My Baby, My Doctor & Me: Hearing from Parents about Early Infant Relationships and the Role of the Health Care System



Key Findings from a Focus Group with African American/Black Mothers Living in Portland, Oregon

> The Center for Improvement of Child and Family Services Portland State University October 31, 2020



Acknowledgements

On behalf of the Early Relational Health research team, we want to extend our gratitude to the African American and Black parents in Portland, Oregon who shared their time and experiences with us. We also want to thank the research liaisons, parent research consultants, community partners, and funders who brought their best to this project. Without the commitment of these individuals to the health and wellbeing of all babies and new parents, this work would not have been possible.

The Center's mission is to engage in equity-driven research, evaluation, and consultation to promote social justice for children, youth, families, and communities.



Background & Project Overview

There is a growing national effort to encourage doctors, nurses and others to see the relationship between parents and their infants as central to children's health, and to support parents in developing these foundational early relationships (sometimes referred to as "early relational health"¹). As this work moves forward, it is important that it includes the voices of historically marginalized parents whose personal and cultural histories, experiences, and beliefs about parenting and the role of the health care system are included. This exploratory study aimed to center the voices of three very different communities to learn more about their beliefs about the nature of their earliest relationships with their young children and their perceptions of the potential role that health care providers could play in supporting them.

To do this, we partnered with teams of "Parent Research Consultants" (PRCs) representing each of the three communities of interest: (1) African American mothers in urban Portland, Oregon; (2) Latinx mothers living in rural areas of Oregon; and (3) rural, geographically isolated White mothers in Southern Oregon. PRCs provided input to the research team about the design, measures, and data collection methods for the study, as well as on the interpretation and development of a set of research briefs, including this document. PRCs were provided an honorarium in return for their time spent on the project. With their guidance, we conducted three focus groups with members of each of these communities. Focus groups asked these parents to talk about:

- What early parent-infant relationships mean to them, and how positive relationships are established;
- Where parents go for support for themselves and their babies;

- Their experiences with, and feelings about, the role of health care providers in supporting these earliest relationships.
- Their ideas and recommendations for how health care providers should sensitively and respectfully approach these issues with families.

This research brief summarizes findings from the focus group held with African American mothers in Portland, Oregon, and was co-created with input from three PRCs, some of whom also participated in the focus group. This team of PRCs was identified and facilitated by Ms. MaryEtta Callier-Wells, who served as a Community-Research Liaison for this project. Ms. Callier-Wells is a long-time staff person at Self-Enhancement, Inc., a culturally-specific, communitybased organization in Northeast Portland. She also facilitated the focus group session and contributed to the development of this brief.

Who Participated & Why?

Five African American mothers participated. These mothers had between 2 and 3 children, ranging in age from <1 to 17. These mothers shared with us their motivation and reasons for joining the group, which reflected a commitment to making changes to improve the lives and experiences of other Black women. Specifically, they mentioned:

- Wanting to provide information to improve relationships between doctors and parents;
- Wanting to share their own experiences with their young children, and to;
- Support each other and "be in a space with other Black mothers".

What Does it Mean to be a Parent?

African American Mothers Took Pride in Their Children's Accomplishments

Portland State

When asked to share a parenting experience with their child that made them feel proud, several mothers reflected on their children's **accomplishments and**

successes, including:

- Academic and life successes;
- Growth in independence;
- Examples of problem-solving abilities; and
- Their **positive**, **ongoing relationships** with older children.

¹ See: https://inclusioninstitute.fpg.unc.edu/sites/inclusioninstitute.fpg.unc.edu/files/handouts/early-relational-health-strategicbrief-2020.pdf



African American Mothers Provide Support for Children's Growth & Development

These mothers talked about the kinds of things they do to help their children grow and develop, including practices identified in child development literature as supporting children's social/emotional well-being, such as:

- Being aware of and responsive to children's nonverbal cues
- Providing routines and repetition
- Doing direct teaching & supporting developmental milestones
- Promoting active play
- Building relationships & learning from other family members

Building Early Secure Relationships

A major theme when these mothers talked about the importance of these early relationships was that **trust is foundational** and "**sets the stage" for a strong longterm parent-child relationship.** These mothers talked about having "close secure relationships" so that when children are older they will "open up to you". To build this foundational relationship, these mothers talked about the importance of providing reassurance and being attuned to babies' needs ("just the check-ins, making sure you both understand each other...make sure you are in tune to them their personality, what they need"). Specifically, African American mothers talked about:

- Being responsive and attuned to children's needs
- Providing re-assurance and emotional support
- Being non-judgmental about behavior (especially for older children)
- Building secure relationships across other adults/adult family members

"I had one of the very few one-year olds who you can drop off at daycare and walk away and they didn't cry. Everybody was like, 'how did you do that?' Well, he knows I'm coming back. He's fine because [he knows], 'oh, my mother will be back. [...] I'm okay. She always comes back.""

These descriptions mirror the child development concept of **secure attachment** – the sense of security that children develop as a result of responsive

parenting. It is worth noting, however, that attachment theory and the preponderance of research related to it, was largely validated and developed using white, middle class children and families.

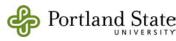
Several of these women talked about how this process of developing a strong relationship requires **ongoing support** and reassurance throughout their lives, and that it is especially important when children have experienced a loss or trauma. These mothers described the importance of being "nonjudgmental" as central to building trust, especially with older children.

"When a child comes from any kind of trauma, that reassurance piece is very important. I went through some situations where I felt like, 'okay, I did all the reassuring and we're good, right? Because it looks like we're good, and it feels like we're good,' but [...] you've got to remember to go back and re-check in, especially when you see that they've gone through different developments and changes and things like that."

"Yes, not being judgmental, that creates secure relationships and connections."

A key reason why these relationships were seen as so important was their role in **protecting the child** from potential negative consequences of not having a close adult to go to in the future, and making sure that children can be resilient in the face of trauma, racism, and other challenges. They shared that having an open, trusting relationship early in the child's life was essential to children being able to come back to their parents – or to another trusted adult- when faced with more serious life challenges in the future. While parents might play this role, these mothers also talked about other family members' as being important as well.

"But if you don't have a close relationship or secure relationship will your parents, you end up in situations like that [negatively impacted by not revealing pregnancy to parents]. Those medical providers, that were in the school, they were very insensitive and rude and nasty, like, 'if you weren't doing this, you wouldn't be in a situation to be here for this.' It was just really insensitive and very uncomfortable. I don't want my kids to have to go to an alley and try to get an abortion, or go try to take some drugs to heal themselves from STDs.



Anything they need help with that they feel ashamed of, they should be able to come talk to you so you can help them get through it."

"Even if they don't have a close relationship with you, just make sure they have it with somebody in the family."

These early relationships were not only seen as important for the child, but for the family as whole,

characterizing this as part of the "glue" that helps hold families together:

"I feel like being open with them [children] and honest with them at their level. Communicating with them at their level, and making sure that they know that it's us against the world. Even if I have to correct you at the house, it is still us against the world."

Supports For Parenting – Where Do African American Families Go?

Families & Friends – People They Trust

Essentially, mothers talked about **going to people they trust, who are non-judgmental and who know them and their values as parents.** Mothers shared that they tend to **go to friends and family members** for help, advice and support, and also described being aware of when it was helpful to connect their child directly to other adults. The theme of having a **network or community of trusted supports came** up in these mothers' stories. In seeking help, it was important to these mothers that they turned to people who know their history and values related to parenting:

"As an adult, where I turn now is my own parents and [other parent in the group]. I think that they understand me in a way that if I tell them something, they understand what I'm not gonna do already. So, they can give me good advice based on a history and a good knowledge of my parenting, my beliefs and my goals."

Two mothers mentioned parenting classes, although one specifically talked about how these are an opportunity for *nonjudgmental peer-to-peer support* (rather than emphasizing the "educational" or "informational" aspects):

"I'm in the parenting class and the parent groups. Sometimes you join and you don't realize that you're going to get a piece of word [insight] that you can take with you [...]. You can ask other mothers in a non-judgmental space."

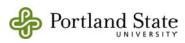
Experiences with Health Care Professionals

When we asked mothers to share their experiences seeking information or support from health care providers, many of the stories they shared underscored the ways that people in these systems have undermined the trust that is needed for effectively meeting the needs of these families. Numerous examples were shared that reflect their experiences of medical professionals being dismissive of Black women's concerns, not listening to them, and not respecting their knowledge and expertise related to their own bodies and their children. The impact of being sometimes repeatedly dismissed creates a foundation of **mistrust**.

"I'm very familiar with what asthma looks like and even though y'all don't want to diagnose her, y'all are treating her every time we go to the doctor. Every time I have to take her to the ER because **you're not listening to me**. Y'all are treating her like she has asthma, getting the breathing treatment, she gets the steroids, you wait and you watch her, and then eventually she gets hospitalized. But I don't know what I'm talking about? I get dismissed. I can't possibly know what I'm talking about, because I'm just a mother. I'm not a medical professional."

"It is literally the most frustrating thing on the planet that, because I don't act the way that you feel that I should act [during labor], there's no possible way that **this** could be my experience."

Several of these women shared their birth-stories as painful examples of not only themselves, but their family members being dismissed and not listened to.



"When I have my extra person [during labor, the baby's father] here, that's here to support me/ help me/this is his child, they're dismissing him. They're not communicating with him. He's asking questions and then they're, you know, I call it white people [expletive], where they're not giving eye contact to the person talking to them but they're looking at someone else. He's asking them questions, but they're talking to me. Right? And he's like, 'Hey, I'm communicating. I'm here. I'm here to support her. That's my child. She's the one that's pregnant carrying the baby, but why are you dismissing me? What's going on?'"

African American Women Encounter Specific Examples of Racism, Bias and Preconceptions

These women attributed the dismissiveness of (predominantly white) medical providers to implicit and explicit race-based bias. This varied from feeling like their perspectives were simply ignored or not considered (e.g., medical systems holding a whitecentered approach not sensitive to the needs of Black women) to being perceived as stupid, uneducated, overly emotional, and as hypochondriacs.

"I feel like they don't have this [Black women's experiences] in mind when they think of that whole concept of, 'let's create this perfect birth plan so we can make you feel as comfortable as possible.' I think that that whole idea and that whole concept is for white women and not us. It just kind of trips me out how much we are not taken care of as Black women. They dismiss us. They don't really listen to us. They have all the answers for how we need to deal with our pregnancy and our labor and things of that nature. And it's never really like, 'How can I make you comfortable? What are your needs? What are your fears?' Things like that."

"I was a young mother and deemed uneducated, from the moment that they met me." "They need to listen to people and take it seriously and have more follow ups, instead of just thinking everybody's a hypochondriac, or because somebody's pregnant it's their first time."

One participant described how the intersection of race and income status may have played an additional role in contributing to discriminatory treatment, talking about receiving different treatment when she sought care under state OHP vs. private medical insurance.

Consequences for Health & Well-Being

Further, these women shared the sometimes serious consequences of not being taken seriously by the family and child health care providers. These consequences include real and serious negative impacts on both maternal and child health and emotional well-being.

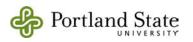
"I kind of kept repeating myself [*about how sick she felt during labor*]. My contractions were killing my son, and he had stopped breathing for six minutes. I just thought they just weren't responding to that. I felt like they weren't listening to me as I was explaining to them that something really bad was happening. I felt that inside me, and I just wanted someone to do something."

"That [negative birth] experience has always been really traumatizing for me. I always think about it. It still comes up. My son's three, and it's just a conversation that comes up..."

Moreover, these experiences contribute to these women's reluctance to seek medical care, and ambivalence about the role of the health care community in being effective supports for parents:

"... My mother passed away and my father's never been around, so I have no parents to lean on to help me raise my kids. You would think that you could talk to your doctor. You would think that you can talk to your nurse. But when you ask questions, they either dismiss you or they act like you're stupid for even having a question, comment or concern."

"... it's things like that that make you feel like, 'Well, why am I even here?' I can figure out



what my ancestors used to do to heal us [...] and just do that, because there's no point in being here if y'all are gonna treat us like this. I

Recommendations for Improving Relationships between Family & Child Health Care Professionals and African American Parents

In the context of these discussions, it became clear that many things need to change in order to build trusting relationships between Black women and child and family health care providers. Such work will be critically important if the health care system truly wants to be able to create the trust needed for these women to share their concerns and be open to input about their early relationships with their children. One woman specifically described medical interactions as "transactional" and noted that if medical care professionals in her life had been more nurturing this might have changed the pattern of her ongoing interactions with this system once she had her own children.

Central to these ideas was the notion of truly approaching Black women (and all people) as the experts they are on their own experiences and their own children:

"I would appreciate it if they did not treat all of us coming in as the same exact person. I don't even just mean treating all Black people [the same]. I mean, just all people like every one of us on here that have the same ailment, but experiencing it differently. More than one of us have said, 'I know me better than you know me. I know that you know medicine better than I do, but I know me. I have something going on, and I need your help, because I can't do it myself. So, can you just listen? Can ya'll please listen and not treat us like we're hypochondriacs.""

"If I came in there [to see a medical professional], I'm worried about someone. I'm worried about myself. Just keep that in your heart that, even if I don't have the right answers, I can explain what is wrong. Even if [you] can't help that person, try to help them find somebody that can. Once we get to that doctor, we need that doctor to really take a motherent and help us figure out what's wrong. I'm not going to the doctor for no reason."

Suggestions for Practice Changes

A number of specific recommendations for changes in practice were made, including:

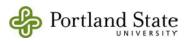
- Pay attention to their feelings and emotional wellbeing;
- Listen to and be responsive to their concerns and questions
- Have a sustained practice of checking-in and providing reassurance
- Seek and use authentic feedback from clients/patients
- Take more time to develop relationships with patients

Suggestions for Systems Changes

Several ideas for how to improve the health care system more broadly were shared, most focused on changes to the workforce. Specifically, mothers suggested:

- Providing better training, and ongoing professional development in empathy and empathic listening and in specific culturally responsive practices and competencies;
- Recruiting and retaining more Black/African American medical providers

"Just educate them on different cultures. We just need more Black doctors, period, because the stuff I've been hearing lately is crazy. Them saying that, 'Black people don't feel pain, our tolerance is different.' We're people. We feel the same pain. Our tolerance levels aren't any different. These doctors just need to be more educated when it comes to empathy and respect."



The Perceived Need for Self-Advocacy

These mothers were profoundly aware that Black women are at disproportionately higher risk for maternal mortality and other health care problems, sharing stories they had read about these issues. They talked about the importance of self-advocacy and skills for navigating these barriers as a literally a matter of life and death:

"What I learned from this situation, which has made all my other situations better, was how to advocate for myself and tell these doctors, 'No, something is wrong' and for every 'no' there will be a 'yes.' If you won't listen to me, that's fine, but you got a boss, and somebody pays your boss. Somebody pays this hospital. If I have to go to the court of public opinion, then I will to make sure that my child gets everything that they need, because just

Summary and Takeaways

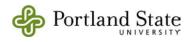
hearing that story is heartbreaking. I'm now dead. My baby's dead because I'm telling you something is wrong with me. I know me best. I've known me my whole life. I absolutely know what's wrong if something is wrong."

"I wanted to say that we as women, especially we as Black women, I find us having these conversations amongst ourselves and not saying it to the right people. This forum is getting to the right people. Absolutely. But... we should have reported what happened to us. We should have said, 'This is a problem. I am reporting this specific situation. This is what happened to me and my child could have lost their life, and those things are a matter of public record.' I just want to make sure that we, from this day forward, just document and report because those things actually do matter, and they do change, and they do help"

A key takeaway from these African American mothers was that they clearly understand, prioritize, and see life-long value in establishing strong parent-child relationships from the very earliest moments of life. This relationship between mother and infant was seen as one that is foundationally related to important larger networks of social connections that serve to build resiliency and serve a protective role against future negative events, including the experience of racism. Key aspects of parenting that were particularly important for these mothers were:

- Being responsive to infants' needs and cues
- Creating security by "being there" for children, and providing ongoing re-assurance
- Promoting healthy development through active play and attention, while also allowing children independence for exploration
- Ensuring children grow up with a network of trusted adults for support

While these mothers expressed real concerns with health care providers and the health care system, based on their past negative experiences, there were clear steps that could be taken to build more trusting relationships. Most fundamental is the need for health care providers to listen, and believe, what these mothers are telling them about their experiences – through both better training as well as longer-term workforce shifts to engage more providers of color and with shared lived experiences. While undoing the damage and mistrust that has been done to the African American community through decades of systemic and institutional racism will no doubt take time, there was a path offered by these mothers. This suggests, however, that perhaps in particular for African American families, that other pathways for offering and providing early parenting supports may be needed.



Focus Group Questions

- 1. First, let's talk about what it means to you to have a positive, caring relationship with your baby.
 - a. What do you do to support your baby's development and take care of your baby?
 - b. What does it mean to have a close, secure, relationship or connection with your baby?
 - c. What do you see in other people with their infants that lets you know that person loves and strives for the best future for their baby?
 - d. What do you think it means for a baby to be "emotionally and socially healthy"? What does this look like to you? Why does it matter?
- 2. What helps parents have positive, caring relationships with their babies? What do parents need to have for this to happen?
 - a. Where do you get support or resources to help you as a parent?
- 3. Other than questions about health, have you ever talked with a doctor or nurse about what's going well or what is challenging about taking care of your baby?
 - a. If so, what has this been like? Was it helpful?
 - b. Has there ever been a time when you, or others in your family or community have had a negative experience with a health care provider, especially regarding your parenting or the way you provide care to you baby? What happened, tell me about this? What would have made this go better?
- 4. What do you think health care providers should know about how you, your family, or others in your community in order to better support parents and their babies?
 - a. What would make visits with your doctor or nurse feel more supportive?
- 5. Is there anything else you think that we need to know about these early relationships, your experiences, what helps other parents and babies have good relationships and how health care providers can help?

