Conversations with Advocates of Color and Allies on Maternal, Infant, and Toddler Health:

PERSPECTIVES FROM LOUISIANA, NORTH CAROLINA, AND TEXAS

Report for American Heart Association's Voices for Healthy Kids

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Executive Summary

Background

Communities of color have endured centuries of inequities due to structural racism. Presently families of color are experiencing the impacts of structural racism in all sectors of their lives, including maternal, infant, and toddler health and wellbeing. Evaluators from the Office of Community Health and Research at the University of Arkansas for Medical Sciences (UAMS) worked with the American Heart Association's Voices for Healthy Kids (VFHK) to conduct five virtual community conversations on the topics of maternal, infant, and toddler health and wellbeing, structural racism, and health equity in conservative states, namely Louisiana (1 group), North Carolina (2 groups), and Texas (2 groups). Conversations were held with advocates of color and allies who were familiar with maternal, infant, and toddler health in their communities and in their respective states.

UAMS recognizes two important limitations in this project. First, although community organizations helped plan and recruit for this project, these recruiting partners did not implement the community conversations and thus not all findings shared in this report are reflective of the community organizations, especially across states. In short, this report does not reflect all views of recruiting partners. Second, small groups in each state participated in these conversations. Thus, findings and discussion cannot be generalized across states and these findings are not representative of all advocates in maternal, infant, and toddler health and wellbeing in their respective states.

Findings and recommendations from the five community conversations with 34 advocates of color and allies to improve maternal, infant, and toddler health in conservative states are shared below.

Summary of Key Findings

Community conversations explored maternal, infant, and toddler health, the supports and services needed for optimal health, and effects of and approaches for policy fighting structural racism. Themes shared across all three states are presented as key findings.

Maternal Health

Conversation participants discussed barriers and challenges to achieving ideal maternal health in their communities. Among those challenges, community and family support, access to healthcare, fragmented systems, cultural insensitivity, and logistics emerged as key themes across the three states.

Advocates shared barriers to access and utilization of maternal, infant, and toddler health supports and services. Centralization of services under one roof and having providers who represent communities of color and provide culturally responsive services could increase access to and utilization of services.

Infant and Toddler Health

Similar to maternal health, conversation participants discussed barriers and challenges to achieving ideal infant and toddler health (as defined as from birth to age three) in their communities. Among those challenges, lack of quality childcare, barriers to health access, a deficit of basic needs, cultural insensitivity, misinformation, and a lack of awareness of available services emerged as key themes across the three states.

Community conversation participants discussed the supports and services needed to help infant and toddlers achieve optimal health. Among needed supports and services, culturally responsive care and services, provision of basic needs, quality childcare, and the ability to thrive emerged as key themes across the three states.

Supports and Services

The community conversations explored ideas on how access to supports and services could be improved and how utilization of supports and services could be increased. A clear key theme that emerged for improving access to supports and services for maternal, infant, and toddler health was centralization of services, such as a centralized location where multiple systems of care can be provided. A centralized and simplified application process was also suggested to increase utilization of supports and services.

Advocates discussed ideas to increase utilization of maternal, infant, and toddler supports and services. Key themes of the discussion included building trust, reducing logistical barriers, simplifying eligibility requirements, providing culturally responsive services, and arranging soft hand-offs between services.

Effects of COVID-19

COVID-19 had both positive and negative impacts on communities. Advocates described how local community organizations shifted and stretched to meet the influx of needs and challenges that arose in communities. They felt community organizations were able to fill community- and family-level gaps that larger organizations were unable to address.

Structural Racism

Advocates explored the effects of structural racism on communities of color in Louisiana, North Carolina, and Texas as it relates to healthcare inequities, career opportunities, food access, voter suppression, allocation of resources, and white systems of power. They shared that structural racism is a root cause of many of the barriers and inequities discussed by participants.

Engaging Conservative Lawmakers

Relatedly, advocates and allies then related their experiences with conservative lawmakers, and they spoke to their approach on influencing conservative lawmakers while not invoking equity language due to being dismissed or ignored when invoking the terms *structural racism, equity, or social justice*. Conversations explored approaches to engaging conservative lawmakers in discussions about equity.

Key themes included making an economic argument, talking about equity without using the word, using data, starting conversations, sharing lived experiences, and engaging lawmakers on the record.

Advice for Others Engaged in Equity Work

Advocates shared advice for others who are currently advancing or interested in advancing maternal, infant, and toddler health equity. Advocates shared advice for white advocates to effectively support advocates of color. Major themes included uplifting community voices and priorities, checking implicit biases, giving up power, hiring people of color in leadership and other organization positions, and sharing the burden.

Advocates also shared overarching advice for systems level change. Key themes included electing champions into office, funding community organizations, dismantling systems, and sharing power with communities.

Advocates are Exhausted

During the community conversations, advocates of color shared that advocacy work is exhausting and often frustrating and demoralizing. They feel they are working in systems that are stuck and find it hard to gain traction on systems level changes, yet they continue to show up in their communities.

Discussion Summary

This section expounds on the larger themes expressed by advocates of color and allies who participated in the community conversations in Louisiana, North Carolina, and Texas.

Intersection of women of color and infants and toddlers of color within white-orientated systems of health care and early childhood care and education

At this intersection among women of color, infants and toddlers of color, and white-orientated systems, advocates report traumatic healthcare episodes and culturally- and linguistically-unresponsive care that causes harm and perpetuates racial/ethnic inequities in maternal, infant, and toddler health. Advocates contend that health and wellbeing outcomes for women and infants and toddlers of color are wholly dependent on the intersectionality of class, race, ethnicity, skin color, gender, sexual orientation, nationality, socioeconomic status, among others. In turn, experiences with pregnancy and caring for infants and toddlers differs with all the intersections above as well as age, geographic location, and political milieu.

Interconnected cause and effect of structural racism in maternal, infant, and toddler health

Continuing disparities for communities of color in maternal, infant, and toddler health and wellbeing are inextricably interconnected with the mechanisms of structural racism. Communities of color who lack basic necessities to maintain sound maternal, infant, and toddler health and wellbeing are mired in this social condition due to generations of residential segregation, disinvestment in majority-minority neighborhoods, unequal educational systems, lack of health insurance, inconsistent and

inaccessible eligibility for programs and services, unsafe housing, unstable, and low-paying employment, among others. Advocates of color and allies across the three states offer a solution to these compounding catastrophes in the form of 'a village.' Advocates wish for a return of the village to aid post-partum parents and to care for infants and toddlers as well as social, physical, and emotional supports.

Relationship between structural racism in maternal, infant, and toddler health in politics/policymaking within era of anti-racist backlash

For advocates of color and allies in conservative states, connecting structural racism to disparities in maternal, infant, and toddler health has proven a difficult bridge to cross with conservative, majority-white policymakers and decision-makers in Louisiana, North Carolina, and Texas. Advocates and allies describe specific, interrelated ways that policymakers and decision-makers maintain status quo frameworks that perpetuate disparities for families of color.

State-specific developments in maternal, infant, and toddler health

All three states of Louisiana, North Carolina, and Texas have advocated for improved maternal outcomes as well as improved access for ECE for communities of color. In particular, North Carolina and Texas have developed their Quality Rating and Improvement System (QRIS) frameworks to assess and ameliorate ECE programming. In Louisiana, advocates have successfully lobbied to invest more than $80 million in ECE programs and services.

Conclusion

The community conversations with advocates of color provided a glimpse into the reality of maternal, infant, and toddler health, and the challenges faced by those working tirelessly to improve that reality. Although it is not an exhaustive representation of all advocates, the voices and perspectives captured by these conversations are no less poignant and indicate that there is more work to do in the realm of maternal, infant, and toddler health to ensure true equity of the birthing and childhood experience for all. Providing the platform for these voices to be heard is one such step toward change and progress. However, advancing the health and well-being of marginalized communities not only takes a village of BIPOC and white allies, it also requires that the individuals and the systems that perpetuate inequity move aside.

Key takeaways from this report are informed by the participants that shared their lived experiences as humans and advocates of color, and should advise existing and future efforts to change the reality faced by so many birthing people, infants, and toddlers. Continuing these conversations with advocates of color in other states and regions would be a meaningful step to increase the number of voices heard and to learn about the status of maternal, infant, and toddler health in other areas of the country. BIPOC advocates need intentional collaboration and support from white allies and lawmakers alike to secure health equity for all birthing persons, infants, and toddlers.

Recommendations

Based on the findings gleaned from the community conversations with advocates of color and allies in Louisiana, North Carolina, and Texas, this report posits the following recommendations:

- Adequately fund smaller community organizations who are often founded and operated by people of color with lived experience in the communities served in lieu of more often than not providing larger organizations with most of available funding;
- Hire more people of color in organizational leadership roles who in turn hire more people of color and diversify racial/ethnic demographics of leadership across more organizations and entities that influence maternal, infant, and toddler health;
- Demand white advocates to share the burden of combatting structural racism and eliminating interpersonal racism so that advocates of color are not always the only voices speaking for families of color;
- Engage conservative lawmakers by asserting an economic argument with powerful data that would improve health outcomes, by advancing equity without using the word equity, by starting conversations and sharing lived experiences, and by engaging lawmakers on the record;
- Elect or help elect champions of maternal, infant, and toddler health into office, especially champions who recognize the impacts of structural racism and acknowledge the centuries of inequities suffered by communities of color; and
- Advocate for dismantling systems that perpetuate racial/ethnic disparities for communities of color.

Introduction

The Office of Community Health and Research at the University of Arkansas for Medical Sciences (UAMS) Northwest worked with the American Heart Association's Voices for Healthy Kids to conduct five virtual community conversations on the topics of maternal, infant, and toddler health and wellbeing, structural racism, and health equity in conservative states, namely Louisiana (1 group), North Carolina (2 groups), and Texas (2 groups). These conversations were intended to leverage expertise directly from advocates of color and allies working in the field of maternal, infant, and toddler health and wellbeing.

Background

Systemic and structural racism are forms of racism that are rooted in systems, laws, written or unwritten policies, entrenched practices, and established beliefs and attitudes that contribute to unequal treatment of people of color in society (Braveman et al., 2022). Structural racism, bias, and stereotyping contribute to differences in healthcare treatment for racial minorities. The COVID-19 pandemic exacerbated racial/ethnic disparities in maternal, infant, and toddler health for people of color (Lopez et al., 2021). Racial-ethnic disparities in maternal health have remained prevalent throughout the United States. Implicit bias in care and structural racism have been documented as predictors of poor pregnancy-related outcomes among African American, American Indian (AI), Alaska Native (AI/AN) women, and Hispanic/Latinx women (Petersen et al., 2019; Saluja and Bryant, 2021). Implicit bias results when medical providers unconsciously dismiss the concerns or pain of pregnant people of color. Pregnant people of color are also more likely to give birth in low-quality health facilities, contributing to higher rates of mortality and morbidity. Hispanic/Latinx women are more likely to deliver at hospitals having higher risk-adjusted severe maternal morbidity rates (Howell et al., 2017).

The majority of maternal deaths are associated with cardiovascular conditions, which are preventable with early access to healthcare (Arteiga et al., 2020; Bairoliya & Fink, 2018). In Texas, Louisiana, and North Carolina non-Hispanic Black women are disproportionality represented in pregnancy related deaths. In Texas, 31% of pregnancy related deaths were among Non-Hispanic Black women, but represent 11% of births (Texas, 2020). In Louisiana this represented 58% of all deaths, but constituted 37% of all births (Bruce et al., 2021). In North Carolina, Black pregnant women are twice as likely to die from pregnancy related complications, in comparison to white women (Small et al., 2020). Moreover, pregnant people who do not receive prenatal care are seven times more likely to deliver a preterm child, in comparison to those who have regular prenatal visits (Howell, 2017). Access to healthcare for birthing people during pregnancy and post-pregnancy helps to prevent complications and mortality related to childbirth. In addition to maternal health, another pivotal aspect to healthy communities involves infant and toddler health and wellbeing; however, like maternal health, infant and toddler health is also impacted by structural racism.

The pandemic highlighted the challenges that the early care and education (ECE) sector were already experiencing as a result of structural racism such as structural flaws, low salaries for employees, lack of access to high-quality centers for children of color, and insufficient funding. About 40 percent of the ECE workforce is composed of women of color (Schilder, 2021). As a result of the pandemic, enrollment declined and many ECEs were not able to sustain themselves. ECEs are critical in advancing emotional and developmental milestones for children living in low-income neighborhoods. Adequately funding ECEs would improve salaries and the quality of ECEs, therefore providing children with necessary educational tools and environments to succeed early on.

Key Findings from Community Conversations

- Community conversation participants shared barriers to access and utilization of maternal, infant, and toddler health supports and services. Centralization of services under one roof and having providers who represent communities of color and provide culturally responsive services could increase access to and utilization of services.
- COVID-19 had both positive and negative impacts on communities. Advocates described how local community organizations shifted and stretched to meet the influx of needs and challenges that arose in communities. They reported community organizations were able to fill gaps that larger organizations were unable to address.
- Structural racism is a root cause of many of the barriers and inequities discussed by participants. Advocates discussed the need to have people of color in positions of power at the policy and organization levels, which would foster a dismantling of structural racism, once equity champions were working on a systems-level
- Advocates represented locally embedded community organizations. They shared a need for more funding to be directed at community organizations, which they felt were better positioned to meet the priorities and needs of their communities and maximize the ability of funding to advance health equity.
- Advocates reported that they avoid using equity language or invoking structural racism to advance health equity in maternal, infant, and toddler health when engaging with conservative lawmakers who are sometimes actively working against equity by maintaining status quo systems of power. Instead, advocates and allies are able to better engage conservative lawmakers through economic arguments with facts and data.

These key findings and more are expanded upon in this report.

Methods

UAMS worked with three organizations in Louisiana, one organization in North Carolina, and three organizations in Texas to plan and recruit for five community conversations. Acting as recruiting partners, these community organizations were identified by Voices for Healthy Kids (VFHK), and had a history of work aligned with maternal, infant, and toddler health and connections to networks within their states. That is, these organizations were chosen for their ability to help recruit advocates across their respective states. VFHK organized an introductory meeting among UAMS and the seven organizations.

Each organization played an essential role in recruiting participants for community conversations and ensuring the conversation guide was appropriate for participants.

All seven organizations identified advocates of color and allies within their states who were in their networks and familiar with maternal, infant, and toddler health in their communities in their respective states. To aid in recruiting, UAMS shared recruitment language and an online interest form that collected basic demographics, contact information, availability, and details about potential participants' advocacy work. The form was entered into REDCap (Research Electronic Data Capture), a secure data collection platform used by UAMS. Community organizations in Louisiana, North Carolina, and Texas, then, shared with their networks, and issued individual introductions to specific advocates in their state. This method was used for recruitment and selection in all three states. Participants were then chosen based on availability, location within the state, type of organization they represented, and demographics. Advocates of color from diverse locations and backgrounds within the state were prioritized for participation.

UAMS conducted the community conversations over Zoom during the time period between April 20, 2022, and May 6, 2022. UAMS had the conversations transcribed by Landmark Associates, a secure, HIPAA-compliant transcription service. The conversations ran 120 minutes, and participants received a $50 gift card for full participation during the 120 minutes. UAMS worked with VFHK to develop a template for rapid coding analysis. Two teams of two divided the transcripts and chat logs and coded them using the template. Through this method, two evaluators separately coded each transcript and chat log. After coding assigned transcripts, each team met to review consistency and agreed on the themes to include in a combined template for each transcript. Themes from the conversations held in North Carolina, Texas, and Louisiana were combined into one template. Overarching themes across all three states were analyzed.

UAMS shared summary findings with all participants from the three states who participated in the community conversation. Participants were asked to review the summary findings for accuracy and add anything not reflected in the findings. To maintain confidentiality, evaluators shared the findings over email using blind carbon copy, or Bcc, for each participant's email. Participants, then, replied with their feedback. Among those who replied (N=7), all replied with positive feedback thanking UAMS for

sharing the summaries as well as agreeing on the accuracy of the summaries. Participants did not identify any additions or revisions in the summary review. Evaluators have compiled findings into this report. Lastly, UAMS engaged participants and community organizations in interpreting findings through a discussion of a preliminary report. Both participants and community organizations provided feedback on accuracy of the findings, framing of the report, and interpretation of the report sections.

Participants

Through the five community conversations, evaluators spoke with a total of 34 advocates of color and allies. The racial/ethnic demographic breakdown of the participants is included in Table 1.

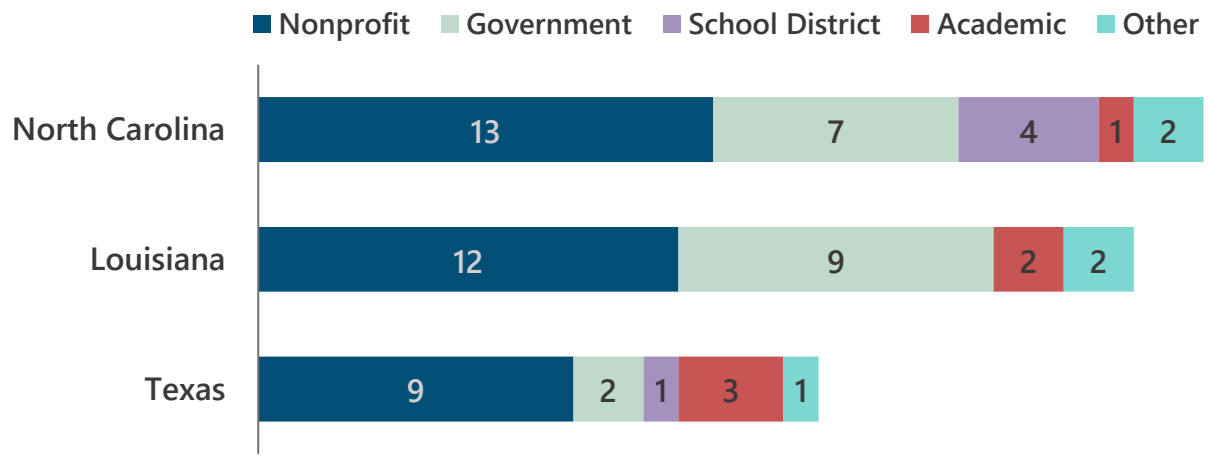
Table 1. Participant Racial/Ethnic Demographics by State

Race/Ethnicity	Louisiana		North Carolina		Texas		Total	
	n	%	n	%	n	%	n	%
African American/Black	6	67%	9	60%	5	50%	20	59%
Hispanic, Latino/a, or Spanish	0	0%	4	26%	3	30%	7	20%
Asian	0	0%	1	7%	2	20%	3	9%
American Indian or Alaska Native	1	11%	0	0%	0	0%	1	3%
White	2	22%	1	7%	0	0%	3	9%
Total Participants	9	-	15	-	10	-	34	100

In the following figures, the number of years active in advocacy within maternal, infant, and toddler health is illustrated as well as the number and type of organizations that participants represent in their states.

Figure 2. Years of Advocacy of Participants by State

Figure 3. Types of Organizations Represented by State

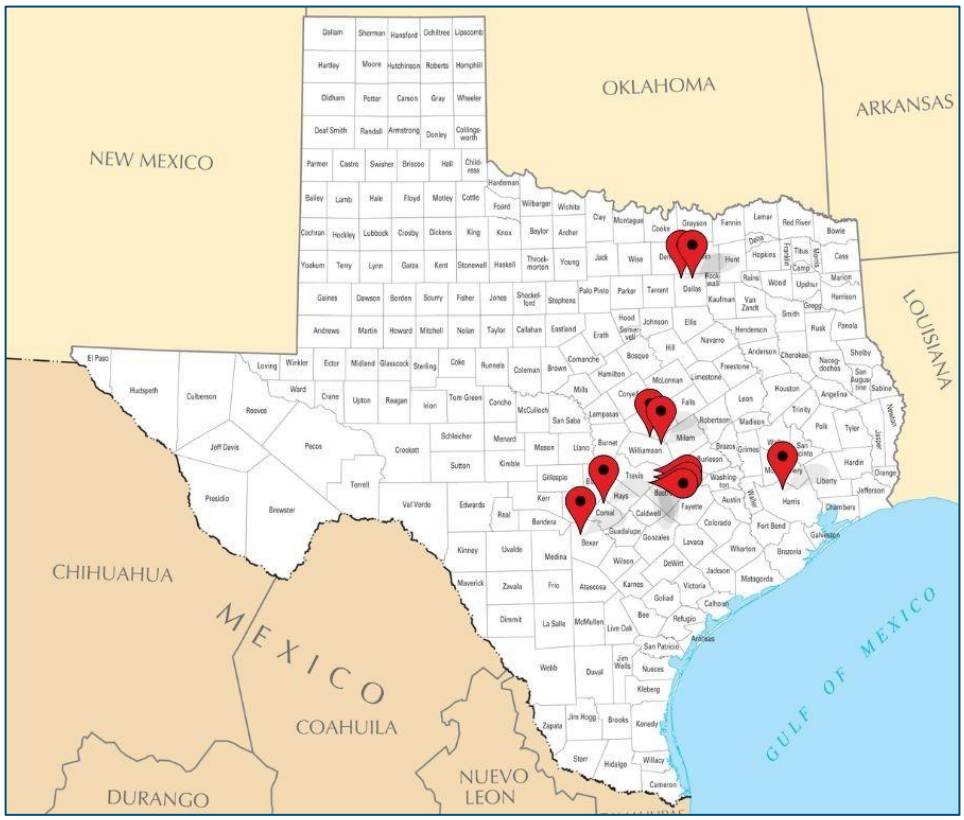


In the next figure, the geographic breakdown of the counties or parishes where these advocates work will be illustrated by each state map.

Figure 4. Geographic Breakdown of Advocates by County or Parish in Louisiana, North Carolina, and Texas
Louisiana

North Carolina

Texas




Conversation Findings

Community conversations explored maternal, infant, and toddler health, the supports and services needed for optimal health, and effects of and approaches for policy fighting structural racism. Themes shared across all three states are presented as key themes in this section. Conversation participants are referred to as 'advocates' in this section.

Maternal Health

Advocates discussed optimal maternal health, including its barriers and supports or services needed for optional health.

Barriers

Conversations explored barriers and challenges to achieving ideal maternal health in communities. Among the challenges discussed by advocates, community and family support, fragmented systems, cultural insensitivity, barriers to abortion, and general access emerged as key themes across the three states.

Community and Family Support

Advocates discussed a lack of community and family support for maternal health, including a lack of parenting education and awareness of supports and services. They shared that parents do not know where to turn to for many of the supports and services they need, as one advocate shared, *"What I've been hearing on the last call I was in, it sounds like there are a lot of pockets of information and resources everywhere, but the people who need them don't know they're there."* Advocates also lamented a decline of community for new parents:

> *My generation of parents do not have a community around them. We are doing this alone as individuals. I imagine that if you are a single parent, that goes up times 10, where you might be feeling very alone. I would just love to see us bring back the village. I want to see us be in*

villages. I don't think we can do maternal health and postpartum health and mental health and all these things alone.

Advocates also identified either a lack or failing of system-level supports. Advocates reported parents are unable to prioritize important needs. Parents have barriers to seeking treatment they need such as substance abuse because of a lack of support, such as childcare for other children in the home or transportation. Some advocates discussed systems meant to protect children were harming families, such as Child Protective Services (CPS):

[The mother] is working at Wal-Mart on her feet. There's nowhere where she can nurse—not nurse, pump, where she can store the milk. She's not getting time to be able to do this and she's trying to go back to work after two weeks [postpartum]. Clearly, she's not ready. She's going to bounce back into the ER because something's going to give. She's going to get an infection or some other problem which is going to then complicate things because who's going to take care of the baby while she's in the hospital? Because the childcare option that we've had in Austin is to call CPS on her. What the literal 'hmm' is that? That's not a solution. She didn't do anything to her child. She got sick, and she brought the child to the ER. The nurses are like, "Oh, we can't be taking care of your kid," so who to call? They call CPS.

This advocate identified fear of CPS as a deterrent to seeking care and support. Another advocate shared a similar concern:

It's hard enough being a pregnant mom, but if you happen to be a pregnant mom and you have substance use disorder; one, you get scared about testing. Two, you think we're going to call and take your kids away. Also, there's lack of provider empathy where you want to treat the mom without feeling like the state is going to come after you because you didn't report something.

Fragmented Systems/Gaps in Services

Several advocates described health systems in their states as chaos:

For me right now, birth looks very chaotic. Because I have not seen it any other way, I'm not sure what it's actually supposed to look like because I have, honestly, seen chaos. Not to say that there are no happy birth experiences out there. I'm not saying that, but when we look at the wider lens, it's chaos.

Advocates discussed fragmented health systems with gaps in services. In the following quote, an advocate described significant care gaps between childhood and pregnancy, as well as limited coverage and long wait times for appointments:

In terms of the care itself, it is very fragmented where it's not a continuum. It's like you're a kid, you see a pediatrician, and then you might see an OB because you're pregnant, and then what? There's no in-between family practitioner or preventive care sort of in-between or even after you have your first child. What's your ongoing source of care to make sure you're getting those annual screenings for cholesterol, for diabetes? There are gaps for the preconception and interconception care. That what we're seeing. Part of it is because there's really limited

> *coverage options. Even the programs that are afforded by the state are very limited in what they do cover, and good luck trying to find a Medicaid provider and good luck finding an appointment within the next two weeks that's not a long wait time.*

Eligibility cliffs were another barrier discussed by advocates. Advocates described how an incremental increase in income can cause ineligibility for a disproportionate amount of services. One advocate described the eligibility threshold as, *"…You're not broke enough to get the services, but you don't make enough to pay for your own."* Advocates discussed limited services available for different types of care, such as teen or young parents, and scarcity for specialized care, as shown in the following quote:

> *There are two certified perinatal psychiatrists in the whole state of Louisiana. Two, and that's it. That itself identifies a gap that is significant in properly diagnosing. There are so many hormonal changes that are going on at the time pre-pregnancy, pregnancy, and then post pregnancy, that having someone who has specialty in looking at those hormonal related considerations is really important.*

Mental health services were also identified as scarce and a few advocates identified barriers of care for incarcerated individuals, *"When you're incarcerated, you lose your access to Medicaid. A lot of times they go that whole entire period without any type of prenatal care."*

Cultural Insensitivity

Advocates pointed out widespread cultural insensitivity among service providers. They felt most service providers do not share lived experiences with communities of color and provide care that is insensitive or not culturally responsive. Language is a barrier for some seeking care or understanding the care they received. Advocates also acknowledged generational trauma as a barrier to seeking services and care. One advocate shared:

> *Being able to address the disparities in healthcare that are huge with women of color and white women, dealing with the generational trauma that women of color have, which affects their access to care also and then their whole pregnancy, it has an impact on their DNA and then their hormonal responses too.*

This advocate described how generational trauma continues to affect an individual's health long after the initial trauma.

Barriers to Abortion

A major barrier discussed by advocates in Texas was policy preventing pregnancy abortion. Advocates discussed Senate Bill 8 (SB 8) [see appendix] and the implications the policy was going to have on birthing persons in Texas and other states as the Supreme Court was nearing reversal of Roe vs. Wade. Advocates discussed that the state didn't have the infrastructure in place to handle the demand for birthing services. One advocate stated, *"[Texas is] not prepared for the ramifications of SB 8 and the amount of clients that are coming to them for their services, all of that—they were not prepared for it."* Another advocate added the following:

They have no connections with the communities, so when these women come to these pregnancy resource centers, they are like—they don't know where to get the diapers. They don't know how to get these kids backpacks. They have none of that. They were just like getting millions of dollars to try and convince women not to have abortions. That was their role and a few of them and only one or two of them had ultrasound machines which they show these women like, "Oh, see. Look, there's your baby. Blah, blah, blah...

One advocate stressed the need to financially support birthing persons who are forced to carry and birth babies, and then continue to support the baby as they develop:

We know who's doing this, so let's start holding them accountable. The only thing, we can talk red, blue, black, white. The only color this country sees is green. Start charging people. Yes. I was just reading this this week. I'd have to go back and see what the source is, but they said it's roughly $6500 a month to actually—what is the word I'm looking for? Like "properly" or you know, so that a child thrives, that you support a child per month. One child. For every woman that some guy gets pregnant, charge his butt $6500 a month that he has to pay her. Rapist, father, uncle—I don't care who you are... Because if you're saying she's got to have the baby, well, then he needs to pay for it. She is not self-pollinating. She did not do this to herself. Then let's have the discussion because if you are so, "Life begins at the moment of conception," okay, I'll go with that. Pay for it. Pay for it. All of you out there that—you're pro-fetus. You don't give a crap about this mother. Pay for that fetus. Pay for that fetus until they are a functioning 18-year-old adult. Then after that, put them through college. Oh, you don't want to pay for a student loan? Then, yeah. You put them through college at the same time, but we're not talking about that. We're not holding the male counterpart, the sperminators, at all, accountable for this. It's just, "These women, these women, these women." No. Start there

General Access

Finally, advocates described more general barriers to accessing healthcare such as transportation to get to and from healthcare appointments and access to short-term childcare so a parent can seek needed individual supports that may not be appropriate for children accompaniment.

Supports and Services Needed for Optimal Health

Community conversation advocates discussed the supports and services needed to help a birthing person achieve optimal prenatal and postnatal health. Among needed supports and services, culturally responsive care, systems for early care and prevention, prenatal and post-partum care, parenting education and awareness of services, and support systems emerged as key themes across the three states.

Culturally Responsive Care

Advocates identified the importance of culturally responsive healthcare and services to properly support birthing persons with their care. One advocate shared:

One of the pieces that I come across with the Muslim community is comfort with the person that's providing care. Specifically for Muslims that wear hijab, talking with a male provider may be uncomfortable. They might want their team to be women-only or to give a heads-up going

in. Just having that conversation up front about who would make you most comfortable when you are giving birth is really helpful.

Systems for Early Care and Prevention

Advocates shared that optimal health for a birthing person begins long before becoming pregnant. Regular health checkups and preventive care alongside healthy lifestyles provides a strong foundation for maternal health during pregnancy. One advocate shared:

> *We can't start these interventions and these services the day you're pregnant and say, 'Oh, now that you have this support, you'll be healthy now' when you don't know if folks have access to health care, produce, safe housing, any of that before inception. That's important to get all systems working together to make sure we are wrapping supports around the whole family and the whole person so when pregnancy does happen, we already have those things in place.*

Insurance came up as a need for birthing persons for navigating healthcare costs.

Advocates also shared that a strong foundation for pregnancy includes having basic needs met, including housing, food, money, and safety. Regarding basic needs, an advocate shared, "*That is protection from domestic violence. That is stable work conditions that give that pregnant person allowances for their pregnancy. Livable wages that allow them to only work maybe one job while they're pregnant instead of having to work multiple jobs.*"

Preconceptive care was another support identified in community conversations for good maternal health. Advocates shared that birthing persons who are ready to become parents often have better mental health and are more likely to seek care throughout pregnancy, as described in the following:

> *I think access to early preconception care, not prenatal care, but preconception, because so many people that are going to become pregnant are not intending to become pregnant, and so they're not really seeking the kind of health care maintenance, chronic disease management, that they really do need to have, or contraception so that if they indeed are not planning to get pregnant then manage that in a way that meets their life goals, their reproductive goals. Having that early preconception care, I think is really important. Plus, that will help with having a healthy pregnancy and a good childbirth, and having a plan for after childbirth.*

Advocates felt mental health is important for birthing persons and identified mental health services as an important support.

Prenatal Care: Doulas, Navigation, and Specialized Care

Advocates discussed the importance of high-quality prenatal care and support for birthing persons. One advocate shared, *"For me, I think it is adequate or proper prenatal care, seeing your doctor on regular visits, avoiding, to the extent possible, environmental stressors, having an effective support system."* Advocates connected doula services, navigation support, and specialized care as key supports for good prenatal care.

Advocates discussed the historical and significant role doulas have played in many communities before, during, and after birth. They shared how doulas help advocate for and guide birthing persons of color in health systems that too often lead to poor birth outcomes. Advocates wanted doulas to be championed in health systems and made more accessible as illustrated in the following quote:

> *Midwives and doulas have always actually been a part of our birthing experiences and processes, as black people. That piece, to me—that's nothing new. What we're missing and lacking is the valuing and the honoring of those folks in this piece. I just had to say that because [doulas are] the hype now, but it's always been what it is. It's always been what is helping to save or decrease these morbidity numbers that we just talk about in our presentations, but not really looking at why these things exist.*

Advocates felt navigation and case management were important for guiding birthing persons and their families through health systems that are difficult to navigate. An advocate discussed having a team available to guide birthing people to the supports and information they need:

> *At the moment that they find out that they are pregnant, that we have nutritionists, and that those appointments with their caregiver or with the person who tells them that they're pregnant or that they're expecting a baby, there needs to be a team on board at that time to let them know what's available.*

Finally, advocates discussed the need for specialized care for birthing people needing support for health conditions that could lead to high-risk pregnancies, such as high blood pressure and diabetes.

Post-partum Care: NICU Support, Navigation, Home Visits, and Parental Leave

For optimal maternal health, advocates emphasized the need for better systems of support for birthing persons beyond birth. A high proportion of pregnancies in communities of color result in premature birth and the need for NICU support. Advocates identified a need for parents to be better supported while their babies are receiving NICU care, as this is an incredibly stressful time for parents.

Advocates suggested all birthing persons be connected with services, such as lactation services and navigation. Lactation services would help birthing persons feel supported and confident in choosing how they want to feed their infants. Advocates felt navigation and case management needed to continue after a person gave birth to ensure they are receiving the post-partum care they need. To help ensure parents are receiving post-partum care and support, advocates identified home visits as a means for ensuring new parents receive post-partum care and parenting support, instead of trying to get new parents to come to provider offices.

Advocates also discussed a need for improved parental leave systems. They shared that longer parental leave would improve mental health and physical health of birthing persons. In the following quote, an advocate shared how inadequate parental leave meant choosing between caring for their infant in the hospital or employment:

Longer than 12 weeks that needs to be looked at from that angle as well because I ended up maxing out every possible leave there was with my job. After, I think, about 12 weeks, I got a letter in the mail, "Either you come back to work, or you no longer have a job," which no longer having a job was my option because my child was in the hospital six months.

Education and Awareness

Advocates identified a need for education around parenting and for increased awareness of services available. They discussed education as empowering for birthing persons and their families and allows for them to be better advocates for their and their baby's health, as described in this quote:

I think the impact on education because education is going to get you to where you can learn better how to speak up for yourself, how to read and understand health care systems, how to advocate for your own health, so I think the impact of structural racism on the educational system is the big contributor.

Infant and Toddler Health

Similar to maternal health, conversation participants discussed barriers and challenges to achieving ideal infant and toddler health (as defined as from birth to age three) in their communities. Among those challenges, lack of quality childcare, barriers to health access, a deficit of basic needs, cultural insensitivity, misinformation, and a lack of awareness of services available emerged as key themes across the three states.

Barriers

Advocates explained specific barriers and challenges affecting infant and toddler health in their communities.

Lack of Quality Childcare

Most advocates discussed significant barriers to receiving quality childcare for infants and toddlers. Advocates pointed to factors such as childcare deserts and shortages, long waitlists for enrollment, underqualified staff, and cost of care. One advocate shared some challenges they faced in Texas:

I also would like to add here that in the state of Texas, we're minimum standards. That means that we're putting our infants and toddlers in a minimum-standard center. When you think about equity and you think about where we have our quality childcare deserts, these are programs that are not nationally accredited. These are programs where staff have not received really amazing training or got an Associate's degree or a CBA, at least in San Antonio... So when we think about a healthy infant and toddler, then we need to look at how the state of Texas views early care and education. If we're saying that it's okay for you to open a center and all you need is minimum standards, just be 18 years old, good background check. "Come on in. You're a baby teacher." Teachers that are in our programs right now in the state of Texas have less training than a nail tech. That means that ... person touching your nails has more training and has to pass a state exam to touch your feet and hands.

At least one advocate in North Carolina discussed some positives around requirements for teacher licensing in the state:

> *One of the biggest things in terms of childcare centers has to do with licensing, and having a quality educational environment, and having teachers who are qualified to provide that environment. I know in our county, most of our centers are 3, 4, 5-star centers, and we have an NC Pre-K program where all of those centers are 4- or 5-star centers. Teachers have to have degrees in our NC Pre-K program. They have to understand early learning environments, play, and getting parents to understand that children are not just playing, but they're actually learning skills, math skills, and science skills. Different types of skills that parents think, well, all they do is play all day. We have to educate parents that children are not just playing all day.*

Some advocates also discussed a need for childcare options for children needing specialized care environments for mental, behavioral, or other health needs.

Barriers to Receiving Health Care

Advocates discussed a number of barriers around receiving adequate health care, including barriers to accessing services and limitations in services available. Healthcare costs and limited insurance coverage were barriers discussed by advocates. They also highlighted unwieldy application processes and eligibility requirements as illustrated in the following quote:

> *I also think there needs to be a policy change, so if programs need my social security number in order for me to get services, I might not have one. That's a policy change. There are many programs out there that require documentation of some things that parents don't have, so it's not that I don't want to access it.*

Advocates discussed shortages in specialized care services, such as for mental and behavioral health or other health needs as well as better access to and awareness around oral hygiene care.

Advocates shared that many children in their communities are lacking basic needs for a strong health foundation and development. These needs include stable housing, access to healthy food and basic food security, and safety. Several advocates described unsafe environments for developing infants and toddlers and the detrimental effect on mental health as illustrated in the following quote:

> *Also, I believe mental health, like you say, for everyone in the household, everyone involved. I know, in a lot of communities, like my community, we experience gunshots so much that you can't play it off any more like, "Oh, those are just fireworks." The kids come running in the house. They can't play or feel safe in their own yard. Safety is one of the hierarchies of needs, so if the child doesn't feel safe in their home, community, wherever—a lot of people adjust and adapt to their situation, not realizing that this is affecting them mentally.*

Cultural Insensitivity

Advocates described that similar to maternal health, cultural insensitivity among health and service providers is a barrier for infant and toddler health as well. One advocate described how parents do not feel respected and listened to by providers:

> *I think a part of the problem is we try to put everybody in this one basket because we know everything, and we forget that we're diminishing, we're tearing apart trust, and we're pushing people away because we don't listen to them and we don't invite them into the space or walk into their space looking at them as the experts because they are and making sure that we are meeting them where they are and bringing in those supports and those resources that they desire for their children.*

Another advocate identified provider training as a root cause of cultural insensitivity, *"I think a part of the trust issue that we have in some of our communities is the fact that many of our providers are trained using an affluent whiteness lens, from affluent whiteness. That's the way they're trained."*

Misinformation

Advocates identified misinformation as a barrier to families seeking services. They discussed how misinformation, especially misinformation that causes fear, can spread quickly in communities and is not easy to override with accurate information. One advocate provided an example where misinformation regarding a policy that would keep undocumented children from attending public schools led to fear of families seeking services for their children:

> *We've heard that some families go to a community event and they are scared to get a free backpack for their kids because they're scared that someone's going to find out and it's going to affect their family. What that means is that we have to be talking to these families and getting them accurate information about this and let them know it is safe to apply, that this will never impact the immigration status for them or for anyone else that they're living with. That also requires a lot of funding because if you want to get that information in the channels that these families are actually listening to—if you want to get a PSA on Univision or Telemundo, that costs a lot of money. As non-profits, we are doing our best to raise money for that and it is just not enough.*

Awareness of Resources

Finally, advocates pointed to a lack of awareness of available resources for families with kids aged three and under

Supports and Services Needed for Optimal Infant and Toddler Health

Community conversation participants discussed the supports and services needed to help infant and toddlers achieve optimal health. Among needed supports and services, culturally responsive care and services, provision of basic needs, quality childcare, and the ability to thrive emerged as key themes across the three states.

Advocates identified access to quality childcare as a significant support needed for optimal infant and toddler health. In particular, advocates discussed a need for more high-quality childcare providers to address childcare deserts. Staff need to have proper training, and licensing policies are needed to ensure staff are well qualified. In order to retain high-quality staff, providers need better pay and

benefits. Advocates discussed that cost for childcare is already a barrier for many families and suggested subsidies to help offset costs.

Advocates expressed a need for services and supports ensuring that basic needs, such as housing, food security, safety, and nurturing environments are met so infants and toddlers have foundational needs for healthy physical and mental development. Advocates iterated parents needed to have mental and behavioral health supports as well so they could be nurturing caregivers.

Advocates argued parents don't just want basic needs for their children, they want their children to have everything they need to truly thrive. They were weary of focusing on minimum standards, and instead wanted to ensure the goal was equity. One advocate stated, *"I want no different for your child than I want for my child. It's pretty simple, so whatever they have in thriving, majority communities, that's what we want in our community."* Another advocate shared the following:

> *Every child 0 - 3 should have everything they need to thrive. Period. [Early and Periodic Screening, Diagnostic and Treatment] (screenings for developmental delays), access to high-quality child care, supports for home learning if parents do not want to use early care, regulated family day homes, access to healthy food, clean air, clean water, safe streets, and loving communities that can provide Positive Childhood Experiences (as opposed to mitigating [Adverse Childhood Experiences]).*

Access and Utilization of Supports and Services

The community conversations explored ideas on how access to supports and services could be improved and how utilization of supports and services could be increased.

How to Improve Access to Supports and Services.

A clear key theme that emerged for improving access to supports and services for maternal, infant, and toddler health was centralization of services. Advocates presented several ways supports and services could be centralized to improve access. Having a centralized location where multiple systems of care can be provided was discussed across all three states. One advocate shared, "*Yeah, that is the vision of the community hub, having multiple systems of care under one roof so once you go in, you have access to all of this...That is the ideal situation."* Advocates discussed how including services like general check-ups, vision, dental, mental and behavioral services, and navigation to other services under one roof would greatly improve access to all of these services. They discussed collaboration among local organizations and service providers to remove silos and increase awareness of their services. Finally, advocates recommended a centralized application for supports and services as described in the following quote:

> *Maybe we should have one application that is—I mean, you're filling in the same information multiple times. For somebody who has, like she said, limited access to things, this becomes a nuisance. You go for care at one point, you have to fill that. Then you go somewhere else, you*

have to fill the same information again. There has to be a way the systems talk to each other because many of these families are in multiple systems of care. There needs to be something more between agencies that they can talk to each other or link somehow like the hospitals do. That has to be across the agencies as well.

A centralized and simplified application process was also suggested to increase utilization of supports and services and is described in the next section.

How to Increase Utilization of Supports and Services

Advocates discussed ideas to increase utilization of maternal, infant, and toddler supports and services. Key themes of the discussion included building trust, reducing logistical barriers, simplifying eligibility requirements, providing culturally responsive services, and arranging soft hand-offs between services.

Build Trust

Advocates discussed the importance of building trust within communities, including nurturing relationships and ensuring information is trusted. Advocates identified trust as a key gateway to information sharing as illustrated in the following quote:

The technical goal of the program is focused on parent-child relationships, social-emotional development, and language and literacy, but we really focus on building that relationship. I think that's the real power of that program and some of the other programs, is just building that relationship so that, yes, you might be focused on this one thing, but you have that trusted resource that you can ask anything else that's going on, any other question you have.

Reduce Logistical Barriers

Advocates suggested reducing logistical barriers to increase utilization of supports and services. They discussed removing transportation barriers by planning around transportation needs such as location consideration or implementing mobile clinics. They also discussed extending hours of operation so that services are available in the evenings or on weekends. Advocates suggested having childcare available so parents could bring their children to appointments without fear of judgement. Finally, advocates discussed increasing access to insurance would help remove many of the cost barriers associated with healthcare.

Simplified Eligibility Requirements

As mentioned previously, advocates discussed simplifying eligibility requirements needed to qualify for services. Besides a universal application for all services, they suggested eliminating required information or documents that are difficult to procure, such as birth records or social security numbers, as illustrated in the following quote:

One thing that we're working on, there are many things, but it's just the application process. The kind of information that's required on an application, tax information, household income, household composition, all sorts of information that a lot of people have trouble completing. One, they don't have it. Two, if they're not in a stable household, they may not have access to it.

They just may not have that information saved like a person living in one place with support and everything, you keep your files here, and then you don't have to ask—do you have to ask your spouse or whoever's in charge of the household?

Culturally Responsive Services

Advocates further emphasized the importance of culturally responsive services to increase utilization of supports and services. People of color need to feel confident that their concerns will be listened to and understood by providers. Ideally, providers should be representative of the communities they serve and share lived experiences with parents.

Soft Hand-offs/Navigation

Advocates also suggested soft hand-offs between services to ensure families are receiving the continuum of care they need and assistance in navigating services. An advocate described this hand off in the quote below:

It's a still a very stigmatized issue, so it's a combination of overcoming the stigma, making sure they know about the benefits of these programs, making sure it's not—it's easy for them to apply. Often, at times, that means making sure that there's someone there with them to help them through every step of the process and answer their questions. Yeah, and that there's funding to support those staff.

Effects of COVID-19 Pandemic

Community conversation participants addressed both the positive and negative effects of the COVID-19 pandemic.

Positive Effects

Among positive effects of COVID-19, shifts to virtual platforms, policy changes, expansion of program services, and a focus on mental health came up as major themes discussed by advocates.

Virtual Platform

Advocates discussed how COVID-19 facilitated a shift towards utilizing virtual platforms for services, meetings, and public forums. Telehealth services expanded which increased access for healthcare services. Advocates also discussed how Zoom allowed them to reach more clients with fewer barriers. Some legislative sessions were conducted online and advocates reported how this provided greater opportunity for advocates and community members to participate, as shared in the following quote:

I think COVID actually provided an interesting opportunity for us in that a lot of offices were open to meeting virtually, so even though it wasn't a hearing, we had the staff and the capacity to reach out and schedule Zoom meetings with a lot of legislative offices at the Capitol. Then we could just tell our storytellers, people with these lived experiences, "Hey. Here's the link." Like, "If you're free, come join us," and a lot of people came and they felt it was a really meaningful chance to share their experiences directly with an office that had power and decision-making power over the process.

Some advocates also acknowledged that shifts to virtual platforms increased barriers for some who did not have access to appropriate technology or skills in operating technology.

Policies

Advocates described COVID-19 as a *"crisis that created political will to improve things a little bit."* They credited COVID-19 with policy changes that improved opportunities for many communities of color. Policies discussed included the Child Tax Credit, Affordable Care improvements, and Medicaid continuation. One advocate described Medicaid continuation as follows:

> *Once women became eligible for pregnant women's Medicaid, they were able to stay on. I'm talking about it from the women's health perspective, but they were able to stay on. The public health emergency did not allow the states to disenroll anyone from Medicaid during that period. That public health emergency is ending soon and there's a big concern about this flood of people who have been eligible and will become ineligible and then what it'll take to get them determined, for those that qualify, get them determined eligible at the end in a timely way.*

As illustrated above, advocates shared that these policies have already ended or will end soon and discussed concern over the loss of benefits.

Expansion of Some Program Services

Advocates described how COVID-19 allowed some community organizations to expand services provided to families. One advocate shared how COVID-19 spotlighted the work many smaller organizations were doing in communities:

> *COVID just kind of moved the big, leaning, towers out of the way and you saw all of these, what we consider to be small organizations, that have been here for years and are actually embedded in the community because we get out and we do the work.*

Focus on Mental Health

Advocates discussed how COVID-19 brought down some of the barriers and stigma around mental health. This was discussed as both a negative and a positive in that the pandemic caused such a deep decline in mental health that it became impossible to ignore. One advocate shared, *"The pandemic has just exacerbated things that we've glossed over before, and now we can't gloss over them anymore."*

Negative Effects

Among negative effects of COVID-19, childcare disruptions, service and staff shortages, lack of support at hospitals, parents leaving the workforce, and abuse in homes came up as major themes discussed by advocates. Advocates discussed how COVID-19 caused many childcare centers to shut down due to staffing shortages or COVID-19 policies which substantially disrupted childcare situations for families. Staffing shortages were also observed in numerous healthcare service providers which resulted in long wait times and other access barriers. Advocates described harm caused to families who were not able to support loved ones in hospitals during childbirth and other procedures. Advocates shared that many parents left the workforce due to childcare disruptions which intensified workforce inequities. Finally,

advocates discussed the negative ramifications for individuals who were isolated in homes with abusers.

Other Effects

During the discussion of effects of COVID-19, advocates devoted considerable time to describing how their organizations made huge pivots to address emerging community needs due to the pandemic that were not being addressed by larger institutions. One advocate shared, *"It's our struggling nonprofits that are making it work for our families."* They described their organizations as having direct links to communities and able to respond to community-level needs, even though the bulk of the work was not well funded. These sentiments are illustrated in the following quotes:

- *We really had to pivot and help our families with basic needs, the things that they needed just to hang on, and I like to say that community-based organizations – we stood in the gap between what the state and what the feds were not doing real-time. We were putting real-time services out there to help our families to survive. We had to realize when you are trying to get a mental health service and you're in the home with the person that's causing that mental health issue, we're going to have to try to provide our services differently. Those were some of the things that we recognized.*
- *Then we won't even talk about the technology divide. We had to step up and put the technology into the hands of our families before we could even continue to provide the services. We didn't get any funding from our government partners to do that. We had to just step out on faith and do what we needed to do to help our families to survive, and it's not over. The challenges of COVID-19 are still present and impacting families today.*
- *In San Antonio, it was our non-profits that work on a shoestring that were there delivering diapers and care for our programs. They just pivoted and made it happen, and other programs shut down. I think we need to really come back and celebrate them, but also, document the ones that did it.*

Structural Racism

The second half of the community conversations explored structural racism and how advocates approach policy and systems level changes in politically conservative environments.

Effects of Structural Racism

The community conversations explored how people of color have been impacted by structural racism. Advocates discussed how structural racism has a major influence on health, education, career opportunities, and other major aspects of livelihood. These aspects are presented in this section.

Health Inequities

Advocates described how structural racism is at the core of most health inequities. They discussed how structural racism causes or amplifies many of the barriers to health care discussed earlier. For example, advocates discussed how built environments are negatively impacted by structural racism,

which can affect transportation for accessing healthcare. Advocates also described how experiences within the healthcare systems are impacted by structural racism. They shared stories of providers displaying less empathy for patients of color than for their white patients and of providers who were unwilling to listen to patients of color and take their concerns seriously. Some of these stories are shared below:

- *This young girl came, 18, 19 years old, and she was recounting her childbirth experience. She is a health worker. She's studying to be one. She said while the doctor was stitching her up and she said, "I can feel you stitching me up after." He said, "No, you can't." She said, "Yes, I can." She said in his mind he thinks I'm not feeling the pain because she said he told her, "No, you're not feeling the pain." She said, "Had it been a White girl, 19, 18-year-old," she would be the frail White girl while she was the thick-skinned Black kid on Medicaid. Honestly, that is the word she used. These are the perceptions when we are talking. These are the things that need to change.*

- *It was a big uproar, but when we finally got to the end of the story when my sister was discharged, ultimately, during that experience, the nurses had noted several times where they couldn't track [her baby's] heart rate for an extended period of time, but they just kept coming into the room and telling her to stop moving. She said, "They came in five or six times and told me stop moving. You're moving, and you're making the monitor move, and we can't track his heartbeat." After about the sixth or seventh time of that happening, finally, one of the nurses checked her to see how far along she was dilated, and they noticed that his umbilical cord was out, prolapsed, and that triggered an emergency C-section... My sister actually almost lost her life during that experience as well 'because she lost a lot of blood, so we almost lost both of them during that experience... I personally question whether the outcome would have been the same—now, my nephew has traumatic brain injury for the rest of his life and is diagnosed with cerebral palsy, severe cerebral palsy for the rest of his life—whether that would have been the same had she not been an oversized black female, ultimately. I think that had a lot to do with that circumstance, whether they would have taken more precautions and been more aware of the situation had she been of a different skin tone.*

- *I'm not saying everyone is evil, but if you all have heard some of the stories that I have heard of folks going into the ER being sent home to have babies on their bathroom floor, sitting in the ER until they have stillbirth, or getting toxic poisoning because the placentas weren't completely moved, or they're bleeding out because the uterus wasn't massaged, having babies on the floor because the doctor wasn't listening when Mommy said, "I need to push right now." Immediately, in a daze, [signing] NDA disclosures before realizing what just happened. "Wait, I lost my child? Wait, I can't sue because y'all have already gotten my signature on this paper? Wait, what happened?" People who are like, "I will have my baby on the sidewalk before I set foot into [a hospital] again." It's really devastating. It all goes down to folks not being listened to and not having access to the care that they request when they request it.*

As illustrated in these quotes, advocates also pointed to the negative effects structural racism has had on health and birthing outcomes.

Career Opportunities

Advocates shared how structural racism effects career opportunities for people of color. They discussed that even with higher education, racism keeps many people of color from career advancement. Advocates also discussed how inequities in career opportunities exacerbates income gaps for people of color, particularly women of color, as described below:

> *I think I spoke to that a little bit earlier when we were talking about caregivers being primarily women of color who also don't have access to the same kind of care or care for their children. I think that is just a prime example of the type of systemic racism that goes under the radar. Even things such as the ability to receive equal pay for equal work. That's a problem that women have in general, but women of color have that by and large, and so while we may have greater disparities in health and our health needs, we also have greater disparities in our ability to meet those needs through the income gap.*

Allocation of Resources

Advocates discussed inequities in allocation of resources, particularly land, housing, and food, as an effect of structural racism. They shared that structural racism amplified issues with affordable housing and neighborhood safety as described in the following quote:

> *Racist housing practices and subsequent gentrification has left many black families unable to afford housing or rent, segregated from other black families, or exposed to high rates of gun violence; lack of safety for black families in Durham so that black families feel like they don't belong where they live.*

Another advocate shared the following:

> *In this Houston area and closer to Galveston County there are higher concentrations of Black and brown families who live in areas that have environmental health concerns and there's that structural racism again. That's also a result of redlining and lending practices in places where Black and brown families have been allowed to purchase homes or build communities. All of those things have a direct pipeline to disparities for maternal health and the health of children and families.*

Voter Suppression

Advocates discussed how structural racism was perpetuated through voter suppression intended to preserve systems of power as described below:

> *We can't even get the people out who are saying we can't expand them because every time we try to get them out, they shift the boundaries of where their districts are. People we had that were in—"who were good people for our districts," they shifted the lines and now we got some old, crusty dude in that district who's going to vote not to expand.*

White Systems of Power

Advocates further described how structural racism kept white systems of power intact. One advocate shared how the system was not build for people of color, *"When we also think about structural racism,*

specifically in our community, it's because this is a system that was not built to care for us, so why would we expect anything different?" Advocates displayed frustration and hopelessness with structural racism. They described structures that are deeply embedded and difficult to change from the outside. The following quotes illustrate their frustrations:

- *When you talk about structural racism, you also have to mention systematic racism because that's the continuum of it. That's how it keeps going. Again, something that was not designed or ever created to serve certain populations. If you do not dismantle the systems in play, then the structural piece continues.*
- *We know what the problem is and we also know how big this problem is and the deep roots this problem has. I don't know how to get at the root of it because we can keep whacking at some of the stuff on the top, ... it's going to grow right back up again in the next iteration. It's very crazy. The system is very much imbalanced and I'm not sure how we dig down to kill those roots so that whatever we can whack up on the top doesn't come back. Then we can really start to flourish with the families, but I don't know.*
- *For me, it's all about power and privilege, the privilege for those who are in power to choose to make laws, to make policies, to spend our collective money the way they choose to. Until we change that system, nothing is going to change.*
- *It comes, really, down to this understanding of policy and understanding that policy is structural—it's embedded with racism. The reason why we have these really crappy laws in Texas is because someone has decided to take their biases and make it a law that other people have to abide by. That's Texas to the T. I mean, we are synonymous with, "Houston, we have a problem," but Texas—we have the biggest problem ever.*
- *There's this perception of how this little boy should behave, how he could show up, how the family should show up. There's just been this consistent nagging, nagging. This child was suspended from a preschool program. Three years old. These types of things are happening across our state, across the country. These are symptoms of structural racism.*
- *We just got the first depiction of a black fetus in 2021. What are we doing? That is really messed up. We don't even see ourself represented in materials, so how the heck do we feel like we're considered as people in practice? I just think it's super deep. It goes back to burn it up and tear it down and start over. We just can't keep doing this.*

Engaging Conservative Lawmakers

Advocates were asked about their experiences as advocates in engaging conservative lawmakers in conversations regarding equity.

Advocates discussed challenges with using language directly referencing "equity." They discussed needing to soften their language for conservative lawmakers, feelings of oppression when changing language for white lawmakers, and fear of retaliation if caught failing to obey unspoken rules of engagement.

Advocates reported that equity is a difficult topic to navigate with conservative lawmakers. They discussed meeting considerable resistance from conservative lawmakers when words like "equity" are used. One advocate reported, *"The resistance has to do with the fact that the truth really makes people uncomfortable."* Another advocate shared the following:

> *It's 100 percent true. I can't say the word equity at the capital and expect to get my policy or my legislation through. We've been, for a couple years, focusing on what we call stealth equity, which is where we do what needs to be done without using the word equity because we know that the politicians, the legislators, the very conservative legislators at our capital are just not going to respond to the word or the conversation. It is absolutely our reality. We try to stay away from the word.*

A few advocates felt some conservative lawmakers perpetuate fear of speaking about equity as a means to oppress people of color and maintain systems of power, as illustrated in the following quote:

> *It's a tool of white supremacy to maintain power, maintain white power, and hold down other perspectives and create this tightrope that anyone has to walk to be able to even suggest a different idea or suggest different thoughts or make a different decision. It's a tightrope that anyone has to walk, and especially for leaders of color to walk, that prevents access to that decision-making space.*

Some advocates questioned whether they should censor equity language, or if censoring was perpetuating harm and side-stepping important issues.

Others shared their fear of retaliation if they were caught breaking unspoken rules of engagement with conservative lawmakers who hold considerable power over resources. One advocate shared the following:

> *Those are the games that these power-holders play. "Oh, you think you want to be in power and you live in public housing? Watch us snatch your public housing. Oh, you want to complain about the system? Watch us snatch your voucher. Watch me snatch your food stamps. Oh, you think you are going to take a picture at a restaurant and we not going to come back and do an audit on your income?*

Advocates questioned if equity was desired by some lawmakers. They reported feeling that some lawmakers were actively working against the interest of equity and instead were actively working to maintain systems of power. An advocate shared the following:

> *I think we've kind of talked about how our conservative white lawmakers do not care about equity. It's not that they don't know about it. It's not that they're ignorant. They want the opposite of equity. So many of the policies we've talked about today, like the lack of Medicaid expansion, the lack of so many basic needs that low-income families need—that is all because our lawmakers actively don't want to care for these families or provide supports to them. We know that appealing to them through the lens of equity isn't going to work. What we do know is*

that at the end of the day, their jobs depend on their voters, and we've tried a number of things to try and activate those voters.

Finally, some advocates expressed doubts that projects like this one could affect meaningful change among conservative lawmakers:

> *Y'all are going to send them the report, and they ain't going to listen to it. Y'all are going to send the notes. Their staffer might read the notes and might shoot up three sentences as a summary. They are going to shoot off that same form email that their office been has been sending me back for the last year about the two efforts they did to help black people in that same copy-and-paste form email. Me and my sister have been getting the same response for over a year. They do not care.*

The following quote also illustrates an advocate's perception of racism among conservative lawmakers:

> *I've personally seen the racism among legislators and policymakers. They 'other.' They want to blame people of color for their lot in life and immediately make the conversation about the "absence of fathers" without taking responsibility for the fact that the criminal justice system in Louisiana incarcerates black men at a rate several times higher than white men.*

Approach to Engage Conservative Lawmakers

Conversations explored approaches to engaging conservative lawmakers in discussions about equity. Key themes included making an economic argument, talking about equity without using the word, using data, starting conversations, sharing lived experiences, and engaging lawmakers on the record.

Advocates described crafting messaging around economic arguments for change. An advocate shared, *"We make the economic argument. Inequity costs money."* Many conservative lawmakers were willing to engage in conversations that made a compelling cost argument, as illustrated in the following quotes:

- *...I tailor my message accordingly, but I'm stating the facts based on research so that they can understand and see the picture based on what needs to happen in [my] county and how it affects the money that may come to the county.*
- *The entire state will cease to be the economic powerhouse that we've always been. It's been on the backs of these persons who are now gaining a majority in the State of Texas, and so it's truly, truly an economic thing. You have to close these disparities in order to keep this state afloat.*
- *Because we're usually asking for funding for programs, a lot of times, you have to take the angle of a cost-benefit analysis for different things...—particularly, I know for disability services and for a lot of other things as well, we are wasting money and supporting programs that aren't the best benefit for some of our communities when we could be getting a better dollar value for other things that could maximize a child's potential for growth and development. Like from the disability side, a lot of times, we're asking our legislators to spend money on certain things, but*

we have proved to them on paper that you're going to spend more over there than you are doing what it is that we're asking. For a lot of them, when you're asking them to spend money, they want to show you're giving them a bang for their buck. When we're advocating for programs that are creating inclusive environments for kids with disabilities, we're showing them that, when you're creating these separate places and these separate entities, you're going to pay.

Advocates also described how they engage conservative lawmakers in discussions about equity without actually using the word 'equity.' Instead, advocates focused conversations on describing how all families or all residents will benefit. For example, an advocate shared the following:

We get them on board with policies that don't use the word equity, but the net outcome is that it impacts equity. For instance, we just killed a bill that required work requirements under SNAP. We focused on how much the employment checks costs and what the benefits are to families.

Advocates shared that data was a powerful tool they used in messaging. Lawmakers seemed to respond to facts and data, for example, reporting disparities by demographic breakdown can open the door for equity related discussions.

Some advocates felt difficult conversations with lawmakers needed to be held with or without equity language. They didn't feel it should be their responsibility to tip toe around difficult conversations or have to make arguments about why they should be listened to. An advocate shared, *"It's something that I grapple with. I have to say at what point do I stop grappling with this and realize that maybe it's not my burden to carry to try to convince someone of my worth?"*

Advocates felt a major barrier to having meaningful discussions with conservative lawmakers was a lack of shared lived experiences. They felt many lawmakers were unable to empathize with the challenges communities of color face because they didn't understand their lived experiences. An advocate shared, *"It doesn't make any sense to keep creating solutions for people when you don't have that lived experience of what might help."* Some advocates suggested having community members share their lived experiences with lawmakers as described below:

I think, in order to make change, it has to do a lot with the conversations that are happening today, continuing to raise awareness around the lived experience. A lot of times, just doing advocacy from the disabilities perspective, the way we've been able to advance policies and legislation over the past few years is because we bring parents to the table who had that lived experience about how a law or a policy has impacted their life.

Other advocates felt lawmakers would benefit from simulations where they could try to experience some of challenges people of color face, as described in the following quote:

I think if they did a workshop and have them appear to be of a different race and economic status and give them a scenario: 'You are a black female or a Hispanic male with three children on a fixed income that maybe says one of your children has a disability or a mental health issue,' and try to ask them to call our systems, call our state, to try to get help and see whether they

can get any leeway. They can see for themselves how hard it is to deal with the different outcomes and the different things like, you may not be able to get this. You may get the runaround. Then they can realize how important funding is, like a walking a mile in my shoes kind of thing.

Finally, some advocates suggested engaging and calling lawmakers out on the record as described below:

I think the other thing that's important, too, is calling elected officials out on the record. They like to say a lot of things unofficially, but let's go on the record and see what your constituency thinks about what it is you have to say about equity, which is why there's this big ordeal about how all these states are doing their redistricting maps because, for any lawmaker, their ultimate goal is to be reelected, and to be reelected, it's their constituency that is the person that's putting them in office. We always hold public forums and invite them to participate on the panels so they can get asked questions by the people who voted for them because it's one thing to have your own personal beliefs, but to actually go on the record about that, that changes the dynamic.

Advice for Advocates

Advocates were asked to share advice for others who are currently advancing or interested in advancing maternal, infant, and toddler health equity.

Advice for White Advocates

Advocates shared advice for white advocates to effectively support advocates of color. Major themes included uplifting community voices and priorities, checking implicit biases, giving up power, hiring people of color in leadership and other organization positions, and sharing the burden.

Advocates wanted white allies to help uplift community voices and ensure that they are advancing community priorities. They asked white allies to check-in with communities about their priorities and the information communities want to be shared. They also requested white advocates to help control misinformation. One advocate shared the following:

I think if we're specifically talking about allies and White advocates in particular, one of the most important things that I share is the adage of nothing about us without us. If you are going to be trying to influence lawmakers, be sure to uplift the voices of those who are affected by the causes that you are an ally for. Take them with you. Make sure you have factual, relevant information. Make sure that what you are saying is exactly what will help that community, as opposed to what you think would help that community.

Advocates advised white advocates to check their own implicit biases and examine their positionality when working with different communities to ensure they are not perpetuating harm. One advocate shared:

I'm angry. I'm always angry because it is all about perceptions. How you're perceiving the person in front of you is how you're going to give care. I've been in healthcare for a long time,

and it is all about how you perceive the person in front of you. It doesn't matter what you have learned as a health care provider or as an organization, as an agency. That is the bottom line. Those unconscious biases that we have within ourselves need to go. That is step one, on a personal level. Only then we can start making changes at an organizational level."

Advocates advised white advocates to give up their power and privilege to make space for people of color as illustrated in the following quote:

> *Allies willing to give up their position of power so that other folks of color can rise. Birth workers, doulas, again, often not paid or paid very, very low wages in order to do this work. I think at times often it's a privilege to be able to do things like go to school or apprentice or do clinicals and not have to worry about providing for yourself or for your family. Once we create conditions where people can be successful in entering those fields in order to give back to the community at a larger level, we'll see more people of color in the spaces that we need.*

Similar to giving up power and privilege, advocates emphasized the importance of intentionally hiring people of color into leadership and other roles within organizations. They discussed a need to have people of color driving decisions that align with community needs, as discussed in the illustrative quotes below:

- *I think we didn't touch on it and I don't know where it goes exactly, but I see the need to hire people of color to be on our team to help direct our work so that we're not speaking with a white voice, you know what I mean, so that we are speaking in a way in our materials, in our efforts, in our partnerships, in the way that's going to maximize addressing racism and equity…Our organizations, not just healthcare, but other organizations reflecting intentionally the people that we need to serve or even not just services, just overall, to have that voice and to help direct our business. I just think that's a really important—it's building the structures to be very inclusive and not just posting jobs and hoping you get the right people, but intentionally seeking out those that you need at the table.*
- *You are so right that representation is needed and most of the people of minority ethnicity and race are at the lower level and leadership, except for organization that are founded by people of color. The white organizations most of the time do not have representation of people of color at the leadership level. Not at all. I mean, it doesn't happen in real—and all the organizations where I have seen people of color lead it are the organizations that have been established by them, founded by them.*
- *For me, it's all about power and privilege, the privilege for those who are in power to choose to make laws, to make policies, to spend our collective money the way they choose to. Until we change that system, nothing is going to change.*

Finally, advocates wanted white advocates to share the burden of educating, increasing awareness, and showing up on the front lines of advocacy work. One advocate shared, *"Why do we have to keep having the conversation? Our allies need to be having those conversations with the people that don't get it. It doesn't always need to be us."* Another advocate shared:

Why is it that a lot of time we have to be the one to share and say, 'This is the need. This is the da, da, da, da, da'? Somebody said it earlier. I can't remember who it was. We don't get invited to that next step. It's those allies need to show up for us in those spaces. At school board events, at policy. Different things. Our own small events, donating.

Advice for all Advocates

Advocates shared general advice for anyone working in advocacy. They requested advocates create opportunities to share lived experiences of people of color, collaborate and work together to achieve more collective impact, and to share data with other organizations.

Overall Advice

Advocates also shared overarching advice for systems level change. Key themes included electing champions into office, funding community organizations, dismantling systems, and sharing power with communities.

Elect Champions into Office

Advocates discussed the importance of electing champions, particularly people of color, into office. They desired elected people who were empathetic to maternal, child, and toddler health and who shared lived experiences with communities of color to be able to champion policies that would benefit communities. The following quotes are illustrative of this theme:

- *I think we need more champions that are in office that understand child development, brain development, and not see it as giving away money. If we have someone that truly believes in this, then I think we could move faster ...We don't have enough people in power right now. We're on the menu, but we're not at the table. There's just few people that are really understanding that it speaks volumes, right, of how we care for our children in this country. I think that's the policy and the advocates that need to be there*
- *I think there needs to be more policies in place that support communities of color period. I think that happens by changing the leadership that we have.*
- *I think it has to do a lot with what somebody typed in the chat about making sure that we have elected officials in office or getting elected officials into office who understand the historical precedent that has taken place that has caused all of these structural inequalities and are willing to acknowledge that racism has impacted and caused our communities to have socially disadvantaged groups and that they are willing to tackle those challenges and dismantle those structures, or whether it's a policy, it's an agency, whatever that entity is that is causing people to not have equity in whatever way, whether it's healthcare or education, that we have people in office who are willing to tackle those and to put better policies and better programs in place to improve people's quality of life.*

Advocates emphasized the importance of electing champions into office as a key step to dismantle structural racism, but they also acknowledged that this would be a daunting accomplishment because systems are currently structured to keep the same people in power.

Fund Community Organizations

Increased funding for community organizations emerged as a major theme from the community conversations. Advocates emphasized the importance of smaller community-based organizations to meet unique community needs that larger organizations were unable or unwilling to support. Advocates reported their organizations were thinly stretched and underfunded, but continued to show up in their communities. They argued more funding needed to be directed to organizations embedded within communities and felt funding at the community level could have a much larger impact on those communities, as illustrated in the following quotes:

- *All the funding all goes to those big organization when many times the work is being done at the grassroot level by smaller organizations which need the funding, who know their community, live within that community, understand, so probably reexamine where the funding is going for more equitable care.*
- *I think even more specific than just smaller organizations, organizations that are representative of the populations that they serve need to receive more funding than they do. Smaller organizations tend to also be of similar color, similar socioeconomic status, similar neighborhoods of the communities that they serve, and I think that it bears saying that sometimes funders are not comfortable with funding organizations led by minorities or women and ways that they need to think differently and do.*
- *In order for that to happen, it requires a lot of funding. Community-based organizations will have to be funded. In Texas, too much of that funding goes to agencies, folks who—it's considered to be at the top, and as we've already said, small, non-profit organizations held it down during the pandemic and continue to, without the large funding that is circulated through this state.*
- *That goes back to fully funding all of these agencies and programs that support our families so that they can have a sustainable educated workforce that is able to provide the support to our families. I forgot who mentioned it earlier. A lot of these programs are really good, and these agencies are really good, but high turnover rates and attrition from some of the staff that may have been there for a while and really have the ins and outs of how a lot of these programs work and how to get access and make things move more smoothly and quicker for our families, that really, like she said, frustrates some of our families.*

Dismantle the System

Advocates discussed their desire to dismantle the system. As previously mentioned, advocates felt many of the systems were not created for them and the only solution was to tear them down and start from scratch. Advocates described getting the right people in power as a key step to dismantling systems. Please see discussion section for more.

Share Power with Communities

Finally, advocates discussed a desire to share power with communities. They felt communities were best aligned with their own needs and could help prioritize and shape services that would be most

beneficial for residents. Advocates wanted to see more power shifted to communities as illustrated in the following three quotes:

- *I think in an ideal world, the Latinx community would access maternal and early childhood services, and these services would have been created by them, by parents in the community. They would be provided by them, by members of the community who are Latinos, speak Spanish.*
- *By that I mean giving people decision-making power, letting people set the agenda, letting folks decide, like, "This is how this process and how this timeline is going to go to make change on this project or this initiative that we're doing." That would be my wish, is to actually see that those who are closest to the most pressing human rights issues in our community would also have actual leadership and decision-making power, not just input and then we're going to give you cash. Not that that's not important, too. That is important, but for me, that's like we need to take it also to the next level.*
- *I was going to add being an early childhood director, we see a lot of systemic racism and power struggles. A lot of times we may be invited to meetings when it comes to giving our input based off of the families that we serve within our community, but we are not invited to the meeting after the meetings, when they're really making the decisions. That is where we're dealing with some of the racism.*

Advice for Engaging the Community

Advocates also provided advice for engaging communities in advocacy work. They discussed educating community members and building relationships so they understand the issues and can better advocate for their needs. One advocate shared:

> *The example of what we're not doing well is that for a long time—we have a Medicaid expansion campaign and that's what we're focused on, but that doesn't resonate with people, right? As I mentioned before, a lot of these things are designed for people to not be able to enter into the conversation at all, and so we are finding that we can't just keep talking about Medicaid expansion. We can't just say like, "Hey, come to this meeting about Medicaid expansion," that we have to meet them where they are and support them and help them and build trust and talk about their health, talk about health as they're experiencing it. Then, over time, be able to connect them to these opportunities to take it to the next level and see how they can advocate for improvements to their health, based on policies that are being considered right now.*

Advocates also suggested widespread racial equity training to help educate community members and encourage them to address implicit biases.

Advocates are Exhausted

During the community conversations, advocates of color shared that advocacy work is exhausting and often frustrating and demoralizing. They feel they are working in systems that are stuck and find it hard to gain traction on systems level changes. Many admitted that they approach their work with

pessimism because they understand the systems they are up against. Despite experiencing much despair and exhaustion from their work, they continue to show up in their communities. The following quotes illustrate feelings of exhaustion and evidence of resilience:

- *Many of us on this call, we're constantly advocating. Our entire careers, we spend most of our time advocating. Hopefully it's going to pay off eventually.*
- *It is very exhausting. It is very disappointing and demoralizing. You can feel very defeated. It is a level of trauma that comes along with doing this work.*
- *There is nothing that we can do to prove our humanity to people who for generations have been told otherwise and have benefited from preaching the adverse narrative. Someone who has gained literally their wealth, their health, and their land from putting down my folks, there's no one presentation, sentence, panel, conference that is going to convince them otherwise. We can't do it. We are exhausting ourselves trying to do it. Stress is real. Weathering is real.*
- *I've tried. I've testified before Congress. I've done all the things. I've sat in front of panels, Ways and Means Committee. The questions that I got back were full of racist vitriol and microaggressive[ness]. They're more worried about as a single parent, how can I afford to look like a decent human being. They were more worried about how folks do. "Why you eating crab legs on food stamps?*
- *We're wasting time. We're wasting money. We're wasting resources. If folks aren't really trying to change, just go ahead and let us know so that we can stop wasting that time and figure out something different. We're not going to do any of this without trust, transparency, and respect. We're not going to come in and say, "Hey, we're going to change things different now" without first acknowledging the harm that we have done to communities for decades and decades and decades."*
- *It's not just a matter of saying we're going to do something different. It's a matter of proving. Y'all asking us for receipts. We're asking y'all for receipts. Prove to me that what is happening is really of a benefit to families, and then we can move forward.*

"It's not just a matter of saying we're going to do something different. It's a matter of proving. Y'all asking us for receipts. We're asking y'all for receipts. Prove to me that what is happening is really of a benefit to families, and then we can move forward."

Discussion

This discussion section expounds on the larger themes expressed by advocates of color and allies who participated in the community conversations in Louisiana, North Carolina, and Texas.

Intersection of women of color and infants and toddlers of color within white-orientated systems of health care and early childhood care and education

At this intersection among women of color, infants and toddlers of color, and white-orientated systems, advocates report traumatic healthcare episodes and culturally- and linguistically-unresponsive care that causes harm and perpetuates racial/ethnic inequities in maternal, infant, and toddler health. Outside of this intersection, advocates of color and allies have created and run programs and services for communities of color that address their particular needs.

Advocates contend that health and wellbeing outcomes for women and infants and toddlers of color are wholly dependent on the intersectionality of class, race, ethnicity, skin color, gender, sexual orientation, nationality, socioeconomic status, among others. In turn, experiences with pregnancy and caring for infants and toddlers differs with all the intersections above as well as age, geographic location, and political milieu. Advocates of color recognize that systems created by white people for white people, white institutions, cannot address the specific needs of their communities.

First, according to the community conversation participants, these white institutions, such as hospital systems, school systems, and social services, are not reaching communities of color. When reached, these institutions are not providing communities of color what they need. One advocate expresses that *"I can't look to these white institutions to save me. I can't look to funders to suddenly be antiracist just because of George Floyd in 2020 and think that that's going to last. This is the reality of black and brown people in America."* In fact, according to the executive directors and founders among the advocates, financial support from funders and donors for community organizations serving communities of color has dwindled in comparison over the past two years as has federal, state, and local support. For instance, funding during the early stages of the pandemic, especially from the CARES Act and ARP, served as a vital infusion of funds to stabilize the childcare sector. Currently, advocates of color worry about funding shortfalls negatively affecting small organizations.

Second, advocates shared that white institutions in healthcare through culturally- and linguistically-unresponsive care cause harm to women and infants and toddlers of color. Advocates of color across the three states relate traumatic healthcare episodes, including first-hand experiences. Women of color, in particular African-American and Black women, are not treated with respect or dignity, often dismissed as addicts or liars about what they are in fact experiencing in their own bodies before, during, and after pregnancy.

Prejudice and stereotyping against women of color causes significant mental, emotional, and physical stress. For example, one advocate says:

I know, particularly to my own personal experience, sometimes—because I had a high-risk pregnancy, I had to go to the hospital every week, sometimes twice a week every other day for different things. Sometimes, a lot of the stress that I endured came from whether I was believed or not about my experience by my own healthcare providers.

Another advocate relates:

I ended up experiencing a condition that caused me to have to go back into the hospital the day after I was—less than 12 hours after I was discharged. I was actually accused of being there because I wanted drugs. I was like, "No. There is a serious issue going on, and I don't know what is happening to me. I need somebody to figure it out, and I'm not leaving until you figure it out. I do not want your drugs. Matter of fact, I think your drugs are the reason I'm probably back here.

In another traumatic retelling, an advocate speaks to the experience of her sister who in almost losing her own life gave birth to a child who experienced a significant period of time with a prolapsed umbilical cord resulting in traumatic brain injury and a subsequent diagnosis of severe cerebral palsy. The advocate poses the rhetorical question, *"whether that [outcome] would have been the same had she not been an oversized black female, ultimately. I think that had a lot to do with that circumstance, whether they would have taken more precautions and been more aware of the situation had she been of a different skin tone."* In these and more traumatic episodes, white institutions have consistently proven unable to meet the specific needs of women and infants and toddlers of color.

Finally, outside of this intersection of poor health and wellbeing outcomes lies programs created and run by communities of color. Importantly, doula and midwife services have historically been a part of the birthing process for communities of color. Doulas provide an integral role as advocate and emotional, mental, and physical support for pregnant people. In African-American and Black communities, in particular, doulas and midwives have helped generations of birthing persons since these roles are often reflective of the communities in which they live and thus culturally appropriate. Significantly, advocates contend that *"doulas and midwives have always been a part of black birthing experiences."* In fact, doulas and midwives have been the primary sources of support in Black birthing experiences since the slave era, into post-reconstruction, during the height of Jim Crow, and now in racially segregated areas without adequate healthcare facilities (Hunter, R., 2022).

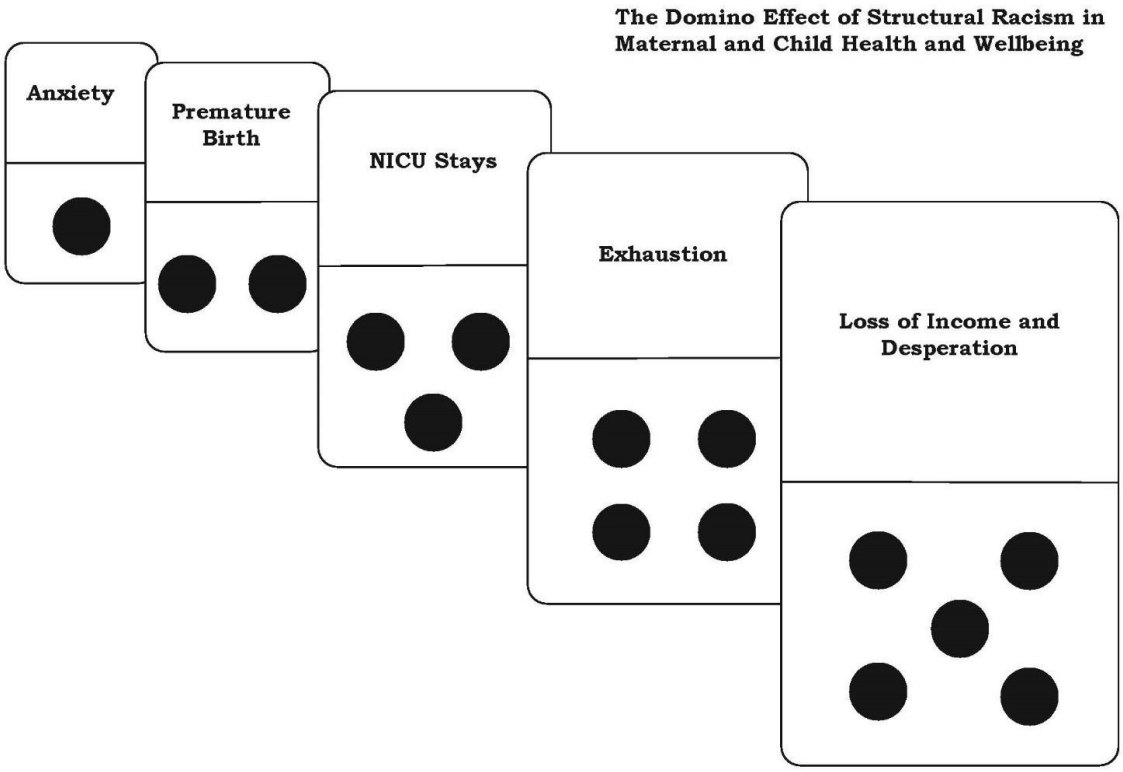
Interconnected cause and effect of structural racism in maternal, infant, and toddler health

Continuing disparities for communities of color in maternal, infant, and toddler health and wellbeing are inextricably interconnected with the mechanisms of structural racism. Communities of color who lack basic necessities to maintain sound maternal, infant, and toddler health and wellbeing are mired in this social condition due to generations of residential segregation, disinvestment in majority-minority neighborhoods, unequal educational systems, lack of health insurance, inconsistent and inaccessible eligibility for programs and services, unsafe housing, unstable, and low-paying

employment, among others. For African-American and Black families, in particular, racist housing practices and subsequent gentrification has left many families unable to afford housing or rent, segregated them from other Black families, and exposed to high rates of gun violence, according to advocates in North Carolina. For some Hispanic/Latinx families, undocumented immigrants delay care or underutilize programs and services due to lack of insurance and due to documentation requirements, respectively. During the Trump administration, a stricter public charge and its subsequent cultural force led to many mixed-status families dropping from federal programs, such as SNAP and WIC (Food Research & Action Center, 2021; Gamboa, 2018). Importantly, advocates stress that these inequities for families of color have been the status quo for generations. The pandemic has only spotlighted the drastic contrast enough that policymakers could not ignore anymore as well as the atypical situation that suddenly many white families were also experiencing lack of access to healthy food, childcare, medical care, etc.

In the following figure, the interconnected causes and effects of structural racism in maternal, infant, and toddler health and wellbeing are visualized.

Figure 5. Domino Effect of Structural Racism in Maternal, Infant, and Toddler Health and Wellbeing



In Figure 5, the following descriptions match the dominoes above illustrating an example of how inequities can snowball into poor health outcomes for communities of color through no fault of their own leading to a seemingly insurmountable problem:

1. High blood pressure and anxiety in African American and Black birthing people
2. Premature birth of underweight infant
3. Long stay in NICU
4. Exhaustion of leave and eventual loss of job
5. Loss of income, overwhelming anxiety, and sense of despair

In another example of cascading inequities that create extremely difficult situations for infants, toddlers, and parents, especially mothers, an advocate relates the following:

> *I think that also is what leads to more children entering care. They were denied, like you said, that stipend to pay for the daycare, so Mom has to work. She's got to keep the roof over their head. She's got to feed them, this and that. She's leaving little Billy with their neighbor or whoever is available to watch them, no matter their history, and bad things happen, and these children enter care, and it's blamed on the mother. The mother was doing what she could. In some cases, the mother was doing what she could so that she could go to work because that's what she was told she needed to do instead of living off of the government. The children are the ones who end up in danger, are the ones hurt from it.*

Families of color experience trauma when systems of inequities conspire to force a working mother to leave her child at sub-standard or harmful childcare arrangements to earn money in order to afford basic necessities and avoid the stigma of a so-called *welfare queen.*

Advocates of color and allies across the three states offer a solution to these compounding catastrophes in the form of 'a village.' Advocates wish for a return of the village to aid post-partum parents and to care for infants and toddlers as well as social, physical, and emotional supports. Advocates, who are themselves parents, express the feeling that their generation of parents are parenting alone and in need of community or a village. They seek help from a community with both clinical and non-clinical needs, food assistance, laundry help, cleaning help, transportation, among others. Notably, an advocate contends, *"We are not supposed to be parenting by ourselves. We are supposed to have aunties and uncles and community members and neighbors around us. I think because of structural racism and so many other things, people don't have that."*

Residential segregation, disinvestment of communities, maternal healthcare deserts among many other impacts of structural racism has isolated families of color from community and from vital supports for maternal, infant, and toddler health and wellbeing.

Relationship between structural racism in maternal, infant, and toddler health in politics/policymaking within era of anti-racist backlash

For advocates of color and allies in conservative states, connecting structural racism to disparities in maternal, infant, and toddler health has proven a difficult bridge to cross with conservative, majority-white policymakers and decision-makers in Louisiana, North Carolina, and Texas. Advocates and allies describe specific, interrelated ways that policymakers and decision-makers maintain status quo frameworks that perpetuate disparities for families of color.

In the community conversations across three states, advocates of color and allies explain that they navigate their language choices when promoting policies, programs, and services that will equitably support families of color. Specifically, advocates and allies in these three states refrain from using the terms *structural racism, systemic racism, social justice* or *equity*, among other anti-racist language, when speaking with policymakers and decision-makers in conservative states. In part, this linguistic tightrope is another facet of the larger anti-critical race theory (anti-CRT) ideology that conservatives lately have been promoting and promulgating across levels of public discourse. Although entirely unconnected to graduate-level legal courses that interrogate how the law entrenches racism, maternal, infant, and toddler health has become another venue for conservative politics that has engineered a moral panic around CRT that lumps in any anti-racist or equity-focused idea, such as Black Lives Matter, social justice, or reparations, into bogeyman catchall (Tensley, 2021). And so, according to advocates and allies, they actively avoid invoking racism and equity in order to pass or fund policies and programs that will help families of color.

In state capitals and other seats of power across the three states, anti-racist language is not used by advocates and allies or when invoked dismissed and rejected. An advocate explains:

> *It's 100 percent true. I can't say the word equity at the capital and expect to get my policy or my legislation through. We've been, for a couple years, focusing on what we call stealth equity, which is where we do what needs to be done without using the word equity because we know that the politicians, the legislators, the very conservative legislators at our capital are just not going to respond to the word or the conversation. It is absolutely our reality. We try to stay away from the word.*

Not only did we hear that advocates and allies have to refrain from using equity language, advocates have heard or experienced interpersonal racism among policymakers. One advocate says that policymakers otherize and blame people of color for their social conditions without recognizing any historical and ongoing inequities. For example, policymakers, according to an advocate, *"make the conversation about the "absence of fathers" without taking responsibility for the fact that the criminal justice system in Louisiana incarcerates black men at a rate several times higher than white men."* The same interpersonal racism from conservative lawmakers has happened to advocates of color in state capitals. An advocate of color relates:

I hate that people even feel like that and think like that and know that I have to have someone else speak for me, or I'm going get cut off. I'm not even going get listened to. I'm not even going get in the door.

Advocates, then, often are forced to make the economic argument through cost-benefit analyses without using equity language but do enact more equitable policies. For example, one advocate relates that their organization successfully promoted a rejection of work requirements for SNAP by focusing on costs to the state.

When advocating in other spheres of influence, advocates of color and allies, especially founders and executive directors of smaller community organizations, struggle to make the equitable case with decision-makers in conservative states. These smaller organizations are often overlooked or dismissed as undeserving of needed funds for communities of color. In all three states, advocates express the necessity of smaller organizations in the communities with staff from the community that provide vital support to families of color. During the pandemic, smaller organizations provided diapers, food assistance, utility assistance, rent assistance, among other lifelines that kept many families of color from dire situations. In Texas, these community organizations that are serving Black and brown families operate on shoestring budgets while much of available funding goes to agencies that do not have such a direct impact on these families, according to advocates.

In these continuing years into the pandemic, Black and brown leaders of community organizations are seeking the same crisis-level funding that occurred early in the pandemic and after the murder of George Floyd. After community organizations received much-needed funding, to continue receiving funding foundations, donors, and other governmental entities are demanding documentation that the intervention worked according to their metrics. One advocate explains:

To truncate these resources for these communities is going to be an extra layer of devastation, and now funders and academia and other folks are like 'Well, we gave you all this money. Prove that it worked. You want more? Prove it.

The funders are seeking progress reports, impact reports, sustainability plans, strategic plans, graphics, and websites among other documentation. One advocate explains it this way:

It's these micro-aggressive carrots that just keep getting dangled in front of us...I really want to show up [as] my authentic self. I'm tired of code switching. I'm tired of charts. I'm tired of graphs. Listen to what's really going on, but that's not going to get us support. That's not going to get us funded. It's just a hard space.

Advocates express that they are continuously navigating a linguistic tightrope that does not fund community organizations, and these advocates are dealing with the emotional and mental burden of living in this unsupported space. Advocates identify this language tightrope as a *"tool of white supremacy to maintain power, maintain white power, and hold down other perspectives...It's a tightrope that anyone has to walk, and especially for leaders of color to walk, that prevents access to*

that decision-making space." In more progressive locations within these conservative states, some advocates express an unwillingness to further put their mental health on the line in trying to convince policymakers and decision-makers of their humanity. One advocate says:

> *There is nothing that we can do to prove our humanity to people who for generations have been told otherwise and have benefited from preaching the adverse narrative. Someone who has gained literally their wealth, their health, and their land from putting down my folks, there's no one presentation, sentence, panel, conference that is going to convince them otherwise. We can't do it. We are exhausting ourselves trying to do it. Stress is real. Weathering is real.*

The advocate names intergenerational trauma experienced by people of color who have been exploited, killed, and dispossessed by white people and institutions who in turn deny these past inequities as precursors of the present. Another advocate puts it simply, *"It is very exhausting. It is very disappointing and demoralizing. You can feel very defeated. It is a level of trauma that comes along with doing this work."*

Ultimately, policies that are not supporting families of color and funding that is not going to community organizations that are run by people of color lead to a devastating intersection of biopolitics and structural racism. One advocate explains:

> *I would say that one of the issues due to racism is death...maternal deaths that are happening and infant deaths that are happening that are preventable. The ones that suffer the bulk of that are African-Americans and Hispanics, just minorities.*

Women and infants and toddlers of color suffer from the adverse relationship between structural racism and politics.

In order to address the perpetual racial/ethnic disparities experienced by families of color, especially Black and brown families, advocates of color express political/electoral, power sharing, and abolitionist solutions. First, some advocates view electoral politics as a solution where elected officials reflect people of color in the community where they hold power. One advocate explains, "*Those closest to the pain should be closest to the power. It doesn't make any sense to keep creating solutions for people when you don't have that lived experience of what might help*." Another advocate views electoral politics as a viable way to remedy the effects of structural racism:

> *...making sure that we have elected officials in office or getting elected officials into office who understand the historical precedent that has taken place that has caused all of these structural inequalities and are willing to acknowledge that racism has impacted and caused our communities to have socially disadvantaged groups and that they are willing to tackle those challenges and dismantle those structures, or whether it's a policy, it's an agency, whatever that entity is that is causing people to not have equity in whatever way, whether it's healthcare or education, that we have people in office who are willing to tackle those and to put better policies and better programs in place to improve people's quality of life.*

Importantly, this advocate names the acceptance of historical and ongoing inequities that are reflected in their policy choices to specifically improve lives of families of color. Although advocates name electoral pathways toward greater health equity in maternal, infant, and toddler health, advocates also invoke recent voting rights legislation in conservative states that could disproportionately affect voters of color. According to advocates, these changes in voting, such as strict voter ID laws, closures of voting locations, truncating early voting periods, among others, could thwart their proposed electoral solutions for health equity.

Another similar political proposed solution from advocates requires educating policymakers and decision makers on their lived experiences. For example, an advocate relays the following:

> *Have them appear to be of a different race and economic status and see how hard is it to receive—you may give them a scenario. You are a black female or a Hispanic male with three children on a fixed income, that maybe says one of your children has a disability or a mental health issue, and try to ask them to call our systems, call our state, to try to get help and see whether they can get any leeway. They can see for themselves how hard it is to deal with the different outcomes and the different things like, you may not be able to get this. You may get the runaround. Then they can realize how important funding is, like a walking a mile in my shoes*

This advocate proposes educating policymakers and decision makers through lived experience and scenarios that elicit the structural barriers present in the lives of many families of color.

Similarly, power sharing places power to those 'closest to the pain' and places leadership roles and decision-making power to those with the lived experience without having to be elected officials. Another advocate rephrased power sharing as avoiding the one of *"a million tokenized efforts"* that ask for input and then leave advocates of color out of future meetings where decisions are made and funding is allocated.

Lastly, many advocates express versions of abolitionist thinking that seeks to dismantle systems and structures that perpetually harm communities of color. Stemming from the abolitionist movement struggling to end the institution of chattel slavery in the U.S., abolition in the last decades has been struggling to dismantle the prison-industrial complex (PIC). Furthermore, prison abolitionists, like Angela Davis and Ruth Wilson Gilmore, view the PIC as causing more harm than solutions for poverty, drug addiction, and other social conditions (Washington, 2018). From this contemporary understanding of abolition, other thinkers in various fields have also sought a way out of the status quo through abolition. According to R. L'Heureux Lewis-McCoy (2020), "abolition is both a worldview, a strategy, and it's also a vision." One advocate expresses an abolitionist view in the following:

> *We're wasting time. We're wasting money. We're wasting resources. If folks aren't really trying to change, just go ahead and let us know so that we can stop wasting that time and figure out something different. We're not going to do any of this without trust, transparency, and respect. We're not going to come in and say, "Hey, we're going to change things different now" without*

first acknowledging the harm that we have done to communities for decades and decades and decades.

This advocate also names the historical wrongs and their ongoing legacies on families of color. Policymakers and decision-makers will continue to waste time, money, and resources when unable or unwilling to address these intergenerational traumas and inequities. Finally, one advocate expresses the frustration when working within the status quo:

It's not that they [conservative white lawmakers] don't know about it. It's not that they're ignorant. They want the opposite of equity. So many of the policies we've talked about today, like the lack of Medicaid expansion, the lack of so many basic needs that low-income families need—that is all because our lawmakers actively don't want to care for these families or provide supports to them. We know that appealing to them through the lens of equity isn't going to work.

This frank assessment of the status quo both expresses abolitionist thinking as well as the exasperation of advocates of color who are trying to address the specific needs of families of color in their communities.

State-specific Developments in Maternal, Infant, and Toddler Health

One tool that was developed to measure the quality of ECE programs is through a Quality Rating and Improvement System (QRIS) framework which considers the curriculum, staff/educator qualifications, nutrition, and a program's physical space (Kofron et al., 2022). The QRIS indicators vary from state to state.

In North Carolina, the University of North Carolina at Greensboro in partnership with Delaware and Kentucky are developing the Early Childhood Quality Improvement Pathway System (EQuIPS) which gathers qualitative data through parent, teacher, and administrator interviews and observational data in the classroom and homes (Program, 2017). This method allowed for a broader understanding of ECE quality with a focus on families as being the unit of study. Several states piloted this new assessment tool for validation of the measures. A more comprehensive tool was developed into the Tiered Quality and Rating and Improvement System (TQRIS).

In Texas, the QRIS system is called the Texas Rising Star (TRS) which was created in the 1970s. TRS has gone through many improvements throughout the years. For instance, in 2013 the Texas state Legislature passed HB376 which mandated a review workgroup, establishment of reimbursement rates based on certification levels, and provided funding to Local Workforce Development Boards (LWDBs) to recruit and hire mentors for providers and assessors (Kofron et al., 2022). In 2021, all childcare providers who received government subsidizes were required to participate in TRS. TRS has streamlined the application process, made childcare more accessible to home providers, increased reimbursement, and improved the criteria for participating childcare providers. Participation in TRS is low in communities of color. CHILDREN AT RISK collaborated with Prairie View A&M and the University

of Houston to conduct a Racial Equity Workforce Survey through focus groups on TRS participation utilizing a racial equity lens (Kofron et al., 2022). The findings suggest that providers need equitable access to supports such as quality coaches, additional funding to expand number of children, statewide platform for networking opportunities, professional opportunities to develop high quality and well-paid ECE workforce, and assessor experience in provider's type of program.

In Louisiana, the Louisiana Early Childhood Education Act was enacted in 2012 to establish a standard QRIS across all funded ECE programs to ensure that children were ready for kindergarten (Bassok et al., 2021). Beginning in 2015-2016 school year, additional changes were made to the QRIS. Louisiana implemented the Classroom Assessment Scoring System (CLASS) to measure the interactions between teachers and children. This enabled the state to measure the experience of children in the classroom.

Moreover, in Louisiana state legislature passed a bill investing $84 million in early childhood education (Louisiana, 2022). This bill will expand access to ECEs and will provide childcare assistance for families with low-income. This new funding will improve and benefit communities in Louisiana. Research demonstrates that access to high-quality early childcare improves school readiness, less referrals to special education, higher high school graduation rates, and less violent crimes (Louisiana, 2021).

Limitations

There were a few limitations associated with this project. Although community organizations helped plan and recruit for this project, these recruiting partners did not implement the community conversations and thus not all findings shared in this report are reflective of the community organizations, especially across states. In short, this report does not reflect all views of recruiting partners.

Another limitation is the number of participants recruited. Project resources allowed for five community conversations. In an effort to maximize participation of participants, the target number of participants per group was eight. Recruitment numbers fell short of this goal making the sample size for each state very small. Thus, findings and discussion cannot be generalized across states, and these findings are not representative of all advocates in maternal, infant, and toddler health and wellbeing in their respective states.

All racial and ethnic groups were also not represented equally. However, community organizations were very successful in recruiting valuable voices from African-American and Black communities. As depicted in the maps above, there were gaps in representation from geographic regions within each state. Representation from more rural areas was lacking and these perspectives were underrepresented in conversations.

Lastly, a final possible limitation is not specifically asking advocates of color and allies in each state about what successes they are experiencing in their states. While an appreciative approach was used

to guide discussions around ideal infant, toddler, and maternal health, conversations tended to concentrate around barriers. Thus, this report skews toward a deficit-based analysis of maternal, infant, and toddler health and wellbeing in Louisiana, North Carolina, and Texas.

Conclusion

The community conversations with advocates of color provided a glimpse into the reality of maternal, infant, and toddler health, and the challenges faced by those working tirelessly to improve that reality. Although it is not an exhaustive representation of all advocates, the voices and perspectives captured by these conversations are no less poignant and indicate that there is more work to do in the realm of maternal, infant, and toddler health to ensure true equity of the birthing and childhood experience for all. Providing the platform for these voices to be heard is one such step toward change and progress. However, advancing the health and well-being of marginalized communities not only takes a village of BIPOC and white allies, it also requires that the individuals and the systems that perpetuate inequity move aside.

Key takeaways from this report are informed by the participants that shared their lived experiences as humans and advocates of color, and should advise existing and future efforts to change the reality faced by so many birthing people, infants, and toddlers. Continuing these conversations with advocates of color in other states and regions would be a meaningful step to increase the number of voices heard and to learn about the status of maternal, infant, and toddler health in other areas of the country. BIPOC advocates need intentional collaboration and support from white allies and lawmakers alike to secure health equity for all birthing persons, infants, and toddlers.

Recommendations

Based on the findings gleaned from the community conversations with advocates of color and allies in Louisiana, North Carolina, and Texas, this report posits the following recommendations:

- Adequately fund smaller community organizations who are often founded and operated by people of color with lived experience in the communities served in lieu of more often than not providing larger organizations with most of available funding;
- Hire more people of color in organizational leadership roles who in turn hire more people of color and diversify racial/ethnic demographics of leadership across more organizations and entities that influence maternal, infant, and toddler health;
- Demand white advocates to share the burden of combatting structural racism and eliminating interpersonal racism so that advocates of color are not always the only voices speaking for families of color;
- Engage conservative lawmakers by asserting an economic argument with powerful data that would improve health outcomes, by advancing equity without using the word equity, by

starting conversations and sharing lived experiences, and by engaging lawmakers on the record;

- Elect or help elect champions of maternal, infant, and toddler health into office, especially champions who recognize the impacts of structural racism and acknowledge the centuries of inequities suffered by communities of color; and
- Advocate for dismantling systems that perpetuate racial/ethnic disparities for communities of color.

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Appendix

Political and Legislative Context

Several political and legislative topics were mentioned throughout the community conversations. These topics include the SB 8 law in Texas, the Public Health Emergency Declaration, the American Rescue Plan (ARP) the Child Tax Credit, and Affordable Care Act (ACA) improvements. Participants referenced these topics when discussing various aspects of maternal, infant, and early childhood health. This section provides background information and context to aid readers as these topics are examined in the following sections.

Senate Bill 8

The Texas Heartbeat Act (2021), also known as SB 8, was introduced in the Texas legislature in early 2021 and was implemented later that year. Under this law, abortions are restricted at six weeks gestation and does not allow for exceptions in cases of incest or rape (Planned Parenthood of Greater Texas, 2022; Texas Heartbeat Act, 2021). The law allows private citizens to pursue legal actions against anyone they suspect of performing or aiding an abortion (Luthra & Rodriguez, 2022). Challenges to the law have been unsuccessful (Luthra & Rodriguez, 2022) and will force Texans to seek abortions elsewhere, forego abortions all together, or attempt an abortion without a licensed medical provider.

Public Health Emergency Declaration, the American Rescue Plan, and Emerging Legislation

Early in the COVID-19 pandemic, a public health emergency declaration allowed for millions of people to retain health care coverage despite not meeting state eligibility requirements (Ernst, 2022; Harper, 2022). In Texas, this resulted in a substantial increase of those covered by Medicaid and significantly affected pregnant people because Medicaid coverage in Texas usually ends 60 days after a pregnant person has given birth (Ernst, 2022). The declaration is expected to end later this year and will affect many Texans that would otherwise be ineligible to receive Medicaid benefits (Harper, 2022). Texas is not a state that elected to adopt Medicaid expansion when the Affordable Care Act provided states the option to expand. Recently, a bill to expand Medicaid in North Carolina was approved by the Senate and is now under review in the House of Representatives (Doran, 2022). Adoption of Medicaid expansion would extend care up to 500,000 North Carolina residents (Doran, 2022).

In 2021, the ARP included a provision that allowed states to extend postpartum Medicaid coverage to a full year. Both North Carolina and Louisiana have adopted and implemented this extension of postpartum care (Kaiser Family Foundation, 2022). Texas has passed a waiver to extend postpartum Medicaid eligibility to 6 months, but has not implemented the ARP 12-month provision. Additional legislative changes include emerging policy in Louisiana from the 2021 legislative session. The new law now requires insurance companies to cover midwives and has created a state board for doulas which can eventually lead to coverage by insurance companies (Westwood, 2021).

Child Tax Credit

Another key component of the American Rescue Plan Act of 2021 included the 1-year expansion of the Child Tax Credit beginning in July 2021 (Shafer, Gutiérrez, Ettinger de Cuba, Bovell-Ammon, & Raifman, 2022). The advance child allowance provided additional income for families to reduce childhood poverty.

The Child Tax Credit underwent eligibility criteria reforms. The three major changes included (1) families having no income became eligible for the full credit amount (2) increased credit from $2000 to $3000 per qualifying child for those aged 6 to 17 years and $3600 for aged 5 years or younger, and (3) monthly advance payments. However, the tax filing requirement may have burdened African American, Hispanic/Latinos, and Native American families who are unable to file taxes because of low-incomes. Evidence showed that food insecurity decreased for many communities of color. The Household Pulse Survey demonstrated that household food insufficiency had the highest percentage decline among Hispanic respondents from 22.3% to 12.3% after the receiving Child Tax Credit (Shafer et al., 2022). For African American respondents, household food insufficiency decreased from 22.3% to 21.1% after receiving the child credit.

Affordable Care Act Improvements

In March 2021, the American Rescue Plan Act (ARPA)'s expanded the Affordable Care Act (ACA) subsidies for marketplace plans to about 15 million uninsured people (Rapfogel & Gee, 2022). The expansion provided premium tax credits which lowered premiums or provided zero-premiums to low-income or unemployed individuals. In 12 states that have expanded Medicaid through ACA, there are 2.2 million low-income, uninsured adults ineligible for Medicaid or marketplace subsidies even though their incomes are below 100 percent of the federal poverty level. This gap includes about 60 percent people of color. The gap exists because policymakers in those states have not passed legislation implementing the federally funded expansion option. Rapfogel and Gee (2022) note that expansion of Medicaid in states that haven't expanded could reduce mortality rates, evictions, and medical debt.

Additionally, states that have expanded Medicaid have benefited from:

- Lower rates of hospitalizations related to opioid use disorder and earlier detection of cancer,
- Reductions in cardiovascular mortality, maternal mortality, infant mortality, mortality of the near-elderly, and overall mortality, and
- Reduced racial disparities in health outcomes, with gains in birth weight for black infants and reductions in maternal mortality for black women.

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