REPRODUCTIVE JUSTICE COLLECTIVE | POLICY BRIEF NO. 3

REPRODUCTIVE JUSTICE IN MATERNAL DESERTS:

CONFRONTING RACISM AND ABLEISM IN OBSTETRIC CARE

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Cover: A mother and son are smiling while sitting on a blanket laid outside on a grassy patch of ground. The little boy is giving his mother a kiss on the cheek as she leans over.

EXECUTIVE SUMMARY

Black disabled women face disproportionately poor outcomes in pregnancy and childbirth due to the intersecting forces of racism, ableism, misogyny, and medical neglect. Black women in the U.S. face a maternal mortality rate three times higher than White women[8], while disabled women are at 11 times greater risk of maternal mortality [1]—demonstrating that race and disability independently elevate risk. These outcomes are not merely individual tragedies—they are symptoms of systemic failure. Many of these inequities are intensified in maternal care deserts, where access to timely, quality obstetric care is dangerously limited. Maternity care deserts are key drivers of the national maternal health crisis [20.] Immediate policy action is needed.

What is obstetric care? It's the medical attention and support provided to expecting mothers before, during, and after childbirth.

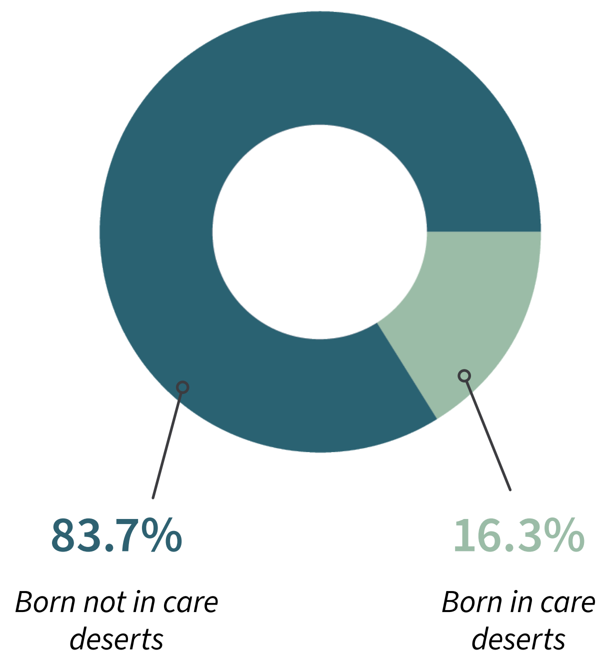
WHAT ARE MATERNAL CARE DESERTS?

- **Geographic Terms:** Areas lacking hospitals or birth centers offering obstetric care and no obstetric providers.
- **Systemic Terms:** When despite the presence of healthcare facilities, systemic barriers like ableism and racism prevent equitable access to quality obstetric care

"Alarmingly, approximately one-third (36%) of US counties are maternity care deserts and this number is growing yearly. These rapid changes are occurring alongside a critical moment in US maternal health in which the country reckons with a rising maternal mortality rate, deep racial disparities in a wide range of maternal health outcomes through the obstetric care continuum from pregnancy to postpartum, and a growing awareness of the role of disrespect and mistreatment in routine maternity health care ."[2]

This 2020 statistic—that 16.3% of Black infants were born in maternal care deserts [2]—underscores the deep structural inequities in healthcare access and the need for urgent, equity-driven policy responses.

Black Babies Born in Maternity Care Deserts in 2020



WHY REFORM IS URGENT

A shift toward intersectional, inclusive, and community-informed maternal policy is urgent and necessary. Current policy, research, and practice fail to address the unmet needs of disabled Black women. The result is a continued cycle of exclusion, poor outcomes, and unaccountable systems.

Recommendations Overview

1. **Advance the Reproductive Equity Act**
2. **Advance Research and Disability Data Equity**
3. **Require Healthcare System and Provider Training**
4. **Establish Community-Based Oversight**

Current Obstetric Care and Its Gaps

Despite national efforts to address maternal health disparities, disabled Black pregnant women remain largely invisible in both policy and practice. Black pregnant women face significant disparities in maternal healthcare due to issues at the intersection of **racism, ableism, and gender bias**. These systemic barriers often lead to poor maternal outcomes, lack of access to respectful and competent care, inaccessibility and invisibility in research. In fact, a recent study found that among subspecialties requiring patient transfers, gynecology had the highest rate of inaccessible practices, with 14 of 32 practices (44%) reporting they could not accommodate the patient [16]—a clear illustration of how disability access barriers are embedded in maternal care. These barriers help sustain maternal care deserts—where access to high-quality obstetric care is limited or completely absent [7.] We need an intersectional approach to maternal health that acknowledges these overlapping oppressions and proposes concrete solutions to eliminate maternal care deserts for this community.

Urgency of an Intersectional Approach to Maternal Health

Without an intersectional lens, policies will continue to fail to address the compounding vulnerabilities of being Black and disabled— reinforcing systemic barriers to care and deepening the maternal care deserts that endanger their lives. Actions that treat racism, ableism, and gender bias as co-constitutive can move us toward equitable outcomes. This means collecting better data, training providers, reforming funding structures, and ensuring disabled people of color help shape policy.

Lived Reality of Disabled Black Mothers

The lived experiences of disabled Black pregnant women reveals the harm caused by intersecting systems of oppression— namely, structural racism, and ableism in healthcare. These systems show up in routine dismissal of pain, mistrust/skepticism about parenting capacity, surveillance, disrespect and lack of culturally affirming care. This leaves disabled Black pregnant women feeling blamed, isolated, and unsafe in medical environments [4].

In an article about how ableism, misogynoir, and toxic narratives about parenthood can threaten Black disabled mothers parental rights, Black disabled women shared their experiences navigating obstetric care:

> **1.** Simmons said. "I think about how Black women aren't trusted, our word isn't trust[ed], our abilities and motives are second-guessed— and I'm disabled. After delivery, nurses watched my every move and wouldn't even let me get into my wheelchair unsupervised which led to me being late to feedings in the NICU. The NICU nurse blamed me and said 'this is what you wanted' (re: breastfeeding) and had no empathy that it takes me longer to do things other moms did."[4]

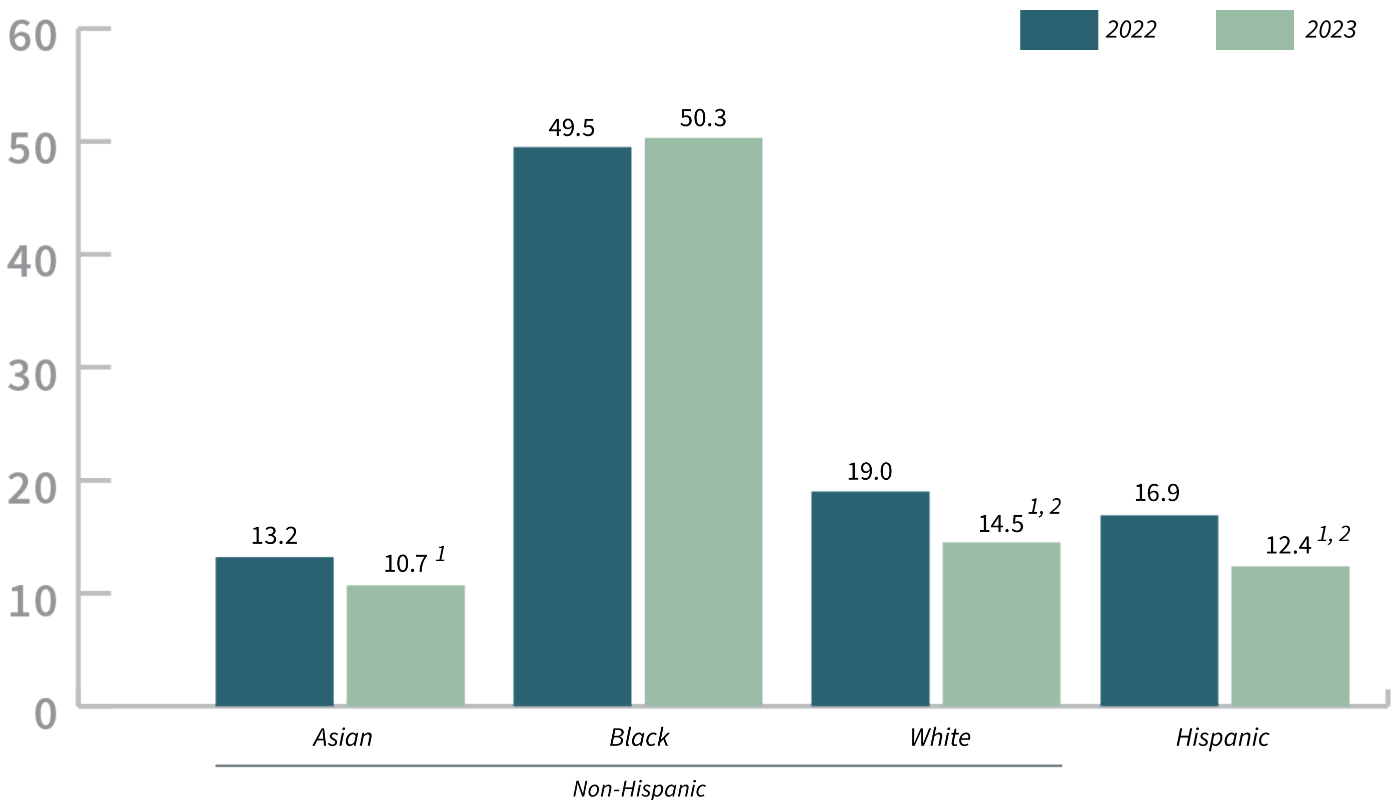
2. "While [I was] in labor, the on-call OB, noting my disability and perhaps my youthful appearance, [again questioned] whether I was confident in being able to provide care for my new baby," she said. "My fiancé at the time—who was my daughter's father—and my mother were in the labor and delivery room, [but] there obviously wasn't a thought given to [my] being interdependent and having help from both of them." [4]

3. McCoy McDeid, who is autistic and requires specific accommodations regarding outside stimuli like being touched and lighting, found her prenatal visits to be "terrible" because of how her needs were often ignored at best, and used to berate her at worst."During one visit, the midwife kept prodding me, in spite of my asking her to not do so and she became belligerent with me," she said. "I reported her and asked to be paired with a different midwife, but was told that I would need to meet with whichever midwife was available during my appointments and eventual labor and delivery." [4]

CONTEXT & IMPORTANCE OF THE PROBLEM

Mainstream maternal health efforts too often overlook disabled Black women, who face unique barriers to obstetric care including provider bias, exclusion from research, and disparities in care [3, 19.] These overlapping factors foster the creation of maternal deserts, leaving entire populations without meaningful access to care. As of 2014, more than half of rural counties in the U.S. were considered maternity care deserts, lacking hospital-based obstetric services—a crisis that has contributed to rising maternal mortality and morbidity among rural residents, especially Black women. While maternal care deserts are often discussed in terms of geographic access, for Black disabled women, these deserts are also systemic. Rural counties with a higher percentage of non-Hispanic Black women were more likely to lose obstetric services than other rural counties [6.] The compounded effects of racism and ableism create further invisibility. Even when healthcare exists, the quality, accessibility, and cultural competency of that care are insufficient to meet their needs [18]

Maternal Mortality Rate, By Race and Hispanic Origin: United States, 2022 and 2023 [8]



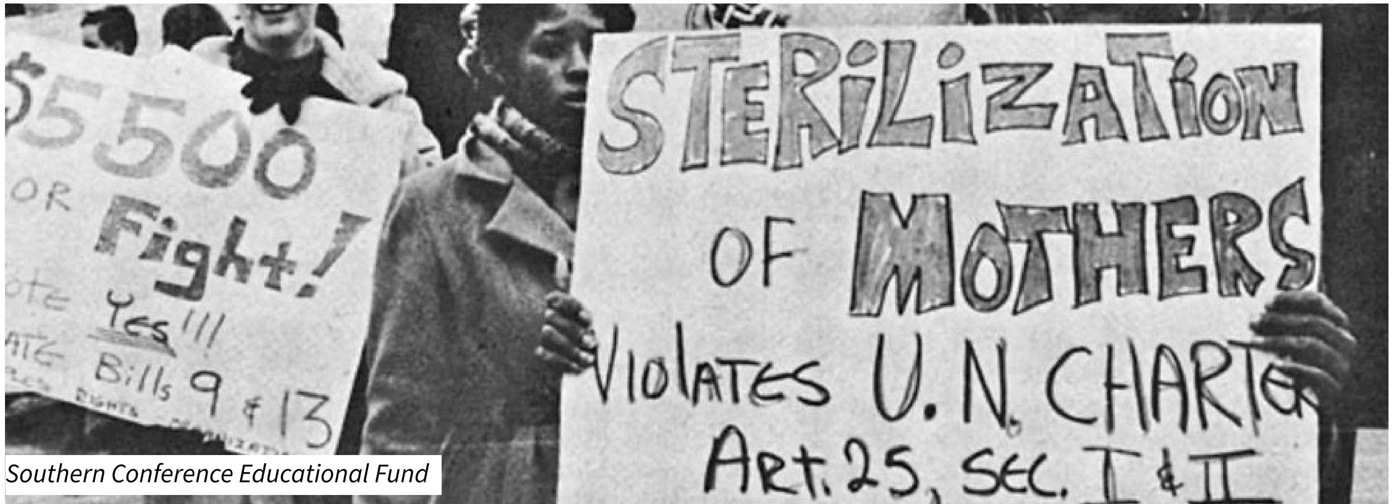
1. Statistically significant difference from Black non-Hispanic (p < 0.05).

2. Statistically significant decrease in rate from previous year (p < 0.05).

NOTES: Race groups are signle race. People of Hispanic origin may be of any race.

SOURCE: National Center for Health Statistics, National Vital Statistics System, ortality data file.

This data paints a clear picture of who is most at risk. Behind each number is a life that could have been saved. While racial disparities are clear, the compounded vulnerabilities faced by disabled Black women remain dangerously invisible— a reminder that maternal health policy must be reimagined to center those who have been historically overlooked.



Southern Conference Educational Fund

HISTORIC AND ROOT CAUSES OF DISPARITIES

These experiences are not new. The U.S. healthcare system has historically subjected Black and disabled bodies to control, exclusion and erasure. For example, between 1929 and 1974, thousands of Black girls and women were forcibly sterilized in the U.S. under eugenics policies — removing their ability to have children — often without their consent. The Relf sisters are a striking example of how sterilization was used to target poor Black girls during this period. Simultaneously, disabled women, particularly those with intellectual disabilities, were also targeted for sterilization.The 1927 *Buck v. Bell* Supreme Court decision confirmed the constitutionality of Virginia's forced sterilization statute, targeting individuals deemed "unfit" to have children. Justification for these practices included baseless claims like "menstrual management," based on assumptions that disabled women could not cope with or manage their menstrual cycles. Stereotypes served as a basis for denying women control over their bodies and autonomy in all areas of life. Today's disparities are not only rooted in this legacy, they reflect its continued presence in the care and treatment of disabled people. [9]

UNTANGLING OUR ROOTS

- **Provider Bias:** Medical professionals often lack training in both disability and racial equity. This leads to disbelief of pain, infantilization, and/or refusal of care [3, 9, 17.] Provider bias isn't just personal—it's institutional. When OB/GYN training lacks curricula on disability and intersectional care, bias becomes the standard of care [10, 11.] As one mother shared: "He told me that being pregnant wouldn't be a good idea because I'm in a wheelchair and fat."[4]
- **Inaccessibility:** Spaces may be physically inaccessible and unprepared for neurodiverse, chronically ill, or intellectually disabled patients and those who communicate using sign language or assistive technology [12, 13.]
- **Policy Neglect:** Key health policies fail to account for the intersectional needs of disabled people of color [14]
- **Data Exclusion:** Federal data systems rarely capture race and disability together, making Black disabled mothers invisible in policymaking. Recent proposals like changes to the Census disability question set that would drastically undercount disability—have faced strong backlash [15.] Similar debates around the race/ethnicity question set show how flawed data collection can reinforce systemic neglect.

Library of Congress

ADDRESSING POLICY SHORTCOMINGS IN MATERNAL CARE

Black disabled women are disproportionately impacted by failures in the healthcare system that may violate several key federal antidiscrimination laws. While laws such as the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA) are intended to ensure equitable access to care, they often fail to address the unmet needs of those at the intersection of race and disability.

Failures result in:

- **Poor maternal outcomes (e.g., diabetes, pregnancy complications, etc) and preventable deaths, which disproportionately impact Black disabled women**
- **Not investing in accessible healthcare systems**
- **Inadequate public health data, impeding equitable care delivery and policies**
- **Erosion of trust in healthcare among marginalized communities**
- **Persistent silos that treat race and disability as separate issues**

A deeper policy critique follows, examining how existing frameworks inadequately serve Black disabled mothers and offering recommendations for intersectional reform.

CRITIQUE OF POLICY OPTIONS

Overview of Policy Options in Focus

Law	Who It Protects	Protected From	How It Fails Black Disabled Mothers
Americans with Disabilities Act	People with disabilities	Discrimination in employment, public services, public accommodations (including healthcare), transportation, and telecommunications	Hospitals often lack accessible medical equipment, interpreters, or trained staff
Section 504 of the Rehabilitation Act	People with disabilities in programs or activities receiving federal funding	Discrimination in any program or activity that receives federal financial assistance, including schools, hospitals, and social services	Does not address race-related bias that compound disability discrimination
Title VI of the Civil Rights Act	People of all races, colors, and national origins	Discrimination in programs and activities receiving federal financial assistance, including education, housing, and healthcare	Doesn't address disability-related bias that compound racial discrimination
Section 1557 of the Affordable Care Act	Individuals protected under civil rights laws including people with disabilities, based on race, color, national origin, sex (including gender identity), age	Discrimination in health programs and activities that receive federal funding or are administered by a federal agency	Doesn't adequately protect people facing multiple/ intersectional forms of discrimination

While these laws technically prohibit discrimination, weak enforcement mechanisms, a lack of oversight, and limited case precedent related to pregnancy-specific care mean violations often go unaddressed.

Several recent regulatory updates to the ADA, Section 504, and ACA Section 1557 would provide important—though still partial and imperfect—protections that could help Black disabled mothers. These Final Rules were passed in 2024, but there is concern regarding their implementation under the current administration.

Regulation	Potential Benefit	Limitations
ADA Digital Access	Improves access to information & services	Does not address clinical racism or bias
ADA Medical Equipment	Physical accessibility for exams/labor	Does not mandate inclusive practices
Section 504 Final Rule	Broad protections in federally funded care	Uneven enforcement and awareness
ACA Section 1557	Explicit nondiscrimination in care	Does not address systemic maternal racism or coercion

Even recent federal initiatives to reduce maternal mortality rarely take a truly intersectional approach. Efforts often address race or disability but not both. For example, policies like the **Black Maternal Health Momnibus Act** have made important strides, but still lack meaningful inclusion of disabled people. Further, the extent to which pregnancy, birth, and reproductive care are protected under policies that aim to improve care for disabled people is a topic that has undergone much debate in-and-of itself, let alone within the context of race.

POLICY GAPS: WHERE DISABILITY AND RACE ARE LEFT BEHIND

1. **Reproductive Autonomy Protections:** Many disabled people, especially those with intellectual or psychosocial disabilities, still face restrictions on reproductive decision-making—sometimes even through guardianship or institutional policies.
2. **Integrated Data Collection:** Most state and national maternal health data disaggregated by race or disability—but not both. This leads to incomplete policy responses.
3. **Bias Training Requirements:** While some providers receive diversity, equity, and inclusion (DEI) training, few are required to complete disability competency training, and almost none are held accountable for practicing that knowledge.
4. **Funding Accountability:** Hospitals that repeatedly violate ADA standards or fail to provide equitable care continue to receive public funding without consequence.

RECOMMENDATIONS

1. ADVANCE THE REPRODUCTIVE EQUITY ACT

Recommendation

To ensure structural policy reform and community accountability, we need to advance the Reproductive Equity Act to include provisions specifically addressing the intersection of race and disability, ensuring it moves beyond able-bodied experiences.

Recommended Action

State governments with existing legislation should amend it to explicitly include provisions that address the needs and rights of disabled birthing people, particularly Black disabled women. This includes disability-inclusive protections, accessibility standards, and funding to ensure equitable reproductive health services for disabled people of color.

Why this Matters

Expanding such legislation with a racial and disability justice lens ensures that Black disabled birthing people are not overlooked in reproductive health policies. It will address current gaps, ensuring disabled people of color have the necessary resources, support and protections during pregnancy, birth and postpartum care.

Optional Model

Oregon's Reproductive Health Equity Act mandates comprehensive reproductive health care access.This model could be enhanced by incorporating explicit disability protections to better serve Black disabled women.

Additional Action

- **Require hospitals to report accessibility metrics alongside maternal outcome data**
- **Include Disability Justice in the Black Maternal Health Momnibus Act**

2. ADVANCE RESEARCH AND DISABILITY DATA EQUITY

Recommendation

The inclusion of disability and race in all federally funded maternal health surveys should be mandatory. Moreover, we must advance the Federal Evidence Agenda on Disability Equity started under President Biden. While this starts with the critical need to disaggregate data by both race and disability to inform evidence-based policy, it also comes down to the data we collect to begin with. In particular, how disability is significantly undercounted in federal and state data, reinforcing disparities in care. This has been the topic of much debate, prompting a U.S. Census Bureau meeting with various stakeholders.

Recommended Action

The Center for Racial and Disability Justice's Disability Data Justice Toolkit offers guidance on combating data ableism by promoting co-produced, community-led data. Recommendations that would advance the Federal Evidence Agenda on Disability Equity include:

- **Develop Disability Data Equity Standards & Principles**
- **Equity Must Address Intersectionality**
- **Invest in Disabled Researchers**
- **Develop New Measures & Methods, Not Adapt Ableist Ones**

These recommendations would ensure data policy that reflects the needs of disabled people of color, avoiding erasure and ensuring equitable health systems.

Why this Matters

Without inclusive, intersectional, and equitable data, policy cannot effectively meet the needs of disabled people of color. Accurate data is crucial for targeted reform and informed decision-making.

Other Recommended Actions

- **Support community-led, participatory action research led by disabled people of color**
- **Audit and revise clinical trial exclusion criteria**
- **Address implicit ableism in clinical trial design (e.g., excluding people with chronic illness or intellectual disabilities without legitimate justification).**

3. HEALTHCARE SYSTEM & PROVIDER TRAINING

Recommendation

Incorporate training on ableism, disability competence, racial bias and equity into OB/GYN medical education curricula and licensing requirements.

Recommended Action

- **Require training in racial bias, disability competency, and intersectionality as part of medical school curricula and continuing education.**
- **Tie completion of approved training programs to hospital accreditation and funding eligibility.**

Why this Matters

Healthcare providers must be trained to address both disability and racial bias. Promoting intersectional education helps ensure providers can offer accessible, culturally competent care for disabled women of color and begin to reduce health disparities.

One study noted: One of the most frequent concerns raised by women with disabilities is a lack of health care professional knowledge and awareness about how their disability could affect their pregnancy and how pregnancy might affect disability-related symptoms, progression, and other concerns. Likewise,

health care professionals report a lack of training and insufficient resources related to disability.

4. COMMUNITY-BASED OVERSIGHT

Recommendation

Introduce the Reproductive Equity Act at the federal level and expand it in states where similar legislation exists to include oversight structures that address disability and racial inequities in maternal health.

Recommended Action

- **Fund community-led reviews of hospital and provider practices, ensuring accountability beyond standard compliance audits**
- **Establish local or state-level equity committees to review maternal mortality cases and recommend targeted policy reforms**

Why this Matters

To advance maternal health equity, policies must reflect the lived experiences of those most affected. Center Black disabled pregnant women in oversight and accountability is essential and achievable—if integrated into broader reproductive justice legislation.

CALL TO ACTION

These steps would help ensure that future research, education, and health policy are designed to reflect the realities of those most impacted. Without meaningful change, disabled pregnant people of color will continue to experience preventable harm in systems that were never built with them in mind. This moment calls for bold, equity-rooted action.

SUGGESTED CITATION

Bailey, K. (2025, April) *Reproductive Justice in Maternal Deserts: Confronting Racism and Ableism in Obstetric Care.* Center for Racial and Disability Justice Reproductive Justice Collective (Policy Brief No. 3).

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