Ohio Eliminating Disparities in Infant Mortality

TASK FORCE

2021

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Context

Among comparable developed countries, the United States has the highest maternal and infant mortality rate and has been slower to improve its consistently higher average rate of infant deaths.

While significant disparities exist within the U.S., African Americans have the highest infant mortality rate of any US group. Survival rates for African American mothers and infants, death rate for black infants is twice that of infants born to non-Hispanic white mothers. Two thirds of infant deaths occur the first month after birth from congenital abnormalities or preterm births.

Listening to Black Voices

The Ohio Eliminating Disparities in Infant Mortality Task Force was formed to provide Governor DeWine with actionable recommendations on how to eliminate the racial disparity in the infant mortality rate and to create a road map that guides Ohio to meet the Healthy People 2030 goals for all babies. To engage Black women, families, and communities throughout the process to ensure that recommendations are grounded in reality, more than 30 Family Listening Sessions were held in 11 counties across the state, between May 1st and May 15th, to understand the health and well-being experiences of Black families and their infants. The listening sessions were hosted by organizations that submitted an application to recruit families and to support the participation of families before, during and after the sessions.
Demographic Data for Local Listening Session Participants

According to the evaluation surveys completed by host organizations. The evaluation surveys find the following:

- There were 174 family participants across the sessions with 150 women and 24 men participating.
- There were 158 participants who identified as Black, 2 as white, 5 as multiracial, and the race of 9 participants was unknown.
- 5 participants identified as being of Hispanic ethnicity.

For listening sessions, facilitators provided participants with structured questions and opportunities to discuss their answers. Facilitators were available to prompt discussion of the questions. The responses from all participants at the listening sessions were gathered and analyzed for themes raised by families and providers while also identifying points of convergence and divergence. The themes were then categorized and totaled. The input from all participants at the listening sessions is presented in this report.

Report Highlights

The findings presented here illuminate some of the preferences, concerns and experiences of the Black women expressed in the sessions. Structural racism in health care and social service delivery systems was central to this experience. Alarming gaps between the women’s experiences and what they would optimally experience and opportunities for improvement for all women were identified and are organized here by the Healthy People 2030 goal areas as follows:

- Health Care Access and Quality
- Education, Access and Quality
- Economic Stability
- Neighborhood and Built Environment
- Social and Community Context

Across all sessions, the focus groups identified shortcomings of the health care system and of the social supports needed to facilitate optimal outcomes. Overall, they had experienced discrimination during childbirth and faced communication barriers with their providers. They lacked practical and emotional support and reported that health care and social service providers fail to treat them with dignity and respect. And while racism drives racial disparities in maternal and infant mortality, the women also reported significant underinvestment in family support, education, and health care programs as well as communities and neighborhoods, which contribute to the alarming trends in maternal and infant health.
While in today’s health care system, many practitioners and providers acknowledge that cultural differences are important, and that they must meet the patient where they are, discrimination based on race and gender is widespread and well documented. The top responses to questions regarding Health Care, Access and Quality centered on the fractured trust with the medical community and the experience of Black women who are often subject to unfair treatment and given a lower quality of care, which can contribute to disparities in maternal and infant health. These are the questions that were asked:

1. Can you describe some of the opportunities and challenges Black mothers, fathers, and families are facing in your neighborhood regarding their ability to get quality health care?

2. What supports related to health care access and quality have been helpful for Black mothers and families?

3. What can or should be done to address these challenges?

Across the listening sessions, these themes emerged:

1. Racial bias in medical care is real and it puts Black women’s lives at risk 42

2. Access is critical to doulas, midwives and other advocates integrated into the healthcare system to provide culturally competent prenatal, birth, and postpartum care and support. 20

3. The type of health insurance you have determines the quality of healthcare you receive 16

4. We need to begin rebuilding trust among providers, families, and communities 11

5. Black patients prefer to be seen by Black providers 7

Box 1-1

Health inequities are systematic differences in the opportunities groups have to achieve optimal health, leading to unfair and avoidable differences in health outcomes.
"When you go to the hospital, you don’t get the adequate care your insurance should provide. Even if you have the top insurance, you don’t get it because of your skin color."

“A hospital is a very dangerous place for a Black woman. We die a lot in the healthcare system and it’s not a mistake.”

“Doctors don’t care until it’s too late. They feel like they know it all because of their degree. Black women don’t get to be heard. They don’t take us seriously because no one else does.”

“There was nothing about my first pregnancy that established me as high risk except for being young and Black.”

“The nurse refused to listen to me. She said she knew better, and they ended up doing an emergency C-section.”

“During pregnancy I need to be heard. I need to be listened to.”

“Access, mistrust and all those things play a major role. My daughter had to change her daughter to a Black pediatrician because I felt like my needs were not being heard, I felt like people weren’t looking at me in the eye."

“The biggest education barrier I had was structure. To come from where we come from, the lack of structure, the lack of a guide, and not understanding what to do or where to go when you’re pregnant. You’re stressed by life, and you also don’t have a guide to help you.”

“Challenge – securing a good birth experience. Getting a doula. I didn’t know what we were going to do with this birth (home birth was wanted, but midwives were expensive), and having to have a hospital birth gave me a lot of anxiety.”

"When I was pregnant I did feel like I didn’t have the appropriate knowledge I needed about a lot of things. I had to educate myself and research myself.”

“If you don’t have health insurance it’s hard to receive adequate health care without going broke or being turned down.”

“My other two were born and I was working for Pickerington school district. The physicians are completely different. I had better insurance and definitely received better care. Their care was 10x better because of the insurance I carried.”

“Everybody’s (in my family) health care became better after I got better insurance.”

“The differential treatment you experience depending on your insurance is something I’m in the middle of experiencing with this second pregnancy.”

“Didn’t realize I was pregnant until well into my first trimester. Nobody would take me. No physician. You’re already about to be in your second trimester and that’s too much of a risk.”

“Access, mistrust and all those things play a major role. My daughter had to change her daughter to a Black pediatrician because I felt like my needs were not being heard, I felt like people weren’t looking at me in the eye."

“Trust is the biggest issue besides translation.”

“Overall lack of healthcare access. People don’t have proper access to the healthcare they need or they aren’t getting adequate care. A big issue is mistrust with doctors”

“When you’re young, uneducated and Black, and come into this situation of being pregnant, and all your doctors are white, they don’t have your best interest at heart. They manipulate you – I was manipulated to have a C-section.”
“You go to school and you expect to have a different type of life, but you end up on food stamps and you’re wondering how you’re going to make it. That creates a sense of distrust in the community. There are a lot of people who just do not trust the system to be fair to them.”

“Building trust between providers, community programs and the community is vital. Communities have been hurt before.”

THEME 1.5: Black Patients Prefer to be Seen by Black Providers

The following are examples of responses:

“I was seeing a lot of white doctors while pregnant, they weren’t taking things seriously, they weren’t giving me the information I needed. It was hard to feel like I mattered in my pregnancy until I had a black doctor and she told me x, y and z. When I first went to the doctor, they told me I was high risk. The black doctor told me I wasn’t high risk – they just said that because I’m an African American woman. But it was misinformation I was given. If I was a white woman, it would be a completely different story.”

“It’s hard for black women to get into medical school. They don’t have the same foundation that other people have had. There’s not a lot of Black people in the healthcare field.”

“I ended up with a black midwife doctor which changed the whole experience. I felt a connection and felt that she was there and would be an advocate for me. I felt like I could relate to her.”

“Best when doctors, providers look like the community they serve. This does not happen that often. We need to continue to have young people become providers.”
Equity gaps based on race, ethnicity and income persist and thrive in the U.S. education system. One of the first steps in closing these gaps is to realize where they begin and why. The responses to questions regarding Education, Access and Quality centered on inequities and structural hurdles in society that start early on for many Black children, and continue throughout the life course. The disparities highlighted by participants reflect a failure of the system that are part of structural and historical failures and permeate all facets of life. These are the questions that were asked:

1. Are you able to get quality education services that support your family’s health and well-being?

2. Can you describe some of the opportunities or challenges Black mothers, fathers, and families are facing in your neighborhood regarding their ability to get quality education services?

3. What kind of supports for getting quality education services have been helpful for Black mothers and families?

4. What can or should be done to address these challenges?

Across the listening sessions, these themes emerged:

1. The lack of access to services and information about services perpetuates systemic inequality 32

2. The neighborhood in which people reside affects their educational achievement and socio-economic opportunities in life 14

3. Access to quality Early Childhood Education is vital to helping communities thrive 10

4. We need stronger education around women’s preconception care and health 7
**THEME 2.1: The Lack of Access to Services and Information About Services Perpetuates Inequality**

The following are examples of responses:

“Many neighborhood/built environment activities and places (museums, libraries, COSI, etc.) are not very accessible or welcoming.”

“There is a lot of stuff available in the community, but it’s hard to get the word out.”

“Programs need to be advertised much more to the community.”

“Oftentimes people don’t know what’s available to them in terms of programs that can assist them in their educational goals.”

“We have recognized while there’s an influx of a lot of housing support because of the CARES Act. We’re looking at what happens in 1, 2, 5 years when these supports go away. Looking at an evaluation of how we can support these families when these resources go away.”

“Multitude of things like transportation and resources. But thinking about black communities and children we need to prioritize, and balance things out based on disparities that exist today.”

“People don’t know where to get help.”

**THEME 2.2: The Neighborhood in Which People Reside Affects Their Educational Achievement and Socio Economic Opportunities in Life**

The following are examples of responses:

“I don’t feel that children’s educational needs are being met unless you have specific connections or live in a certain area.”

“I think it depends on where you live and what school system you’re in. Based on where I’ve lived, it’s made a difference in the quality of education.”

“The type of services you receive in education depends on where you’re centered.”

“The education on this side of town is not the same as on the other side of town.”

“Only the ‘good’ districts have these (money management classes, app development classes, be your own boss classes) a lot of times, and then you have parents forging addresses for things everyone should be able to have access to.”

**THEME 2.3: Access to Quality Early Childhood Education is Vital to Helping Communities Thrive**

The following are examples of responses:

“Child Care is very difficult to obtain when you have a job; sad to watch; don’t go to school or work because they can’t afford child care.”

“Quality child care is critical, especially Pre-K. Giving them building blocks and preparing them to start first grade and being competitively ready.”

“Childcare that’s accessible for people in the community – increase funding for early head start and early learning programs.”

“Free daycare in the schools for young kids so it doesn’t stop people from going to school.”

“There needs to be a streamlined process for entry into early childhood.”

“I remember daycare expenses were a challenge. They went on both of our household incomes.”

**THEME 2.4: We Need Stronger Education Around Women’s Preconception Care and Health**

The following are examples of responses:

“A lot of people have to drop out because they’re pregnant.”

“Lack of support for teenage pregnancy – because then people fear that there will be an increase in teen pregnancy. Then we don’t support those who are teen parents.”

“I think we need to place a program in the schools. Start with sex education and transition to what is pregnancy, what can happen and how should they be treated. Our babies are having babies and have no clue what to do or expect.”

“It was a challenge being a teenage mother. I was not ready, still being a kid myself. It was hard to focus on high school while becoming a mother at that age.”

“Youth don’t always have access to services; especially pregnant teens.”
Racial and economic inequality has left many Black workers with few good options for protecting both their health and economic well-being. The top responses to questions regarding Economic Stability centered on the pitfalls of the so-called ‘benefits cliff’ whereby even a modest wage increase can result in a significant reduction in benefits which can in turn discourage people from engaging in workforce development programs or from even seeking employment in the first place. These are the questions that were asked:

1. Can you describe some of the opportunities and challenges Black mothers, fathers, and families are facing in your neighborhood regarding economic stability?

2. What supports for creating economic stability have been helpful for Black mothers and families?

3. What else can or should be done to address these challenges?

Box 3-1

Income can predict a number of health outcomes and indicators, such as life expectancy, infant mortality, asthma, heart conditions, obesity, and many others. Access to financial resources, be it income or wealth, affects health by buffering individuals against the financial threat of large medical bills while also facilitating access to health-promoting resources such as access to healthy neighborhoods, homes, and parks.

Across the listening sessions, these themes emerged:

1. The benefits cliff is real and a barrier to progress 28

2. Lack of access to basic needs & safe, affordable housing is a significant barrier to economic progress 21

3. Many experience a vicious cycle of economic struggle 17

4. We need stronger education around financial literacy 10
**THEME 3.1: The Benefits Cliff is Real and a Barrier to Progress**

The following are examples of responses:

“It’s like I have to lose my job to get services.”

“It’s hard to focus on employment, when other basic needs aren’t met, such as food and housing. There is a cycle in which when you get a higher paying job, benefits are decreased, and then families are in a bad spot again.”

“The minute they receive a dollar too much, they take away all the support. Women think what’s the point in getting a better paying job when they will take away food, housing, childcare.”

“Income eligibility for a lot of things – it’s either that you make too much so you don’t get the support, or you’re right at the cut off.

“Child Care is very difficult to obtain when you have a job; sad to watch; don’t go to school or work because they can’t afford child care because if you do the math, sometimes child care adds up to more than how much you make. You have to weigh your options.”

**THEME 3.2: Lack of Access to Basic Needs and Safe, Affordable Housing is a Significant Barrier to Economic Progress**

The following are examples of responses:

“Not many opportunities for low-income or subsidized housing. Really long wait lists, unsafe housing due to violent neighborhoods, etc.”

“Section 8 housing is helpful when you lose or change jobs or need to take time off with your babies.”

“It is hard for marginalized individuals to get housing. They don’t have a right to live and be in a decent neighborhood.”

“Habitat for Humanity- helps families get a house.”

“Every house we have lived in had lead; babies were poisoned with high levels.”

“Housing for felons is also an issue. You can’t be put on somebody’s lease. Where am I going to go and what’s going to happen to me?”

“Without a place to live, I didn’t qualify for custody.”

**THEME 3.3: Many Experience a Vicious Cycle of Economic Struggle**

The following are examples of responses:

“You have to choose between working and making money, and going to school.”

“We’re all one paycheck or situation away from the homeless shelter.”

“You want me to read a book and get an education, when I can’t think past today.”

“At the end of the day, America wants us to pull ourselves up by the bootstraps, when we all have flip flops.”

“Having a record impacts people’s ability to access jobs; most black men in the community have records and they can only get jobs in the factories.”

**THEME 3.4: We Need Stronger Education Around Financial Literacy**

The following are examples of responses:

“Financial education is a great thing in theory – but it doesn’t work if we’re already behind, and they want us to be behind.”

“In our community we don’t have assets. We struggle meeting basic needs because no one taught us financial literacy.”

“It’s scary being in this system and not even knowing or fully understanding the rules and regulations of the systems. Being economically educated around credit, savings, and filling out paperwork properly, we get stuck in a vicious cycle of the system.”

“Financial literacy is part of it, but it’s going to take a mindset change across the board. Half of us are focused on survival and half of us are focused on thriving.”

“This thing they call credit – it’s mysterious, fake money, a lot of black families don’t have that so we don’t have the same stability. We understand what we need to do for our families. We go to these banks, and ask for loans to get started, and they want credit scores. How would we know that if we weren’t taught that coming up?”
Beyond the current structural inequities in society are historical inequities such as redlining, suburbization, and banks that refused to make loans to Black people, or offered them loans at higher rates. These policies and racism created a ripple effect and led to housing segregation that persists to this day. The top responses to questions regarding Neighborhood and Built Environment centered on the reality that people living just a few blocks apart may have vastly different opportunities available to them or even live a longer life due to the social determinants of health. As one participant put it succinctly: “Social determinants of health are the largest barriers in a family’s life.” These are the questions that were asked:

1. Can you describe some of the opportunities and challenges Black mothers, fathers, and families are facing in your neighborhood regarding neighborhood and built environment?

2. What supports related to neighborhood and built environment have been helpful for Black mothers and families?

3. What can or should be done to address these challenges

Across the listening sessions, these themes emerged:

1. Infrastructure and systemic inadequacies (transportation, digital divide) inhibit access to resources and opportunities. 30

2. There is a lack of access to high quality food in neighborhoods 11

3. The economic disparities are visible by neighborhood 10

Box 4-1
The physical environment reflects the place, including the human-made physical components, design, permitted use of space, and natural environment. All of these physical factors shape the safety, accessibility, and livability of any locale, thus providing the context in which people live, learn, work, and play.
“Major issue for my area is transportation. Children can’t get transportation for school.”

“Because I take the bus, it makes it difficult to get some of the resources I need.”

“If you don’t catch the bus you don’t get around and they are not challenging but difficult. No transportation.”

“Neighborhood walkability and transportation is a problem.”

“A lot of schools don’t offer transportation, like for preschoolers. As well as after school activities, they don’t join because they don’t have transportation.”

“Transportation is not the most accessible. I have a car, but it is still challenging for me to get around. I have support, but it’s limited.”

“Healthy food we don’t have access to any decent grocery stores. Food is not available without transportation.”

“There are food deserts in certain areas. Downtown (Cincinnati) has one Kroger, and has a lot of corner stores that don’t have fruits/veggies, but more junk food. Having access to good food is a problem.”

“If you’re not properly nourished, it turns into behavioral issues for children.”

“The resources aren’t split evenly [among counties and communities]. The food pantries in Cleveland are handing out things with no nutritious value compared to other communities.”

“All the grocery stores are shut down on the West side of town.”
The factors that make up the root causes of health inequity are diverse, complex, evolving, and interdependent in nature. It is well documented that health inequity arises from social, economic, environmental, and structural disparities that contribute to intergroup differences in health outcomes. The social environment can be thought of as reflecting the individuals, families, businesses, and organizations within a community; the interactions among them; and norms and culture. The top responses to questions regarding Social and Community Context centered on the importance of community participation by all its members including male engagement. These are the questions that were asked:

1. Can you describe some of the opportunities and challenges Black mothers, fathers, and families are facing in your neighborhood regarding social and community context?

2. What social and community context supports have been helpful for Black mothers and families?

3. What can or should be done to address these challenges?

Across the listening sessions, these themes emerged:

1. We need greater access to mental health services 19
2. The exclusion of men and fathers has both social and economic consequences 19
3. We need safer communities, increased community participation and leadership 10

Box 5-1
The social environment interacts with features of the physical environment at the neighborhood level to shape health behaviors, stress, and ultimately, health outcomes.
THEME 5.1: We Need Greater Access to Mental Health Services

The following are examples of responses:

“So when we are talking about mental health these are things that we deal with just living our everyday lives.”

“There’s a lot of stigma in the Black community around mental health. A change has to happen.”

“I don’t feel the doctors took the time to tell me what was happening.”

“In terms of mental health – I’d like to talk to someone that looks like me that understands me.”

“My 9-months pregnant mom passed away last month. It is so hard to get services for depression and mental health. Jobs and family services are very difficult to get.”

“In the black community mental health is so taboo.”

“Families are very sad but don’t seek mental health. Now here we are trying to get services for the 9 month old. The paperwork that was filled out for my 8-year-old who is suicidal, but we are having trouble getting help. After getting help when we went to the Dr. it was well, he does not want to cooperate.”

THEME 5.2: The Exclusion of Men and Fathers has Both Social and Economic Consequences

The following are examples of responses:

“System is designed to force Black fathers to pay to be involved with their children.”

“Having a record impacts people’s ability to access jobs; most black men in the community have records and they can only get jobs in the factories.”

“Having the men be a part of the economic growth or a part of the household. A lot of the times when we’re getting resources, the fathers aren’t allowed to be a part of those resources.”

“My dad’s a felon, I’m a felon, is my son going to be a felon now? That’s not what I want.”

“All programs are geared towards women. There should be programs to help men become better fathers to their children. Regardless of what they’ve done, they’re still fathers”

“There’s a lack of support for males in the community.”

THEME 5.3: We Need Safer Communities, Increased Community Participation and Leadership

The following are examples of responses:

“Community participation is important because it takes that village”

“Unification is important, and it helps increase community trust when the community is together.”

“When people are struggling, and you have a community then you can get help easier.”

“It’s kind of just a struggle in our community and in society in general... It starts with us coming to the table to talk first.”

“If the community was together, there would be a lot less violence going on. People aren’t comfortable going to their neighbor because that might be the person that robs them in 2 days.”

“I am scared to release my daughter to a public space I’m not present in. I’m scared to death to drop her off in a classroom.”

“System is designed to force Black fathers to pay to be involved with their children.”
Conclusion
Observations

The root causes of health inequity begin with historical and contemporary inequities that have been shaped by institutional and societal structures, policies, and norms in the United States. These structures, policies, and norms – such as segregation, redlining, and foreclosure, and implicit bias – play out on the terrain of the social, economic, environmental and cultural determinants of health. Black women’s voices and lived experiences are essential for understanding, and then addressing, the challenges the U.S. health care system faces, particularly the stark disparities in patient experiences and health outcomes of Black women.

The accumulated experience of racism across the life course can have detrimental effects on the overall health of Black women and, specifically, on birth outcomes, including increasing the risk of premature birth. Across all respondents, the Listening Sessions identified shortcomings of the health care system and of the social supports provided to pregnant and parenting women in Ohio. These findings make clear that the health care system is falling short for all women, but especially for pregnant and parenting Black women. If we are serious about ensuring that Black women thrive before, during and after childbirth, we must do more to eliminate bias and discrimination in health care and address their clinical and nonclinical needs.
Acknowledgements

A special thank you to the families that shared their journeys in order to improve the opportunities and resources available to their children and to strengthen their communities.

Below is a list of organizations that work with families every day and volunteered to step up to host a listening session.

- Abundant Season Anointed Ministries International
- Action for Children
- Alta Head Start
- Blaq Birth Circle
- Butler County Educational Services Center & CBI
- Canton City Public Health
- CelebrateOne
- Child Care Resource Center
- Cincinnati Hamilton County Community Action Agency
- Cradle Cincinnati-Queens Village
- Help Me Grow-Allen County
- Kiddie Academy of Reynoldsburg
- Libby’s Corner
- Mary Church Terrell Club
- Neighborhood Leadership Institute
- Passages Connecting Fathers and Families, Inc.
- Pathway Inc.
- Project Ujima
- ProMedica Health System
- Public Health - Dayton & Montgomery County
- Stark County Community Action Agency
- Stark Education Partnership
- The Center for Family Safety and Healing
- The Child Development Council of Franklin County
- United Way Greater Cincinnati
- UnitedHealthcare Community Plan of Ohio
- University Hospitals
- YWCA of Northwest Ohio

Two organizations provided the organizational support to complete the listening sessions.

- **GroundWork Ohio** is a committed, nonpartisan public-policy research and advocacy organization that champions high-quality early learning and healthy development strategies from the prenatal period to age five, that lay a strong foundation for Ohio kids, families and communities.

The alignment with GroundWork Ohio’s Center for Family Voice allowed the state to leverage the growing infrastructure of local organizations working with families every day to recruit families for participation in the listening sessions.

- **The BUILD Initiative** is a national organization that advances work on behalf of young children from prenatal to five, their families, and communities. The BUILD staff partners with early childhood state leaders focused on early learning, health, mental health, nutrition, child welfare, and family support and engagement to create the policies, infrastructure, and cross-sector connections necessary for quality and equity. BUILD envisions a time when all children reach their full potential and when race, place, and income are no longer predictors of outcomes.

BUILD’s support of this project allowed their team to act on their commitment to hear from those most directly impacted by state policy—in this case Black mothers and fathers and the community organizations that seek to support them—and to facilitate state leaders involvement in structured feedback loops and development of responsive policy, programs, and practices that remediate inequities. BUILD’s participation, led by Dr. Sherri Killins Stewart and including Daisy Copeland, Susan Hibbard and Saeed Mirfattah, was made possible through generous funding from the Pritzker Children's Initiative and the George Gund Foundation. Ohio is a BUILD partner state.