Tangible supports to new, young and first time mothers especially important, and more education to younger mothers who may be engaging in risky behaviors (i.e. smoking, drinking, recreational drug use, poor nutrition, insufficient rest) while pregnant.
- Absence of family, and partners contribute to mothers' stress and subsequently the health of the babies.
- Significant need for **culturally competent** pre/post pregnancy support programs and more diverse staff expressed (i.e. in programs like Centering Pregnancy, home visiting, prenatal education classes and amongst midwife pool.
- Most participants had not heard about Centering Pregnancy; those who did cited a lack of diversity in the staffing of persons leading these groups.
- Also expressed was the need for more timely appointments.

#### Participant Post-It Note Responses

"Not listened to when describing symptoms."

"Not listened to and them not being willing to support my decisions about my body."





#### Q23: How to Make Experience Better with Health Care Providers

- Culturally competent providers
- Diverse Providers
- Listen & acknowledge my questions and concerns
- Care about my wellbeing

#### 8. Resource-rich but hard to access

Participants by and large agree that Dane County is a resource rich community and that this is a major asset. They expressed positive sentiments toward a culture of support for families, particularly struggling families, and an appreciation for a community culture and plethora of agencies committed to giving families a helping hand. However, there was a sense that services are disconnected, uncoordinated, hard to access, and hampered by red tape and competing qualifying requirements.

- Dane County is known to be a resource-rich community, but resources can be difficult to access.
- Resources are scattered, not well aligned, and require one to "jump through many hoops"
- Persons with limited transportation or computer access face particular challenges.
- Many desire fewer or a single access channel, and less red tape and problematic qualification criteria.

#### Participant Post-It Note Responses

"Great resources if you know how to access them."

"Sometimes I feel there are resources but only certain people are invited to participate in them."

#### 9. Systemic Barriers to Advancement

Participants across all sessions consistently cited systemic barriers present in their daily experiences and those of their families and communities. Despite general agreement that there are many services and supports available in Dane County for struggling individuals and families, comments on the open ended questionnaire and facilitated group discussion expressed a pattern of persistent disadvantage that plagues general advancement of Black families in the county, keeping a pattern of struggle and high levels of generational poverty in place.

There were several times throughout the engagement sessions where feelings of "the system keeping you trapped", blocking opportunity, or impeding personal and family cohesion and independence were conveyed. In sessions that included a higher number of persons with lower incomes, these sentiments were expressed most





passionately. Following are our summarized interpretations of how feeling "trapped" and undermined by faulty system policies manifested in participant comments.

- Many believe that Dane County systems and service agencies reinforce a culture of dependency and poverty among Black families. Services designed to provide support are needed but should not be needed forever if the system was truly helping people to elevate their social and economic position.
- Many cited policies that penalize mothers/parents by removing income, housing, or childcare assistance safety nets immediately (versus incrementally) when they experience slight increases in income/employment status. This, they feel, often deters women from pursuing greater opportunities or education out of fear of losing basic necessities like housing and childcare--hence sustaining the high and disproportionate poverty levels experienced by Black families and children in Dane County.
- Some cited being discouraged from working by providers to in order to keep benefits, a trend they believe keeps many Black families in a pattern of dependence.
- Policies that penalize unmarried women when their children's fathers or male partners are present in the home were mentioned frequently (often resulting in loss of critical family-stabilizing benefits for low-income families), in addition to faulty child support policies that create adversarial dynamics between mothers and fathers and often lead to criminal justice system involvement of Black fathers; and a statewide Birth Cost Recovery (BCR) policy that further magnifies financial instability for non-custodial fathers, or penalize mothers with healthcare coverage loss if they refuse to provide father's names. Such policies deepen many men's struggles to financially support their children and create strained family dynamics.
- There was a general sense that participants want policy and service models that emphasize empowerment, capacity-building and increasing family wealth.

#### Participant Post-It Note Responses

"There are barriers and people are not willing to help".

"This community keeps you down even with a degree ... it is very difficult to cut the barriers that are in place due to racism."

"Systems wear you down until you stop trying...no one is on your side or advocating for you."

"Feeling of a systemic trap around wage and income / key support is lost when a little bit of additional income increases -- ex: dishwasher to cashier, a bump in income but lose benefits."

"Systemic racism is keeping black men from their families and children and creating a broken cycle."

"Opportunities and barriers in service work and difficulty advancing."





### 10. Chronic Stress

Ultimately, participants communicated a looming state of stress in "living while Black" in Dane County. This stress is characterized by a sense of working against the tide to overcome entrenched barriers while working to secure opportunities that result in upward mobility and economic stability, and to achieve well-being for themselves and their immediate and extended families. These stressors were clearly identified as driving forces behind Black birth outcomes, but active in other areas of their lives where they felt the impacts of implicit or explicit bias (education (personally or per their children's experiences), work and employment/career advancement, navigating social or community services, interactions in professional, social and recreational settings, etc.), all requiring a constant state of advocacy and vigilance. In summary:

- The collective impact of persistent racism, discrimination, bias, economic insecurity, social isolation, and barriers to opportunity and advancement = stress.
- Chronic stress contributes to strained physical and mental health, family dynamics, and a state of survival versus living and thriving.
- These cumulative factors outlined in the preceding 10 themes place Black women's pregnancies and babies--unborn and newborn--at greater risk.

### Participant Post-It Note Responses

"Stress = lack of mental health, lack of support, lack of sleep, microaggressions, housing, partner support, family support."

"Stress and (impact on) mental, physical and spiritual well-being of Black mothers is causing poor birth outcomes".

### Participant Survey Responses

Q47: Which Best Describes Your Stress?				
7% <b>34%</b> 29% <b>24%</b> 6%	Stress Free Stressed at Times Stressed Often Manage my Stress No Response			

Q45: How would you describe your current financial situation.					
<ul><li>234 out 256 responded</li><li>91% response rate</li></ul>	66% said "living paycheck to paycheck" or that "money was a major stressor"				





# V. Implications of What We Heard for Solutions

- 1. Improved Black maternal and child health outcomes and general health equity won't occur without intentionally and deeply addressing systemic racism, barriers, and inequities that impact Black family systems; a deep investment is required.
- 2. Solutions must be broad and cross-sector beyond healthcare partners (private sector).
- 3. Alignment of efforts across health systems and other sectors is crucial to make real impacts and to move needle on disparities.
- 4. Siloed programs and initiatives within and between the Health Council members need a common set of measures.
- 5. Health systems/Council must change how you talk about "health" in order to spur cross-sector work to address larger social determinants that impact and drive health.
- 6. Health Systems and Health Council members must determine your role in advocacy and policy change to achieve desired conditions that specifically contribute to improved maternal and child health outcomes for all, and broad health equity.

## VI. Proposed Next Steps and Role for FFBWW & EQT By Design:

- 1. Assist in design and strategy for DCHC on next steps for Phase 2.
- 2. Develop and move forward on an action plan based on recommendations proposed in Phase 1.
- 3. Integration of the action plan into the work of the Health Council and its member organizations.
- 4. Assist in implementation of specific community engagement efforts that convene and engage the Black community and related community partners.
- 5. Assist in development of a sustainable model for Dane County Health Council members to continue the work.



"Black Women will achieve health equity when there are no social, economic or political barriers to keep us from living our best lives".

> --Linda Goler Blount, President Black Women's Health Imperative

( 2018 Black Women's Wellness Day Keynote Speaker)





# VII. Multi-Year Plan Recommendations

## A. Internal Health System actions

- 1. **Expand promising Initiatives** (i.e. Centering Pregnancy, Home Visits, expansion of Doulas and their presence in hospitals/clinics)
- 2. **Prioritize cultural competence** and workforce diversity in all current programs (Centering, Midwives, Prenatal Ed Classes, PHMDC)
- 3. **Root out racial bias** and invest deeply in efforts that embed equity in the member organizations
- 4. Root solutions in highest need zip codes.
- 5. Continue to **invest in and partner deeply** with existing community-based efforts and organizations that address health disparities and well-being in the Black community
- 6. **Align efforts**, initiatives and Community Health Needs Assessments (CHNA's) across systems for greater systemic impact

## B. Community Investments

- 1. Create a Black Maternal and Child Health Dashboard
- 2. Care Coordination: Go forward with care coordination/resource sharing system for better patient connections with community resources and services. In addition:
  - i. Consider incorporating the <u>1 Key Question</u> at time of patient intake to assess woman's reproductive plans, prompting pre-pregnancy support or discussion of contraception options
  - ii. Screen for domestic violence at point of every patient intake, particularly but not exclusively for pregnant women, to promptly identify, intervene, assist, and refer to appropriate support and protective services.

### 3. Expand African American Doulas

- i. Develop payment pathway (public/private and Medicaid)
- ii. Establish Doula Training Fund
- iii. Pilot model that integrates Doulas in Maternal Child Health/ pre and postnatal care delivery

#### 4. Fund the Annual Wisconsin Black Maternal and Child Health Summit

- i. Start and fund annually
- ii. To share and highlight the issue, best practices, solutions and to spur collaboration
- iii. April 2020 launch





### 5. Establish the Black Maternal and Child Health Task Force

- i. Create independent body of community stakeholders
- ii. To assist with systemic work and alignments across agencies and sectors
- iii. Partner with Fetal Infant Mortality Review Board (FIMR)

### 6. Fund Phase 2 Engagement to include:

- i. Neighborhood-based education in high need zip codes
- ii. Develop Neighborhood based Action Teams/Healthy Birth Ambassadors (and work with Black churches more deeply)
- iii. Engagement that intentionally includes Black fathers and informed by the Black male perspective as a parent and a support to their family.

### 7. MMSD: Teen Education and Support Component

- i. Improve sexual and reproductive health education
- ii. Mentor and create social supports
- iii. Embed in Black Excellence initiative
- iv. Both high school girls and boys

### MMSD: Overhaul School Aged Parents Program (SAPAR)

- v. To be more effective and culturally relevant
- vi. Hire diverse staff reflective of student body
- vii. Focus on aspirational life goals, career preparation for 21st century economy, economic independence and self-reliance
- viii. Consider the frame of Pathways Model or AVID

# C. System and and Policy Actions

- 1. Reframe and tie "healthcare" to economic and regional advancement
- 2. Include and Engage Black Men/Fathers/Partners and Family Systems in Maternal-Child Health Solutions
- **3.** Convene Cross-Sector Partners -- strategically convene and collaboratively address social determinants of health; and drive systemic alliances that generate:
  - i. Economic and income security/living wage work for Black families
  - ii. Affordable housing and housing security
  - iii. Equal employment opportunity
  - iv. Workforce/career development solutions and education access esp. for single mothers
  - v. Affordable childcare & robust, accessible transportation
  - vi. Sensible human services policies (that strengthen, elevate, stabilizes families)





- vii. Restructure/extend grace periods for benefit programs like housing, foodshare, childcare etc.
- viii. Implement policy and service models that emphasize family empowerment, capacity-building, and economic stability.

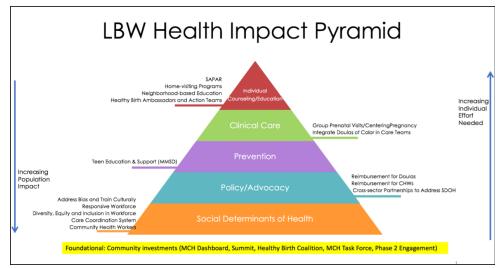
### 4. Advocacy and Alliances for public policy

- i. Favorable Medicaid policy (Doulas/Cmty Health Wkrs)
- ii. Extension for paid Medical Leave
- iii. Extend Medicaid coverage for extended Postpartum coverage

### 5. Prioritize Diversity, Equity and Inclusion (DEI) commitment

- Establish DEI leadership Infrastructure across each member organization
- ii. Achieve workforce diversity from top to bottom of organization
- iii. Embed within maternal child health programming especially customer service and bedside engagement that touch Black women and families
- iv. Implement provider education that generates unique awareness and information for care delivery when working with Black mothers and families (See CA effort)
- v. Require professional development, growth, and training at every level of staff who engage with Black women/families. (specifically Cultural competence and implicit bias)
- vi. Tie DEI to performance excellence expectations

# Dane County Health Council LBW Impact Pyramid with FFBWW-EQT By Designs Recommendations



Adapted by Dane County Health Council from: Frieden T. American Journal of Public Health | April 2010, Vol 100(4).





### About the Foundation for Black Women's Wellness

Established in June 2012, the Foundation for Black Women's Wellness is a Wisconsin based non-profit organization committed to eliminating health disparities and other barriers impacting the lives of African American women and girls. The organization engages Black women of all ages in health promotion, education, and advocacy programming year round, and works with health systems and community partners to create the conditions that enable Black women and families to thrive. Visit our official site at www.ffbww.org.

## **About EQT By Design**

EQT By Design, LLC works to ensure inclusion and engagement is front and center in their work. Annette Miller has 25+ years of strong professional policy and analytic skills, a wide network within Madison and Dane County's diverse populations. She works as a strong connector between community, business, government and nonprofits to develop and implement ideas and strategies that are inclusive, resilient and evolve into a strong community backbone. Visit www.eqtbydesign.com







## **APPENDICES**

Appendix A - 50 Question Survey for all participants - page 44-46

Appendix B - Community Engagement Questions - page 47-50

Appendix C - Participant Sampling of Responses -page 51 - 52

Appendix D - Low Birth Weight Engagement Sessions and Schedule -page 53-54

Appendix E - - Engagement Session Questions for Healthcare Providers - page 55

Appendix F -MMSD Student Engagement Presentation & Key Messages -page 56-60

Appendix G - Data Charts and Statistics of Participants -page 61





## **Appendix A - Participant Survey**

# African American Infant Low Birth Weight Project PARTICIPANT SURVEY w/ RESULTS

[N= 256 unless otherwise noted differently]

Question	Response Results		Question	Response Results
	PERSONA	L INFORMATION	ON/DEMOGRAPHICS	
How did you learn about today's session?			Fill in the blank answer - not retrieved	
Which best describes your racial/ethnic identity? Circle all that apply.	African American/ Black/ African Multiracial Prefer not to answer	90% 7% 3%	City & state where you were born?	WI = 44% IL = 33% Other = 22%
What is your gender?	Female Male	91% 9%	How many years have you lived in Dane County?	Fill in the blank answer - not retrieved
Annual household income (Circle):	a) less than \$10,000 b) \$10,000 - \$24,999 c) \$25,000 - \$49,999 d) \$50,000 - \$74,999 e) \$75,000 - \$99,999 f) \$100,000 or more	23% 18% 21% 15% 4% 9%	Number of People in your household?	Fill in the blank answer - not retrieved

African American Infant Low Birth Weight Project PARTICIPANT SURVEY w/ RESULTS

[N= 256 unless otherwise noted differently]

Your Current Education Level (Circle)	Less than high school diploma Associates degree PhD/Doctoral or Higher High School diploma/GED Bachelor's Degree Some College Master's Degree	6% 6% 1% 13% 6% 17% 9%	Current relationship status?	Engaged NA Married 21% Committed Part.(not married) 11% Single (never married) 48% Single (incl. Div,Wid) 16%
		HEALTH HIS	TORY	
How would you describe your own health? Circle the best answer:	Excellent Very good Good Fair Poor	11% 27% 32% 26% 4%	What is your primary health and wellness concern right now?	WEIGHT
Have you been diagnosed with a health condition or illness within the last 5 yrs?	Yes No	37% 63%	Do you currently have health insurance coverage for yourself?	Yes 85% No 10%
Do you currently have health insurance coverage for your family members or dependents? n=203	Yes No	77% 23%	Who do you rely on most in your life for support?	Family/Friends _Wife/Husband/Partner





# African American Infant Low Birth Weight Project PARTICIPANT SURVEY w/ RESULTS

[N= 256 unless otherwise noted differently]

Are you satisfied with the care you receive from your primary health care provider or doctor? N=242	Yes No Sometimes Not Response	66% 6% 25% 5%	Do you feel that you are treated with respect and dignity by your healthcare provider or doctor?	Yes, Always Sometimes No	66% 28% 5%
Do you feel welcomed by staff when you visit your healthcare provider's office?	Yes, Always Yes, Sometimes Not Really No	67% 25% 5% 2%	Do you feel listened to by your healthcare provider or doctor?	Yes, Always Yes, Sometimes Not Really No	61% 30% NA 9%
Overall, how would you describe your interactions with healthcare professionals in Dane County?	Very positive Fairly positive Somewhat positive Negative No Response	37% 41% 18% 2% 2%	What is one thing that would make your experience with health care providers better in Dane County? Explain briefly.	Culturally Competer Diverse providers a Listen and acknowle concerns and quest Care about my well	nd staff edge my ions
Have you been pregnant before?	YES NO	67% 33%	For prior pregnancies, did you receive regular pre-natal care? N=172	Yes, for full length of Yes, for a portion of p Only for a few months No, I did not receive of	reg. s of preg.
How many children have you given birth to?	Fill in the blank answer - not	retrieved	Have you had complications with a current or previous pregnancy? n=172	YES NO	44% 56%

[-3

# African American Infant Low Birth Weight Project PARTICIPANT SURVEY w/ RESULTS

Have you had a miscarriage before? N=172	YES NO	25% 75%	Have you given birth to a stillborn child? N=172	YES NO	5% 95%
Have you given birth to a baby who died before her/his first birthday? N=172	YES NO	6% 94%	Have you experienced domestic violence during a pregnancy? N=172	YES NO Prefer Not to Answer	17% 81% 2%
	REPRODUCTIVE/I	PRE-CONCEPTION	N PLANNING/CONTRACEPTION	•	
Did you plan your pregnancies? N=172	Yes No	30% 70%	Did your healthcare provider ever talk to you about getting healthy before you got pregnant or spacing between pregnancies? N=172	Yes No	29% 71%
Would you like to become pregnant in the next year? N=172	Yes No Unsure	8% 77% 5%	If you do not want to be pregnant in the next year, are you currently using birth control? N=172	Yes No Not Applicable (current preg/tubes tied to be preg.)	23% 48% 48% d/ or want
What do you worry about the most?	Fill in the blank answer - not ret	rieved	I feel loved by others.	None of the time Rarely Some of the time Most of the time All of the time	0% 5% 19% 40% 34%





# African American Infant Low Birth Weight Project PARTICIPANT SURVEY w/ RESULTS

[N= 256 unless otherwise noted differently]

I feel supported by others.	None of the time Rarely Some of the time Most of the time All of the time	1% 1% 24% 36% 28%	What is your housing situation today?	I do not have housing I have housing today, worried about losing it I have housing.	but I am
Circle any you have had access to or taken advantage of in Dane County:	Breastfeeding help/education Pre-natal education/childbirth classes Post-partum home visits or support WIC or FoodShare SNAP or TANF Childcare Assistance or Headstart Medicaid or BadgerCare Section 8	22% 22% 57% 28% 22% 47% 22%	Within the last 12 months, we worried that our food would run out before we got money to buy more.	Often true Sometimes true Never true No Response	7% 30% 52% 11%
Do you feel that your race/ethnicity has ever impacted your healthcare services or treatment?	Yes_39% No_35% Not sure .	27%	I feel safe in my neighborhood.	None of the time Rarely Some of the tim Most of the tim All of the time No response	1% 3% 15% 43% 30% 8%
How would you describe your current financial situation? (Circle all that apply)	I live paycheck to paycheck.  Money is a major stressor in my life. I have enough money to live comfortabl without stress.  Both C & D I am financially secure and meet my and family needs	31%	Which best describes your child/rens biological father'(s) presence in your life? Mark all that apply.	Very present and active 31% Somewhat present and life. Rarely present and active Both C & D. Not a part of our lives at Not applicable	active in 12% ye in 1ife.

### African American Infant Low Birth Weight Project PARTICIPANT SURVEY w/ RESULTS

[N= 256 unless otherwise noted differently]

Which best describes your experience with stress?	I am stressed often; almost always I am stressed at times, but not generally 34% I have found effective ways to minimize my stress. 24% I am stress free and feeling great. 7%	My community offers the support and resources I need to live a healthy life.  N-214  Strongly Agree 25%  Agree 25%  Somewhat Agree 14%  Disagree 14%  Strongly Disagree 5%
with 1 being biggest Income/money Education level Employment, job conditions (for se Childhood experior Access to food Housing/housing Supportive relative Feeling socially it Mental health Feeling safe in your /community Healthcare acces Gender/gender of Race/racism Disability Transportation Addiction: Alcohe Abuse/domestic Other:	o security, working If and partner) ience & development If stability onships included/excluded our home, neighborhood ass and services discrimination ol, drug, tobacco	Is there anything else you would like to share? Use the space below or the attached sheet.  Fill in the blank answer - not retrieved





## **Appendix B - Engagement Sessions Questions**

# **COMMUNITY ENGAGEMENT SESSION QUESTIONS**

### Lifestyle and Living in Dane County

- 1. What do <u>you</u> like about living in Dane County? What makes it hard to live in Dane County? (overall mindset)
- 2. What do you think is the biggest issue impacting your well-being as a <u>Black</u> woman living in Dane County?
- 3. What is the biggest challenge <u>Black families</u> face in trying to live healthy, stable lives in Dane County?
- 4. What are the issues that women in your family talk about most when identifying things that would make their lives better overall?
- 5. What are key day-to-day stressors in your life?
- 6. What were/are key stressors during the first 9-months and the 1st year after giving birth?

### **Health and Wellness**

- 7. Why do you think so many black babies are being born less healthy than other babies in Dane County?
- 8. What can help a woman *ensure* she has a healthy pregnancy from <u>conception</u> to giving birth?
- 9. What are the biggest challenges a woman faces after having given birth and is back home?
- 10. What is the most important change that needs to occur to help Black women have healthier babies?

### **Healthcare Providers**

- 11. In general, how do you get information about healthcare for you and your family?
- 12. Discuss your experiences with healthcare providers in Dane County when seeing a healthcare professional?
- 13. Have you ever felt that your race, gender, or income impacted how you were served or treated when seeking healthcare services? If yes, how?





- 14. What specific programs, services, resource do you or have you relied on in Dane County to support you and your family?
- 15. What resource, program, or services do you need that are NOT available to you in Dane County?

### **Relationships and Support**

- 16. What are some of the reasons a woman does not always get the social and emotional support she needs?
- 17. What role, if any, does a parental partner(s) (biological/non-biological) play in your life or in the life of your child(ren)?
- 18. What relationships are particularly meaningful for you in your life?
- 19. What support is particularly meaningful to you (in general or specifically as a mother?). And, do you feel like you have this support?
- 20. If you had to make a change in your health; who would be the 2 most influential people in helping you make that decision?





## MMSD HIGH SCHOOL SESSION QUESTIONS

### Lifestyle & Living in Dane County

Tell us about yourself:
Your name
Grade level 4 seniors, 3 juniors
Why you decided to join us today for this session
What your big goals and aspirations are after you graduate

### Lifestyle & Living in Dane County

- 1. What do you like about living in Dane County? What makes it hard to live in Dane County? (overall mindset)
- 2. What do you think is the biggest issue impacting your well-being as a Black woman living in Dane County?
- 3. What is the biggest challenge Black families face in trying to live healthy, stable lives in Dane County?
- 4. What are the issues that women in your family talk about most when identifying things that would make their lives better overall?
- 5. What are key day-to-day stressors in your life?
- 6. What were/are key stressors during the first 9-months and the 1st year after giving birth?

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10. What is the most important *change* that needs to occur to help Black women have healthier babies?

### **Healthcare Providers**

- 11. In general, how do you get information about healthcare for you and your family?
- 12. Discuss your experiences with healthcare providers in Dane County when seeing a healthcare professional?
- 13. Have you ever felt that your race, gender, or income impacted how you were served or treated when seeking healthcare services? If yes, how?





# Appendix C: Sample of Participant Focus Group Discussion Responses



## Life & Living in Dane County



### Positive

- Safe place, great resources if you know how to access.
- Access to green space,
- UW-Madison, culture, research, diversity.
- Access to healthcare, better quality of care
- More event-oriented activities
- Progressive/ tolerant of diversity
- More opportunity here and safer than other places
- Came from a domestic violence situation -got a job, apt, healthcare, and her children's needs were met.
- I like living in Dane County because of the safety; it's better opportunities for the children. What makes it hard is the cost of living.
- I like how there is plenty of help and resources for my babies. It's hard finding a job. I'm comfortable working and keeping up with high rent.

#### Negative

- Not a good place -- African Americans perceived negatively, and then the AA community does not support each other
- Child support system locks you up if don't pay / and high hurdles on expectations from employers (locked up due to child support, then have to say yes on form, creates a cycle of failure)
- Madison forces the women to report the men/fathers in order to get resources -- this is a plus for some women and a negative for others....In Chicago there was no help.
- School system almost a criminalization of young black boys, perceptions of teachers that end up making a situation worse due to their own biases rather than actual happenings.
- When people arrive it is not easy for people to connect - people don't know - no mechanism to find out - until it's too late for the person (ie they become homeless, or without a job etc)

## **Health & Wellness Challenges**

- (Needs) financial and support from community so she can manage the physical and mental strain
- Lack of prenatal education/support awareness specifically focused fro women of color
- · Lack of support from fathers, families, community, access to healthcare
- Attitude adjustment from healthcare provides
- Increased awareness of resources
- Equality/access
- Changing unhealthy lifestyles
- Raise health literacy of women
- Black mothers have a lot of stress, need more support and for some more resources
- Better health care
- Black women have to trust provider regardless of provider, more black healthcare providers, trusted credible navigators to help trust providers
- . Mother's don't know or are not educated to understand risk factors, risky behaviors
- Relationship stress -- (partner not there, emotional stress, unrealistic expectations of mothers/women
- Health care providers lack of cultural competency
- Lack of prenatal care and support for quitting addictions or parenting; unhealthy habits; relationship stress during pregnancy.
- Postnatal care to help take care of her body, mental health support, and physical supports to
  ensure they are doing okay [and don't] need help.
- Need transportation, eat healthy food and drink, mother and baby need lots of love.









### **Healthcare Providers/Interactions**

- · Not listening to my concerns- acting annoyed when I am persistent
- It appears that they give a different level of care if they can't seem to acknowledge your humanity, you have to insist/advocate for yourself
- I am often educating them! I would've wanted them to know more about treating me as a person
  - Docs don't know about the issues and research that impact AA girls and women and their bodies even when asked.
  - o I [as patient] bring up research and they don't know about it.
- They are 'cordial' (not heartfelt connection)
- [Impact of race with Health Providers] No I don't feel it has (not to my face at least)
- Limited time...visits feel pushed- don't take time to listen or don't take time to check more out or take other needed tests or assess condition
- Some come [into the room] with clear bias and assumptions of who you are (your level of education, income)
  - Had back-to-back babies and doctor was commenting on the closeness.
  - o Asked if wanted tubes tied (21 years old when asked) / she is 22 now.
- 35 years looking for someone of color. White people don't understand black people and the white therapists just don't have the cultural competence or cultural humility.
  - More open to someone who understand and relate and looks like and understand the experience
- Yes, I feel my race has impacted me as being seen as less than, disregarded or stupid. I feel my
  income has gotten me better treatment than others.





# **Relationships and Support**

(what they need, what's missing)

- Trust, transportation, intimidation, and lack of support
- Generational stigma
- Black people who need help can't give what they also don't have
- Not knowing how to advocate
- Taking care of everyone else
- Lack of understanding of what type of support a woman needs
- Lack of resources (of others) adds stress on family (mom, partner, sister, brother) and others
  who could be more emotionally supportive
- Lack of community resources
- Not always being open about needs due to shame and stigma
- Stereotypes of jezebel, sapphire, welfare queen
- Not knowing what to ask
- The people she seeks help from are already overwhelmed themselves
- Balance/ perspective
- Financial
- Helping and supporting parenting decisions
- · Positive role model being there
- My OBGYN is a black woman and I feel safe speaking with her a lot about everything
- I've had a terrific doctor that treated my healthcare as a partnership
- A woman may not ask for help, doesn't think she needs it, no support system





# Appendix D - Low Birth Weight Engagement Sessions and Schedule Summary

### African American Women Health and Low Birth Weight

on behalf of Dane County Health Council

### **Engagement Sessions UPDATE**

November 27, 2018

In total, we hosted 22 sessions per the table below in which 302 individuals participated. The breakdown of participants was as follows:

- 256 target audience (Black/African American/African descent/of color/multiracial participants):
  - o 232 females
  - o 23 males
  - 1 no gender indicated
  - Ages 15 60+
- **31 healthcare/community services professionals**; feedback will not be included in the data analysis but will be highlighted as supplemental information in final report.

### • 15 additional participants

- Target audience participants who did not complete their required documents.
- Non-target audience attendees; feedback will not be included in analysis or final report.

	Session Date	Location	Co-host/Partner	# Recruited	Actual Attendees
1.	May 5th –	ULGM	N/A	42	13
	Open Session				
2.	June 14 <sup>th</sup>	Kennedy Heights CC	Patrina White, Dir	15	9
3.	July 10 <sup>th</sup>	Mt Zion Baptist Church	Carola Gaines	40	27
4.	July 18th	Open Session - ULGM	N/A	32	14
5.	July 20th	Allied Wellness Ctr	Gloria Farr	20	15
6.	July 21st	Meadowood Health Partnership	Sheray Wallace	25	22
7.	July 25th	Mentoring Positives, Darbo-Worthington	Will Green	15	5
8.	July 26th	One City/Deltas	Carola Gaines	15	15
9.	August 15th	Northport Comm Ctr	Pat Wongit	13	13
10.	August 16th	Lussier Comm Ctr	Nikki Conklin	15	15





11.	August 29	Stoughton Public Library	Oleka Parker	10	3
12.	Sept 9	Zion City Church	Myra McNair	20	15
13.	Sept 12	Badger Rock CC	Hedi Rudd	21	21
14.	Sept 28	East High School	MMSD/Mike Hernandez & Ebrahim Amara	15	14
15.	Sept 29	Urban League	Open Session	15	5
16.	Oct 1	Capital High – East	MMSD/Karyn Stocks Glover	10	10
17.	Oct 5	Memorial High School	MMSD/Suzanne Blackamore	10	7
18.	Oct 11	West High School	MMSD/Sean Gray	10	9
19.	Oct 16	LaFollette HS	MMSD/John Milton	21	21
20.	Oct 26	Sun Prairie	Theodora Hodge	9	9
21.	Nov 5	Healthcare Profess/Allies	Open Session/UW South Partnership	37	31* (not in data analysis)
22.	Nov 7	African American Men's Health Ctr (at One CIty)	Aaron Perry, Founder	9	9
	TOTALS			419	302

The following engagements were canceled by the partner agencies due to shifts in their schedules or challenges beyond their control in pulling the groups together (we invited them thereafter to attend other sessions per their availability):

- Sat., Sept. 15<sup>th</sup> East Madison Community Center/Project Babies/Harambee Village
- Sun., Sept. 30<sup>th</sup> Fountain of Life Church/Nehemiah
- September Alpha Kappa Alpha Sorority
- Capital High School, West School could not accommodate due to scheduling challenges

Now that outreach has concluded, we are cleaning, processing, and analyzing all data. Please refer to the summary we provided previously for the CHNA report which best reflects overarching themes on which we will expound and add to where needed for the final report.

Lisa Peyton-Caire and Annette Miller Co-Consultants Submitted 11/27/2018





# Appendix E: Engagement Session Questions for Healthcare and Social Service Providers





### Saving Our Babies – African American Low Birthweight Engagement Session for Healthcare Providers & Allies On behalf of the Dane Health Council

- 1. Briefly describe your work with Black mothers/fathers, babies & families in Dane County.
- 2. What agency/organization do you work for?
- 3. From your interactions and observations with Black women patients/clients in Dane County, what factors do you see that impact a black mother's health and well-being the most before, during and after pregnancy?
- 4. What particular challenges, if any, do you observe or hear from Black women patients/clients or families about their lived experiences in Dane County that impact their quality of life and health?
- 5. What community assets, services or opportunities exist that you feel positively support the health and well-being of Black women, men, children and families in Dane County?
- 6. What gaps or inequities in community assets, services or opportunities do you observe tha negatively impact the health and well-being of Black women, men, children and families in Dane County?
- 7. From your professional vantage point and experience, what do you view as the root cause(s) or major contributing factors to black babies being born disproportionately at a low birth weight in Dane County?
- 8. What interventions or best practices have you seen or witnessed to be effective in improving the health and well-being of Black mothers and babies before, during and after birth -- or generally?
- 9. In what ways, if any, is your organization working to address disparities in healthcare, community service delivery, access to opportunities, or other areas impacting Black women and their families and children in Dane County?
- 10. In what ways would you like to be involved in crafting solutions that improve the birth outcomes of Black women and their babies?
- 11. What additional information do you want us to know that you feel is critical to consider as we make recommendations to improve Black maternal and infant health in Dane County?

Thank you for participating today!





## **Appendix F: MMSD Focused Engagement Summary**



## **Overview**



In March 2018, the Dane County Health Council initiated a community engagement campaign around the African American low birthweight crisis.

The aim of the engagement is to bring the voice of the community most impacted by the issue to the table as an active partner in identifying what they believe to be root causes and solutions.

The Council contracted with The Foundation for Black Women's Wellness and its project partner EQT by Design to undertake this series of engagement sessions to gather concerns and feedback of local Black women, fathers, and their communities.

Feedback from the engagement effort will inform critical steps towards identifying sustainable strategies & solutions for reducing and eliminating the low birthweight gap impacting Black babies and families.

DCHC Low Birthweight Engagement, Jan 2019 for MMSD

2





# **Our Process**

- Participant Survey 50 questions completed by each participant to capture consistent data on personal demographics, health history, health care experiences, family planning and pregnancy, well-being, race, and social determinants of health.
- Participant Questionnaire 8 questions completed with facilitated group discussion. Designed to understand qualitatively how highschool participants viewed their life and lifestyle in Dane County, health and wellness around low birthweight and infant mortality, healthcare and healthcare providers, and relationships and social emotional support.
- Format: Two hour sessions with food and refreshments. Used a world café style to ensure full participation by entire group and to capture core themes while also scribing comments based on group discussion and interaction.

DCHC Low Birthweight Engagement, Jan 2019 for MMSD









# Participant Profile - Who We Engaged

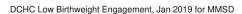
### **Target Audience engagement:**

256 participants of Black/African American/African descent/of color/multiracial participants

- 232 females
- 23 males
- 1 no gender indicated

### Sub target audience engagement:

- MMSD High Schools
  - ☐ Capital High, East and West
  - ☐ Lafollette and Madison Memorial
  - ☐ 60 Females (2 Males were not included)
  - ☐ Between ages 14-17





4





# **Big Messages We Heard**

Though African Americans see Dane County as a place of opportunity, that opportunity does not translate consistently into success or stability for them and their families despite their efforts.

These young women see and experience the backdrop of racial and economic inequality in their lives, their schools, and in Dane County.

The dual impact of **economic insecurity and racial inequality** on the Black family system, past and present, is observed and experienced. They also understand the toxic cycle of stress and pressure that is impacting their families.

They aspirationally want support to have a different future and outcomes.

DCHC Low Birthweight Engagement, Jan 2019 for MMSD









# **MMSD Big Messages Heard**

- Feel like they are responsible for ROLE Models on what it means to be Black. -- East HS
- They want to excel in school but feel vulnerable speaking out when need help -- West HS
- They want to feel "respected, intelligent and smart"
- They want to see educators of color and/or in positions of power
- They want more space to talk about issues of health, relationships, sex, families, boys/men
- Feel like they are seen in a deficit modality rather than as positive/asset -- Lafollette HS
- They are feeling and emboding the same stressors as the women in their lives at the highschool level. - Capital High

DCHC Low Birthweight Engagement, Jan 2019 for MMSD

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# Sample Participant Feedback











## **Quotes from Students**

- "Hard to access honors and AP classes"
- "If your family does not have connections, it is hard to access opportunities"
- "Last faculty and Principal did not recruit any educators of color"
- "Don't want to be the only African American in AP classes"
- "Having to represent for white peers and for teachers"
- "When ask for help people look at them like they are dumb" (referring to regular classes)
- "The liberal trying to fight for "us" but we need to fight for ourselves"
- "Young women should know more and how to get help" healthcare, wellness, medical et

Preliminary Observations of the DCHC Low Birthweight Engagement, Dec. 19th, 2018

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# **Quotes from Students**

- "Planned Parenthood" and "Google" is their go to resource
- "Schools think they are teaching them but the students don't feel like it" getting enough information about being a mother
- "Understand where we are coming from and not judge"
- "Want Black women who can relate and have experience"
- "Have a meeting 1-2x a month on a topic would be helpful around these issues" - referring to engagement session
- "Not enough support, stigmatized, their extended family is stressed too" what they observe in homes regarding "stress or hear from women in their
  household"

Preliminary Observations of the DCHC Low Birthweight Engagement, Dec. 19th, 2018









# **Critical and Consistent Themes**

- Inadequate social supports
- Gaps in health literacy, education and support
- See disconnect in community resources
- See the barriers to individual and family advancement
- Chronic stress of family members
- Want to be connected to their fathers
- See the inequity of how girls/women carry burden of raising kids while boys/men don't
- Feel expectation to be role models but don't have accessible role models in school
- Have aspirations for college and the future ... want help accomplishing
- Friends and school is important to them

Preliminary Observations of the DCHC Low Birthweight Engagement, Dec. 19th, 2018

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EQT by design

# THE FOUNDATION FOR BLACK WOMEN'S WELLNESS

# **Early Implications of What We Heard**

- Empower the young women to advocate and lead decisions on their needs through groups (61% happiest with friends and school, 40% feel supported all or most of the time)
- Black Excellence proposed by school district is right direction
- SAPAR ... should be revamped ... friends and school a strong connection for them (90% don't want to get pregnant, however, 60% not on birth control)



Preliminary Observations of the DCHC Low Birthweight Engagement, Dec. 19th, 2018





## Appendix G - Data charts and Key Stats

TABLE 1: Low Birthweight Engagement Participant Profile - Race, Ethnicity, Age

N=256 all participants

# Participant Profile - Race, Ethnicity, Age

Q2: Race/ Ethnicity	Number	Percent
	0	0.00%
African		
American/Black/ African	229	89.45%
Multiracial	17	6.64%
Native American/African		
American	1	0.39%
Other	5	1.95%
Prefer not to		
answer	4	1.56%
Grand Total	256	100.00%

Number	Percent
232	90.63%
23	8.98%
1	0.39%
256	100.00%
	23

Q4: Age	Number	Percent
15	1	0.39%
14-17	60	23.44%
18-24	15	5.86%
25-34	47	18.36%
35-44	39	15.23%
45-54	40	15.63%
55-64	43	16.80%
65 or older	9	3.52%
no response	2	0.78%
Grand Total	256	100.00%

TABLE 2: Low Birthweight Engagement Participant Profile - Income and Education

# Who We Engaged – Income & Education

Q11: Annual household income	Number	Percent
\$10,000-\$24,999	45	17.58%
\$25,000-\$49,999	55	21.48%
\$50,000-\$74,999	39	15.23%
\$75,000-\$99,999	10	3.91%
less than \$10,000	58	22.66%
more than \$100,000	23	8.98%
N/A	ĩ	0.39%
No Response	25	9.77%
Grand Total	256	100.00%

Q5: Education	Number	Р	ercent
Associates Degree	1	6	6.27%
Bachelor's Degree	4	14	17.25%
HS Diploma/GED	3	3	12.94%
In High school	6	3	24.71%
Master's Degree	2	4	9.41%
No HS Diploma	1	.5	5.88%
PhD plus		4	1.18%
Some College	5	7	22.35%
Grand Total	25	6	100.00%



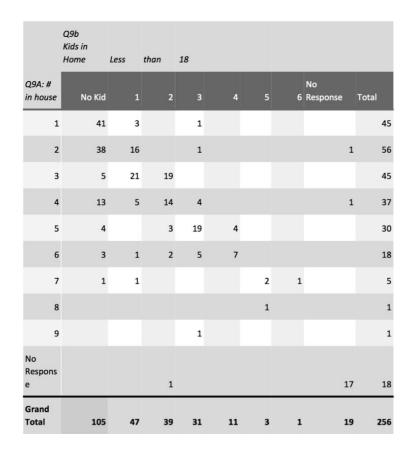


TABLE 3: Low Birthweight Engagement Participant Profile -Birthplace and Relationship Status

Q7: Birth city	Number	Percent
Africa	19	9 3.52%
Dane County	9	1 35.55%
Illinois	86	0 31.25%
No Response	1	7 6.64%
U.S.A	4	4 17.18%
Wisconsin	1	5 5.86%
Grand Total	25	6 100.00%

Q10:Relationship status	Number	Percent
Committed partner (not married)	27	10.55%
Married	55	21.48%
No Response	11	4.29%
Single	41	16.01%
Single (never married)	122	47.66%
Grand Total	256	100.00%

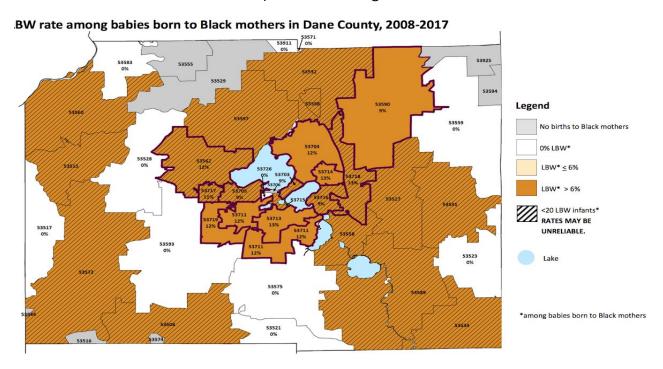
TABLE 4: Low Birthweight Engagement Participant Profile -Participants with Children Under Age 18 at Home







## \*TABLE 5: Dane County Low Birthweight Rates, 2008 - 2017



\*TABLE 6: Dane County Low Birthweight Averages by Zip Code, 2008 – 2017

During 2008-2017, 8 in 10 low birth weight babies born to Black mothers were born in 6 Dane County zip codes: 53704, 53711, 53713, 53714, 53719, and 53590. The graphs below show 3-year rolling average low birth weight rates among babies born to Black mothers for each of these zip codes, with the most recent rate (2015-2017) indicated.

Low birth weight rates did not change statistically from 2008 to 2017 for either Dane County or in any of the 6 zip codes where the majority of births to Black mothers occurred.\*



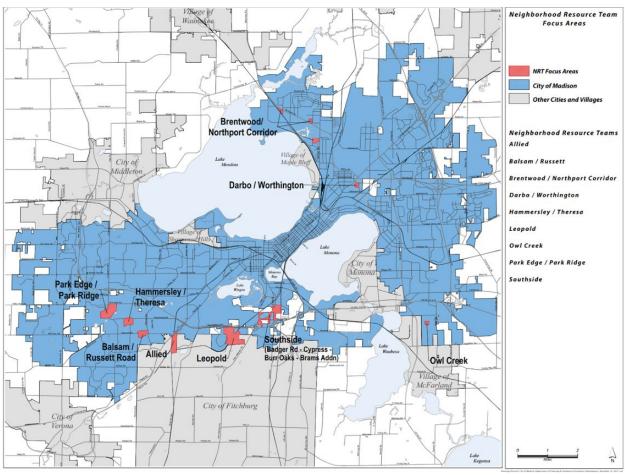
\*Source: Public Health Madison & Dane County





### TABLE 7: Map of Engagement Impact

This map is borrowed from the City of Madison Equity Initiatives Report as a general visual representation of the Greater Madison/Dane County area in which this outreach effort was conducted. Participants in this engagement effort largely represented zip codes and residential areas in and around these areas, in addition to County wide communities of Fitchburg, Sun Prairie, Verona, Middleton, and Stoughton.



Source: https://www.cityofmadison.com/mayor/documents/Equity2014.pdf

# Neighborhoods/Areas Touched

- Allied/Dunn's Marsh Neighborhood
- Bridge Lakepoint Waunona
- Badger Rock
- Darbo/Worthington
- Kennedy Heights

- Lussier/Wexford Ridge
- Meadowood
- Northport-Packers
- Stoughton
- Sun Prairie
- Greater Madison at-large