The Color of Infertility

RACE, INFERTILITY, AND REPRODUCTIVE JUSTICE IN THE U.S.



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"The ability to create a family is a basic human right."



able of Contents

RECOMMENDATIONS	4
FOREWORD	5
INTRODUCTION	10
BIRTH JUSTICE AND REPRODUCTIVE JUSTICE	15
RACE AND HEALTH	18
STIGMA AND CULTURAL BARRIERS	20
INFORMATION, AWARENESS, AND EDUCATION	24
CLINICAL FACTORS	25
ACCESS TO TREATMENT	27
GENDER, RELATIONSHIP STATUS, AND SEXUALITY DISCRIMINATION	29
FINANCIAL COSTS	31
DISABILITY JUSTICE	34
POST ROE LEGAL CONTEXT	35
CONCLUSION	37
RECOMMENDATIONS	38
MORE RESEARCH NEEDED	39
ABOUT Ms. FOUNDATION FOR WOMEN	41
ABOUT THE BIRTH JUSTICE INITIATIVE	42
THANK YOU	44



Support holistic approaches among women and nonbinary people of color-led reproductive justice and birth justice organizations to address family building, maternal health care including fertility information, awareness, and education; evaluation, testing, and diagnosis; and culturally competent and gender-affirming treatment.

Recognize and fund infertility issues as part of an intersectional birth justice and reproductive justice movement, connected to economic justice, LGBTQ+ justice, racial and gender justice, parenting justice, disability justice, immigrant justice, climate justice, and many additional social justice issues.

Support integrated, holistic policy advocacy to expand state-based and federal insurance mandates for infertility coverage, including Medicaid coverage, and specific cost barriers and access needs for immigrant, disability, and LGBTQ+ communities.

Support advocacy work addressing disparities in fertility treatment services, particularly in regions like the South, and address access barriers within immigrant, disability, and LGBTQ+ communities.

Support organizations working on culture change and narrative shift strategies focused on increased dialogue and awareness to counter stigma, address harmful myths and stereotypes, and acknowledge individuals' feelings of isolation and shame.

FOREWORD

This year – 2024 – is momentous for many reasons. For one, it marks the 30th anniversary of reproductive justice. It was in July of 1994 when 12 Black women coined the term reproductive justice at a meeting sponsored by Ms. Foundation, initiating a powerful movement that has catalyzed transformative organizing and impactful change in the lives of women and nonbinary people of color and advanced equity and human rights in reproductive and sexual health in the U.S. and globally. Reproductive justice is defined by three primary tenets: (1) the right not to have a child, (2) the right to have a child; and (3) the right to parent children in safe and healthy environments. Reproductive justice also demands sexual autonomy and gender freedom for every person.² The development of reproductive justice as both a theoretical framework and a tool of organizing and activism was then, and continues to be now, groundbreaking not only in the recognition of women of color as an active constituency and power base but also in demonstrating women of color's agency to articulate new visions of selfdetermination, collective unity, and liberation practices.³

The Ms. Foundation has a long history of supporting the reproductive justice movement. Beginning in the 1980s and 1990s, the Ms. Foundation funded many new and emerging reproductive justice organizations led by women of color,⁴ representing critical voices and issues that were left out of traditional mainstream, pro-choice, feminist, reproductive health and rights conversations. Then and now, organizations and grassroots voices led by Black women, Latinx women, Asian-American and Pacific Islander (AAPI) women, Indigenous women, undocumented, rural, low-income, and incarcerated women, as well as LGBTQ+ and gender-expansive folks are fighting for fundamental human rights, conditions of safety and dignity, and

^{1.} Editorial note: We know that Black and Indigenous women and nonbinary people experience these issues most acutely; for the sake of brevity and inclusivity, we'll use the term "women and nonbinary people of color" throughout this paper.

^{2.} Ibid, Ross.

^{3.} Ibid, Ross.

^{4.} Reproductive Justice organizations Ms. Foundation funded in the early 1980s-90s include: SisterSong Women of Color Reproductive Justice Collective, National Black Women's Reproductive Justice Agenda; National Asian Pacific American Women's Forum; National Latina Institute for Reproductive Justice; United for Reproductive and Gender Equity (formerly Choice USA); Native American Community Board; Bold Futures (formerly Young Women United), California Latinas for Reproductive Justice, Colorado Organization for Latina Opportunity and Reproductive Justice; Forward Together (formerly Asian Communities for Reproductive Justice)

against such egregious conditions as forced and coerced sterilization, shackling within prisons and detention centers, ICE immigration raids during childbirth, toxic waste on lands and in the neighborhoods of communities of color, forced separation and removal of children from family and kin, systemic sexual violence, police brutality, mass incarceration, gun violence and safety of neighborhoods. They also faced myriad intersecting economic justice issues such as living wages, affordable housing, and child care, in addition to the primary issues of reproductive health care, including sexual health education, abortion care, access to contraception, maternity care, pre- and postnatal care, and culturally competent, nondiscriminatory birthing care.

The Ms. Foundation plays a critical role by highlighting and amplifying important issues and stories that are invisible. unrecognized, and overlooked, as well as providing an analysis and context of the structural systems and root causes at play that contribute to gender and racial inequities. In this paper, Ms. Foundation aims to provide an overview and analysis of the landscape of infertility as a key issue within the reproductive justice movement and intrinsically connected to the reproductive justice value focused on the human right to have children.



In centering women and nonbinary people of color, we highlight the deep racial, ethnic, gender, ableist, and class-based disparities that fertility challenges bring, as well as the stigmas and biases inherent within our health care systems and social, political, and cultural contexts.

It is important to note that publication of this paper comes on the heels of the February 2024 Alabama Supreme Court's hostile decision impacting in vitro fertilization (IVF), which ruled that frozen embryos can be afforded the same rights as children under state law. This extremist position mirrors goals and strategies that conservatives have been testing for decades in states with fetal personhood legislation and ballot initiatives defining personhood at the moment of conception - resulting in the outlawing of abortion and

criminalizing health care providers and pregnant people. The impact of the recent Alabama ruling was felt immediately as hospital systems, fertility treatment centers, and health clinics halted all IVF services. The ruling continues to have profound reverberating effects across the country, creating additional barriers for an already complex, expensive, emotional, and difficult to navigate process. More than two dozen bills have been introduced in state legislatures this year in an attempt to establish fetal personhood, and it is clear that conservatives are using personhood to build upon their agenda to restrict, ban, criminalize, and ultimately eliminate the right to an abortion, a goal that grew closer to success in June 2022 with Dobbs v. Jackson Women's Health Organization, the Supreme Court decision that overturned Roe v. Wade.

Today, just two years after the newly-constituted conservative majority Supreme Court ended nearly 50 years of constitutional protections for abortion in the United States, we continue to see and experience the harmful impacts of this ruling. An estimated 22 million women, or one in three, in addition to gender nonbinary people who may become pregnant, now live in states where abortion is either

unavailable or severely restricted. The reality is that laws banning abortion cause chaos, confusion, and jeopardizes prompt and efficient health care for people experiencing miscarriages, pregnancy loss, medical emergencies, and complications during pregnancy.

Women's rights, reproductive freedom, bodily autonomy, and gender justice are deeply connected to democracy. Research indicates that attacks on abortion are indicative of rising authoritarianism.6 Indeed, the U.S. has experienced an acceleration of restrictive legislation on abortion, but also on contraception, genderaffirming care, and IVF, at the same time as a proliferation of voter suppression laws across states, impacting people of color the most. As of the time of this paper's publication, we are awaiting yet another landmark Supreme Court ruling on mifepristone, which could again significantly alter the landscape of abortion access via telemedicine and medication abortion pills, and undermine the authority of the FDA as a regulatory institution by allowing special interest groups with no standing to substitute their own unscientific claims about the safety of medicines.

^{5. 100} Days Post Roe

^{6.} Why Strongmen Attack Women's Rights

This moment calls for philanthropy to be responsive, nimble, and deeply trust and commit to women and nonbinary people, organizations, and grassroots leaders in states most impacted by regressive reproductive laws and policies and working with multiple constraints and limited resources to support those in need of critical, holistic, and reproductive healthcare services. The Ms. Foundation stands with leaders and organizations in these states, as well as service providers, activists, and supporters in reproductive freedom-friendly states to welcome and ensure care for all who travel within their state borders and are working proactively to expand legislation to protect and enshrine reproductive freedom into state constitutions.

Ellen Liu Chief Program Officer Sona Smith Birth Justice Program Officer



About Ms. Foundation Birth Justice Initiative

Ms. Foundation launched its Birth Justice Initiative in 2022 as a grantmaking strategy to advance equitable birth outcomes and experiences; strengthen the capacity, organizational infrastructure, and financial stability of grassroots women and nonbinary people of color-led birth justice organizations; and expand the frame of birth justice to support intersectional movements and strategies that recognize the full spectrum of experiences and identities in birthing, parenting, and family building. To date, Ms. Foundation has invested approximately \$5 million dollars in support of 60+ grassroots organizations led by women and nonbinary people of color to build power within the birth justice movement and address race based health disparities in birth experiences and birth outcomes.

INTRODUCTION

The ability to create a family is a basic human right. However, this right is difficult to access for the many people who experience infertility or impaired fecundity, two of the most common health conditions facing people 20-45 years old in the United States. 1 in 8 heterosexual couples experiences infertility, defined as the failure to achieve a pregnancy after 12 months or more of unprotected sex. (Note: because of this definition, single individuals and LGBTQ+ couples often face barriers to being diagnosed as infertile, which is a required entry point for accessing fertility treatment services). In addition to fertility challenges, impaired fecundity—referring to difficulty in carrying a pregnancy to full term—impacts approximately 6.7 million women in the U.S., more than 11% of those of reproductive age. Despite how common these conditions are, little is known about their causes and consequences. In particular, very little is known about their racial and ethnic dimensions.

^{7.} American Society for Reproductive Medicine (ASRM). 2021. "Disparities in Access to Effective Treatment for Infertility in the United States: An Ethics Committee Opinion," Fertility and Sterility, 116(1): 54-63.

^{8.} We note that the traditional medical definition of infertility is inherently biased, based on the assumption of sexual intercourse between a heterosexual couple.

^{9.} ASRM. 2017a. Quick Facts about Infertility.

^{10.} Chandra A, Copen CE, Stephen, EH. 2013. "Infertility and Impaired Fecundity in the United States, 1982-2010: Data from the National Survey of Family Growth." National Health Statistics Reports 67: 1-18.

In this paper, we explore the dimensions of fertility challenges among people of color, in particular trans and cis women and nonbinary people of color, as well as queer people of color.

We recognize that the literature predominantly uses gender-specific terminology that reflects the prevailing biases of heteronormativity and cisnormativity found in reproductive medicine research. In many instances, we also use gender-specific terms in order to be consistent with the cited literature, while acknowledging that this is an inherently limiting practice given that many individuals identify beyond the gender binary. We understand that inclusive language is an ongoing process that evolves with our understanding of gender and gender identity, and where possible we do our best to use language that is most fitting to each person's unique fertility journey.



Fertility challenges are marked by deep racial, ethnic, gender, ableist, and class-based disparities. Research demonstrates that Black women are twice as likely as white women to experience infertility, even after adjusting for socioeconomic status, pregnancy intent, age, smoking, presence of fibroids, and ovarian volume. A study of 1,350 women found that African-American and Latina women spent an average of 1.5 years longer trying to conceive, and faced more obstacles in getting treatment appointments, taking time off from work, and paying for treatment, compared to white women.¹² Although there are relatively fewer studies focused on fertility challenges among Indigenous and Asian-American and Pacific Islander (AAPI) women, there is evidence that suggests that these groups do experience higher rates of infertility and impaired fecundity due to environmental exposures. 13 14

On the journey to overcome infertility, individuals of color face significant barriers at every step, including diagnosis, specialist referrals, securing appointments with specialists, accessing fertility

treatment, undergoing assisted reproductive procedures, achieving a pregnancy, achieving a live birth, and in particular, feeling safe and seen along the journey.¹⁵

These barriers include structural and medical racism, financial challenges, and limited access to fertility centers, culturally competent care, or insurance coverage. Even when these challenges are overcome, racial disparities leave people of color less likely to have successful fertility treatment outcomes. These treatment challenges are deep and pervasive, and are further amplified by broader systemic and cultural factors that contribute to individuals' feelings of stigma, uncertainty, sadness, grief, and a general sense of shame that relegate infertility to the shadows.

Many reproductive justice and birth justice organizations face constraints due to limited funds, capacity, and staffing.



^{11.} Wellons MF, Lewis CE, Schwartz SM, Gunderson EP, Schreiner PJ, Sternfeld B, et al. 2008. "Racial Differences in Self-Reported Infertility and Risk Factors for Infertility in a Cohort of Black and White Women: The CARDIA Women's Study." Fertility & Sterility 90: 1640-48.

^{12.} Missmer S.A., Seifer D.B., Jain T. 2011. "Cultural Factors Contributing to Health Care Disparities Among Patients with Infertility in Midwestern United States." Fertility and Sterility. 95(6):1943–9.

^{13.} Craig LB, Peck JD, Janitz AE. 2019. "The Prevalence of Infertility in American Indian/Alaska Natives and Other Racial/Ethnic Groups: National Survey of Family Growth (NSFG)." Paediatr Perinat Epidemiol. 33(2): 119-125. doi: 10.1111/ppe.12538.

^{14.} Vu MH, Nguyen AA, Alur-Gupta S. 2022. "Asian Americans and Infertility: Genetic Susceptibilities, Sociocultural Stigma, and Access to Care." FS Rep 3(2 Suppl): 40-45. doi:10.1016.j.xfre.2021.12.004.

^{15.} Weiss MS, Marsh, EE. 2023. Navigating Unequal Paths: Racial Disparities in the Infertility Journey. Obstetrics & Gynecology 142(4): 940-947. Doi: 10.1097/AOG.00000000000005354.

Ms. Foundation's report, Living With Pocket Change: What it Means to Do More With Less, describes the cycle of chronic disinvestment and underinvestment among organizations by and for women and nonbinary people of color, which takes the form of short-term. small, and restrictive grants, making it more difficult to recruit and retain staff, and ultimately having a multiplicative impact on leaders' and organizations' health, wellness, and sustainability.16 As a result, organizations whose missions would align well with addressing fertility challenges may not directly address it in their work. In addition to the constraints noted above, organizations face additional challenges, including staff time, energy, and organizational resources are often absorbed by the ever-present struggle and necessity to respond to and defend against constant attacks on abortion and contraception.

Due to a pervasive lack of basic information about fertility and reproduction, many people only begin to learn about fertility challenges when they experience them firsthand, making proactive and preventive work difficult; and a lack of donor funding makes it difficult to add infertility work to already-full organizational program and policy agendas.

Further, foundations that fund in the field of reproductive health, rights, and justice are unaware that fertility is an reproductive justice issue: given that the mainstream struggle for reproductive rights has historically prioritized abortion access, funders have biases and a lower awareness of how women and nonbinary people of color have long struggled for the right to have children, an inherent component of reproductive justice (see next section). And finally, the grief, shame, and loss that often accompany infertility ensure that it largely remains shrouded in silence, even within the reproductive justice community.



16. Living With Pocket Change: What it Means to Do More With Less page 27

In bringing these issues to light, this paper rejects that silence, instead providing a landscape analysis that can also serve as a resource to advocate for an increased presence of infertility, family building, and parenting justice programming in reproductive justice organizations in the United States.

Given that infertility and impaired fecundity are reproductive health challenges marked by racial disparity, the reproductive justice community is well poised to address this set of issues through an increased emphasis on birth justice work. Funders are needed who will meet the moment with support for a holistic agenda at the intersection of these areas. With this paper, the Ms. Foundation seeks to invite dialogue, contribute to a broader discussion and narrative shift in the landscape, and also unite funders and movement leaders within the reproductive justice and birth justice movements in an effort to remove infertility from the shadows. Our aim is to place it front and center in an agenda of comprehensive reproductive justice and birth justice, as defined in the next section.

REPRODUCTIVE JUSTICE & BIRTHJUSTICE

Reproductive justice is a framework for policy, programming, and activism that links reproductive rights with human rights and social justice. It rests on three key pillars: the right to not have children, the right to have children, and the right to parent children with the resources necessary to ensure their safety and health. Although the right to have wanted children is a core component of the reproductive justice framework, access to fertility treatment and services are often overlooked.

Following Perrit, et al., we argue that "a vision for reproductive health and wellbeing that truly supports reproductive justice must include access to infertility care regardless of race, income, geography, or insurance status."17 We argue that birth justice is a necessary component of this work. According to Southern Birth Justice Network, birth justice is a framework that acknowledges that "all peoples can birth and be parents, [and that] people of color, immigrant peoples, and LGBTQ+ communities in particular have survived a history of trauma and oppression around our decisions to have and not have babies...[thus] Birth justice includes the right to choose whether or not to carry a pregnancy, to choose when, where, how, and with whom to birth...[and argues that] the complete range of pregnancy, labor, and birth options should be available to everyone as an integral part of reproductive justice and birth justice are perspectives rooted in an acknowledgement of the deeply unequal social and structural conditions that shape the conditions in which people in the U.S. experience fertility, reproduction, birth, and parenting.

The United States has a long history of reproductive oppression at the intersections of race, gender, and poverty. Population control in the form of coerced sterilization; surveillance and governance of the reproductive lives of low income women on welfare; and discourses and narratives that rendered women of color's fertility, childbearing, and motherhood problematic, even criminal, have long roots in U.S. policy.¹⁹

17. Perritt J, Eugene N. 2021. "Inequity and Injustice: Recognizing Infertility as a Reproductive Justice Issue." F&S Reports.

18. Southern Birth Justice Network, "Birth Justice Framework."

19. Roberts, D. 1994. Killing the Black Body: Race, Reproduction, and the Meaning of Liberty. New York, NY: Vintage Books; Davis, A. 1981. Women, Race & Class. New York, NY: Vintage Books

These policies are based on troublesome myths of overpopulation that blame fertility and reproduction for social, economic, and environmental problems. In times of crisis, particularly social and environmental crises, "overpopulation," particularly among low-income people and people of color, is often targeted as a source of large-scale problems, rather than systemic and structural forces.²⁰ These injustices derive in part from the fact that racial stereotypes often shape perceptions of the sexuality and fertility of women of color.

Historically, Black and Latina women in the U.S. have been thought of as hypersexual and hyper fertile - damaging stereotypes that persist to this day. In a 2016 study of 435 university undergraduates, respondents perceived Black women to be more sexually active, more likely to engage in risky sex, more likely to be unprepared for motherhood, and if pregnant, more likely to be a single mother and to need public assistance.21 These kinds of stereotypes are dangerous, as they also impact clinical encounters between doctors and patients. Studies have shown that conscious and unconscious biases

among physicians shape their perceptions of who should be a parent, and who wants or deserves infertility treatment.²²

Other research has found physician bias in terms of negative perceptions of the race and socio-economic status of patients, which in turn influences the quality of care they provide.²³ Many reproductive justice and birth justice organizations are currently engaged in work to address obstetric violence and traumatic birth experiences, maternal mortality, and more. Added to that, we need additional work to address physician bias so that patients at all steps in their reproductive journeys can feel safe, seen, and affirmed in clinical encounters.



^{20.} Sasser, Jade. 2018. On Infertile Ground: Population Control and Women's Rights in the Era of Climate Change. New York, NY:

NYU Press.

21. Rosenthal L, Lobel M. 2016. "Stereotypes of Black American Women Related to Sexuality and Motherhood." Psychology of Women Quarterly. 40(3): 414-27.

22. White L, McQuillan J., Greil A.L. 2006. "Explaining Disparities in Treatment Seeking: The Case of Infertility." Fertility and Sterility.

^{23.} van Ryn M, Burke J. 2000. "The Effect of Patient Race and Socio-economic Status on Physicians' Perceptions of Patients." Social Science and Medicine. 50(6):813-28.

Doctors are gatekeepers who can have the power to help people who need it, and therefore also have a duty to provide this help to everyone. So if it's not equally available, then that's automatically for me an injustice. These are medical issues: if your organs do not function the way that they are intended to, including ovaries creating eggs and sperm that swim and can fertilize an egg, then you deserve treatment. It's not about who can or can't afford it. It's about equitably providing access to medical care.

Dr. Tia Jackson-Bey, Reproductive Medicine Associates of New York

Structural racism has broad impacts that shape fertility and a range of other health issues as well. For example, research has shown that Black women's health begins to deteriorate at early ages based on cumulative physical stress from social, economic, and political marginalization. These cumulative impacts, known as "weathering," or allostatic load, are higher in Black women than in their male or white counterparts.²⁴ The impact of structural racism results in women and nonbinary people of color, in general, having higher incidences of chronic health issues that impact fertility (such as obesity, diabetes, and high blood pressure), due in part to a lack of access to consistent, high-quality healthcare.

Autoimmune conditions also play a role in infertility, particularly as they are associated with endometriosis and thyroid autoimmunity.25 Moreover, as many as 78% of people with autoimmune conditions are women,26 and women of color disproportionately experience autoimmune conditions such as lupus: lupus rates are nine times higher in women than in men, and highest among Indigenous, Black, and Latina women.27 While lupus does not directly cause infertility, it is associated with fertility complications including premature ovarian failure. Other autoimmune conditions affecting the thyroid, such as Graves disease, do have a direct impact on infertility through disrupted ovulation. Graves disease has a significantly higher incidence among Black and Asian-American/Pacific Islander communities.²⁸

24. Geronimus A, Hicken M, Keene D, Bound J. 2006. "Weathering" and Age Patterns of Allostatic Load Scores Among Blacks and Whites in the United States." American Journal of Public Health (6(5): 826-833.
25. Khhizroeva J, et al. 2019. "Infertility in Women with Systemic Autoimmune Diseases." Best Pract Res Clin Endocrinol Metab. 33(6): 101369. Doi: 10.1016/j.beem.2019.101369.
26. Fairweather D, Rose, NR. 2004. "Women and Autoimmune Diseases." Emerg Infect Dis. 10(11): 2005-2011.
27. Izmirly P, Parton H, Wang L, et al. 2021. "Prevalence of Systemic Lupus Erythematosus in the United States: Estimates from a Meta-Analysis of the Centers for Disease Control and Prevention National Lupus Registries." Arthritis & Rheumatology 73(6): 991-996.
28. McLeod DSA, Caturegli P, Cooper, DS, et al. 2014. "Variation in Rates of Autoimmune Thyroid Disease by Race/Ethnicity in U.S. Military Personnel." JAMA 311(15): 1563-65.

More research is needed to understand the gender dimensions of autoimmune conditions, which disproportionately impact women overall, and women of color in particular. They are often diagnosed at later ages, which runs the risk of further exacerbating infertility.

One possible explanation for these disparities is that communities of color are disproportionately exposed to environmental toxins. Indigenous communities have long experienced disproportionate exposure to toxic chemicals on reservations due to government-led extraction of minerals and other natural resources, as well as the historical legacy of weapons testing on Native lands.

The U.S. government's history of violating treaties with Indigenous nations has facilitated the ongoing pollution of their lands, soil, food, and water, and exposure to toxic pollutants has been linked to widespread chronic diseases, altered sex ratios, and high levels of toxic chemicals in blood and breastmilk in Indigenous communities.30

Communities of color in urban areas also face higher exposure to toxic environmental pollution, which can impact fertility, pregnancy, and miscarriage. Studies have shown that people of color are disproportionately exposed to endocrine disruptors, including phthalates, bisphenol A, and parabens, in diet, housing, workplace conditions, and consumer products.31 These exposures are particularly concentrated in places like hair salons, where chemical

products are linked to uterinefibroids, miscarriages, immune disorders, and cancers. 32 Exposure to endocrine disruptors is linked to autoimmune conditions in women³³ and decreased sperm in men; there has been as much as a 50% decline in sperm volume among men in western countries since the 1970s.34

Despite existing evidence, research into the relationships between race, toxic exposures, and reproductive health outcomes, including fibroids, infertility, and pregnancy complications, is limited. This reflects an overall devaluing of women's health research at the federal level: of the approximately \$45 billion the National Institutes of Health spends annually on medical research, less than \$5 billion is allocated to researching women's health.35

29. Manjeshwar, S. 2021. "The Lasting harms of Toxic Exposure in Native American Communities." Berkeley Political Review. 30. Hoover E, CookmK, Plain R, Sanchez K, Waghiyi V, Miller P, Dufault R, Sislin C, Carpenter DO. 2012. "Indigenous Peoples of North America: Environmental Exposures and Reproductive Justice." Environ Health Perspect. 120(12): 1645-1649.

31. Kobrosly RW, Parlett LE, Stahlhut RW, Barrett ES, Swan SH. 2012. "Socioeconomic factors and phthalate metabolite concentrations among United States women of reproductive age." Environ Res. 2012;115:11-7. doi:10.1016/j.envres.2012.03.008; Liu R, Nelson DO, Hurley S, Petreas MX, Park J, Wang Y, et al. 2016. Association between serum polybrominated diphenylether levels and residential proximity to solid waste facilities. Environmental Science and Technology. doi:10.1021/acs.est.5b04715.

32. Reproductive justice organization, Black Women for Wellness, has done groundbreaking research on the relationship between ongoing exposure to hair product chemicals and negative reproductive outcomes among hair salon employees. For more information, see Natural Hair Evolutions: One Hair Story.

33. Cleghorn, Elinor. 2021. Unwell Women: Misdiagnosis and Myth in a Man-Made World. New York, NY: Dutton.

34. Swann, S, Colino, S. 2021. Count Down: How our Modern World is Threatening Sperm Counts, Altering Male and Female Reproductive Development, and Imperiling the Future of the Human Race. USA: Scribner.

35. Mikulic, M. 2023. "Total Women's Health Funding by National Institutes for Health 2013-2024." Statista.

TIRAL BARRIFI

There is an overarching myth of hyperfertility within communities of color due to a lack of awareness and information from medical providers about reproductive function, what constitutes infertility or impaired fecundity, and when to seek treatment. This myth has direct, negative impacts on the experiences of isolation, stigma, and loneliness that arise when women and nonbinary people of color have difficulty becoming pregnant. These feelings are also associated with negative mental health outcomes, including depression, anxiety, and grief.

The impacts of infertility and impaired fecundity extend beyond physical health into mental, emotional, and cultural realms. The experience of infertility can negatively impact women and nonbinary people's sense of self and gender identity, particularly in the context of cultural, racial, and religious norms and expectations. One in-depth study found that Black women experience shame, silence, and isolation within their relationships with friends and family members as a result of their fertility struggles. A quarter of the women in the study had experiences with doctors who made negative assumptions about their sexual behavior, ability to pay for treatment, or their weight. Nearly all women in the study noted feeling isolated, lonely, and like they had failed. The study also demonstrated that Black women delay care and are half as likely as white women to seek treatment for fertility, even in the absence of financial barriers.³⁷

Fertility and reproductive justice advocate Regina Townsend of the Broken Brown Egg emphasizes the importance of addressing shame and stigma from a culturally relevant perspective. Townsend states,

36. American Psychological Association. "Infertility and BIPOC (Black, Indigenous & People of Color) Women: Fact Sheet from the Committee on Women in Psychology."

37. Ceballo R, Graham ET, Hart J. 2015. "Silent and Infertile: An Intersectional Analysis of the Experiences of Socioeconomically Diverse African American Women with Infertility." Psychology of Women Quarterly. 39(4): 497-511.

"When I started our online support group, I had to make it a secret on Facebook, and unsearchable because so many people didn't even want their name associated, like, don't put my name. I don't want anybody to be able to find me in it."

Townsend noted that this has changed over time through the work of advocacy organizations that are bringing infertility out of the shadows and empowering people to talk about it more. "I feel like part of the shift has been these organizations, you know, such as mine, such as Fertility for Colored Girls and the Cade Foundation, who've been out here in the trenches, kind of just talking, and empowering more women to feel like you're not alone. That helps take some of the shame off of it. It also helps to hear celebrities like Chrissy Tiegen and Gabrielle Union and Michelle Obama talk about their own struggles. That made it like, oh, this is affecting other Black women and women of color. I'm not alone."

One of the core aspects of infertility and impaired fecundity is the ongoing experience of grief, loss, and trauma. The struggle to conceive and maintain a pregnancy may involve miscarriage and stillbirth, as well as non-fertilization of eggs and non-implantation of fertilized embryos. These experiences come with a significant amount of pain and uncertainty, made all the more challenging because they are usually shrouded in silence. Well-meaning friends, family, and co-workers often ask intrusive questions, make unhelpful suggestions, or challenge an

infertile person's faith practice.³⁸Religious and spiritual impacts are particularly devastating, as religious life is often a very important source of community and cultural life for women and nonbinary people of color. These experiences may take a significant toll on spousal relationships, a sense of identity and connection to one's role as a family community member. They also may intensify already existing gendered assumptions and expectations - both in families and society at large - associating women with motherhood. As a result of these expectations, those who do not fulfill the motherhood role may experience significant social pressure.

Vu-An Foster, who holds a Master of Public Health (MPH) degree, experienced two distressing and avoidable pregnancy losses in which structural racism and implicit bias were clearly contributing factors. As a result, she established Life After 2 Losses, a nonprofit organization dedicated to providing information, support, and empowerment to women, families, and communities coping with miscarriage, pregnancy, and infant loss. Additionally, the organization offers strategies to mitigate the risk of pregnancy loss. Similar to many emerging organizations, Vu-An Foster encounters significant obstacles in securing sustainable funding despite the profound impact its programs have on bereaved families and the numerous requests it receives to leverage its expertise and lived experience in advocating for policy and systemic changes at the local and state levels.

Erica McAfee, a full spectrum doula at Sisters in Loss, argues that having a public outlet to share infertility stories is a powerful way of dealing, not only with stigma and shame, but with the ongoing sense of loss that accompanies infertility. Through her work, she helps turn that loss into a renewed sense of possibility: "I wanted to have an outlet to share stories of Black women or women of color with experience of loss and infertility in a storytelling format, but also provide people what the alternatives to motherhood look like so that they know that there's not one right path, that they can vary from what the traditional path looks like," she stated. "And, you know, think of surrogacy and gestational carriers, adoption and fostering-to-adoption as other alternatives to become mothers. People may think that those are not available to Black women, or people of color in general. But it is, and what I had started initially as a selfish thing to provide myself with resources and support really turned into a whole community of support, a grief support community. It became a space to navigate the ins and outs of the healthcare system as Black women and as women of color, as we are trying to become mothers

and really stay pregnant and bring healthy babies home."

A huge gap is that most people don't talk about infertility. Most people talk about maternal care, prenatal care, birth justice, doulas, and all of that. The movement space in general does a really poor job of talking about women's desires to have children as much as the desire to not have children. I don't know of an RJ organization that advocates for the ability to have more children. We're not out there on the frontline. Some do address environmental issues and their impact. This is a whole other arm that we have to develop. Some of the expectations are funder driven. Most funders are driven by population issues and haven't centered giving autonomy to our desire to have children.

Sung Yeon Choimorrow, NAPAWF

INFORMATION, AWARENESS, & EDUCATION

One of the biggest challenges to addressing infertility is a general lack of knowledge, information, and awareness. School-based education, when it does address sex and reproduction, focuses on basic reproductive functions of bodies, prevention and transmission of sexually transmitted infections, and how to avoid pregnancy. Beyond school, specific information about fertility is usually relegated to doctor's offices, where it often enters the conversation when a person is attempting to become pregnant and encounters challenges. This reveals a fundamental gap: between the formal education system and the medical system, individuals and couples are often on their own, left to navigate cultural ideas, stereotypes, and assumptions about their fertility. Broad shifts are necessary to properly support comprehensive education on fertility, causes and treatments of infertility, and how best to proactively plan for family creation throughout the reproductive years. Furthermore, the gaps for people living with disabilities and LGBTQ+ couples navigating family building are multi-faceted and complex and range from culturally competent providers to additional policy, insurance, and cost barriers, on top of social and cultural stigma. As noted elsewhere, in a society deeply impacted by racist stereotypes, gender biases, ableism, and heteronormative beliefs, a diagnosis of infertility is made even more challenging.

Many people say they don't want to find out something might be wrong, but information and knowledge are power. If we educate, we can address cultural stigma and gender biases; we can help women understand that they and their bodies haven't failed. If we do a good job educating, then employers will understand that this isn't an elective perk. People who are educated will go to their work and advocate for expanded services. Education will improve our providers too, and even if doctors don't bring it up, patients can self advocate. Education is so important on this issue across the board.

Dr. Fahimeh Sasan, Kindbody

CLINICAL FACTORS

As a physical health condition, infertility involves navigating a complex medical system that includes systemic barriers to equitable care. An infertility evaluation usually involves making an appointment with a medical specialist, such as a reproductive endocrinologist, to review a patient's medical history and perform a series of diagnostic tests. These tests include physical examination, blood tests to assess hormone levels, and other tests such as an ultrasound or imaging of the fallopian tubes and uterus. Factors including uterine fibroids (which will affect as many as 80% of Black women by the age of 50), endometriosis, polycystic ovarian syndrome (PCOS), blockages of the fallopian tubes, and problems with ovulation are the most common causes of fertility challenge. For those with genetic and inherited conditions such as sickle cell anemia, additional medical expertise and attention is needed during infertility evaluation. Age is also a strong factor. Fertility begins to decline significantly in the mid-30s, and more rapidly in the late 30s, both because of a decline in the number of available eggs in the ovaries, and also because of a decline in egg quality. Older women have a lower response to fertility medications and a higher miscarriage rate than younger women, as well as a higher chance of having a chromosomally abnormal embryo.

Finally, despite the tendency to focus on women, it is important to note that male factor infertility is very common. The male partner is either the sole or a contributing cause of infertility in 40-50% of cases, thus semen analysis is an important part of the evaluation. Racial dynamics may also play a role in male infertility; a study comparing Black and white men in the U.S. found that Black men had lower semen volumes, concentration, and total sperm counts.³⁹



PEATN/

Even after overcoming barriers to diagnosis, women and nonbinary people of color who seek treatment for infertility face significant challenges. Multiple studies have shown that women of color in the U.S. are less likely to use assisted reproductive technology (ART) compared to non-Hispanic white women, due to access issues such as cost, education, cultural beliefs, stigma, and structural barriers. Fertility centers are usually located in more affluent neighborhoods with higher white populations, which may be harder for lowincome women and women of color to access. Some treatments require frequent clinical visits, which presents a challenge for those who must take time off from work and travel long distances to treatment clinics. Further, when patients arrive at the center, they may be the only person/couple of color, increasing their sense of isolation.⁴⁰

For example, African-American women tend to wait longer before seeking fertility treatment; Latina women cite concerns about language barriers. appointment scheduling, and limited treatment accessibility. 41 When women of color do utilize ART, their outcomes are less successful: they are infertile for longer, have lower rates of implantation, and experience fewer pregnancies even when they have the same number of eggs retrieved and embryos transferred, compared to white women.42A large study looking at the outcomes of more than 139,000 non-donor ART cycles found lower clinical pregnancy rates in Asian-American and Pacific Islander (AAPI) women; lower live birth rates in African-American, Latina, and AAPI women; and higher rates of preterm delivery among African Americans and Latinas.43 Researchers have also found that, compared to white women, Black women using ART have lower live birth rates and higher incidences of spontaneous miscarriages.44

^{40.} Townsend 2021.
41. Jain T. 2006. Socioeconomic and racial disparities among infertility patients seeking care. Fertility and Sterility. 85(4):876–881; Nachtigall RD, Castrillo M, Shah N, Turner D, Harrington J, Jackson R. 2009. "The Challenge of Providing Infertility Services to a Low-income Immigrant Latino Population." Fertility and Sterility. 92(1):116–22.
42. Armstrong A, Plowden T. 2012. "Ethnicity and Assisted Reproductive Technologies." Clinical Practice. 9(6): 651-8.
43. Fujimoto VY, Luke B, Brown MB, et al. 2010. "Racial and Ethnic Disparities in Assisted Reproductive Technology Outcomes in the United States." Fertility and Sterility. 93(2):382–390.
44. Feinberg EC, Larsen FW, Catherino WH, Zhang J, Armstrong AY. 2006. "Comparison of Assisted Reproductive Technology Utilization and Outcomes Between Caucasian and African American Patients in an Equal-Access-to-Care Setting." Fertility and Sterility. 85(4): 888-94.

The existing research on racial outcomes in ART is largely focused on comparing Black and white women, which excludes other racial and ethnic groups, and makes it difficult to draw conclusions about group-specific challenges. For example, Latinas use fertility services at lower rates compared to white women, even when they have equal access to care.45The few studies focused on AAPI women have found that those who underwent artificial insemination (also known as intrauterine insemination or IUI) had significantly lower pregnancy rates than white women who underwent the same procedure. Other research found that, in comparing success of in-vitro fertilization (IVF) treatment rates, AAPI women had lower clinical pregnancy rates and lower live birth rates. Researchers could find no clear reason for the difference.46

Additionally, immigrant communities may face language and cultural barriers that prevent patients from fully understanding medical diagnoses and treatments; challenges with navigating complex medical systems that require multiple clinical visits and timed laboratory procedures; and limited availability and affordability of treatment.⁴⁷ More research is needed to understand the differential success rates among women and nonbinary people of color and treatment outcomes. Another challenge to treatment is that of

finding sperm or egg donors of color. In large cryobanks (facilities that extract and store sperm, eggs, and other human tissue), eggs and sperm from Black, Latinx, or AAPI donors represent a very small percentage of donor specimens. This is both because of very strict restrictions that exclude large numbers of people from the donor process—some cryobanks note that only one to two percent of potential sperm donor applicants are actually accepted—and also because people of color are less likely to apply to become donors to begin with. 48 Low rates of donor applications from people of color stem from lack of familiarity with sperm or egg donation, perceptions that such donation is not a culturally acceptable practice, concerns about medical racism, and general lack of awareness of higher infertility rates in communities of color. 49 This ultimately serves as another barrier to people of color seeking to use ART, if they place a high value on finding sperm or egg donors with racial and cultural backgrounds similar to their own.

45. Feinberg EC, Larsen FW, Wah RM, Alvero RJ, Armstrong AY. 2007. "Economics May Not Explain Hispanic Underutilization of Assisted Reproductive Technology Services." Fertility and Sterility. 88(5): 1439-41.
46. Purcell K, Schembri M, Frazier LM, et al. 2007. "Asian Ethnicity is Associated with Reduced Pregnancy Outcomes after Assisted Reproductive Technology." Fertility and Sterility. 87(2): 297-302.
47. Nachtigall RD, Castrillo M, Shah N, Turner D, Harrington J, Jackson R. 2009. "The Challenge of Providing Infertility Services to a Lowincome Immigrant Latino Population." Fertility and Sterility. 92(1):116–22.
48. Pérez, MZ. 2018. "Where are All the Sperm Donors of Color?" Rewire News Group. November 28, 2018. 49. Hatem, Angela. 2020. "Sperm Donors are Almost Always White, and It's Pushing Black Parents Using IVF to Start Families that Don't Look Like Them." Insider. September 17, 2020.

CENDER, RELATIONSHIP STATUS, &, SEXUALITY DISCRIMINATION

Equal access to evaluation, diagnosis, and treatment of infertility is a particular challenge for those who fall outside of the model of long-term, heterosexual couples. Non-partnered women, gender nonconforming individuals, and LGBTQ+ couples experience pervasive discrimination throughout the process of seeking infertility diagnosis and treatment. To begin with, the clinical definition of infertility is based on the sex practices of married, heterosexual couples, and thus being diagnosed as infertile—which is necessary to qualify for fertility treatment services that are covered by insurance—can be very challenging for those outside of this category. Further, some private fertility treatment centers refuse to accept non-partnered individuals and same sex couples as clients; while some states have laws prohibiting such discrimination, there are no laws at the federal level nor in every state.⁵¹

LGBTQ+ individuals and couples frequently experience stereotyping and discrimination from medical providers, which can lead to medical neglect, poor health outcomes, and even premature death. Sex- and gender-based discrimination in healthcare can amplify the effects of discrimination and exclusion within families, communities, and religious institutions. When taken together with racial discrimination and vulnerability due to immigration status, the experience of compounding oppression may be overwhelming.

^{50.} Weigel C, Ranji U, Long M, Salganicoff A. 2020. Coverage and Use of Fertility Services in the U.S. Kaiser Family Foundation Issue Briefs. 51. ASRM. 2013. "Access to Fertility Treatment by Gays, Lesbians, and Unmarried Persons: A Committee Opinion." Fertility and Sterility. 100(6): 1524-7.

It is thus particularly important that LGBTQ+ people are able to access fertility services that are gender and family affirming. It is particularly important that these services be financially accessible, given that LGBTQ+ adults in the U.S. are significantly more likely to be living in poverty than their straight and cisgender counterparts.

This disparity is even higher for gender nonconforming individuals and LGBTQ+ people of color.⁵³ Given the context of social vulnerability and discrimination, the financial costs and burdens of accessing fertility treatment (see next section) must be prioritized as an important arena in the struggle for reproductive justice and birth justice.

53. Wilson BDM, Bouton LJA, Badgett MVL, Macklin ML. 2023. LGBT Poverty in the United States. UCLA School of Law Williams Institute. The main thing for LGBTQ families is, a lot of us are going through those same processes and those same issues that other folks might be going through around fertility, building their families, and with the additional lens of being queer and being trans. In addition to IVF, which is so expensive, you have to find a provider who will diagnose you with infertility so that you can qualify for insurance. And that part of the journey can feel really isolating for folks. Having spaces for folks to connect with each other, to hopefully build community with other folks who are going through similar situations so they can have emotional support as they go through their fertility journeys, is really important.

Nourbese Flint, Planned Parenthood Federation of America

FINANCIAL COSTS

The U.S. private fertility industry is booming – the market is estimated to be valued at \$8 billion. For example, the average cost of one IVF cycle can range from \$12,000 to \$20,000; which many insurance plans do not cover, leaving individuals and couples to cover private fertility services largely out of pocket. Those who do pursue medical treatment for infertility tend to be white, of higher income, and covered by private insurance.

Private health insurance coverage plays a significant role, along with state laws. There is currently no federal mandate that private health insurers cover infertility diagnosis or treatment. As of the end of 2023, 21 states and the District of Columbia had laws on the books requiring private insurers to either cover or offer coverage for fertility services. However, these laws differ widely in the services insurers cover, leaving significant gaps, including for single women and LGBTQ+ families. Even with coverage such as an insurance mandate, access issues arise along the lines of race and class as well as sexual orientation. For example, a 2005 study in Massachusetts, a state that had an insurance mandate, found that even with reduced costs and increased access, the majority of women who sought infertility treatment were white, wealthy, and highly educated. However, expanding insurance mandates to cover fertility treatment in all states is an important step in the right direction for ensuring affordability and accessibility of treatment.

Another important step is the expansion of public health coverage through Medicaid." Currently, only four states cover some aspect of fertility treatment, whether sperm and egg banking, or fertility medications, through Medicaid. Some states may require Medicaid to cover treatment for conditions that impact fertility, including medications for thyroid conditions or surgery for conditions such as fibroids or endometriosis. However, currently no state Medicaid program covers IUI, IVF, or cryopreservation services (freezing of eggs or embryos), although the program covers many services for pregnancy or pregnancy prevention. Lack of Medicaid coverage has a significant impact on women of color, given that the program covers 30% of Black and 26% of Latina women of reproductive age, compared to 15% of white women.57

Employer-funded benefits plans play a key role in whether women and nonbinary people can access fertility services.

In addition to financial costs, there are significant time costs associated with doctor visits, clinicsupervised treatments, and testing procedures. Fertility treatment requires patients to take significant time away from work for office visits, in part because they may have to travel for repeat visits at specialty clinics that may be far from home. Many employers do not cover fertility treatment services, nor allow time off for employees to access care. For example, the Federal Employee Health Benefit program, the single largest employer-sponsored group insurance program in the country with close to nine million enrollees, only covers fertility preservation, such as egg freezing, in the case of "iatrogenic infertility" caused by necessary medical intervention such as chemotherapy. The plan does not cover elective egg freezing, IVF, or egg storage, thus leaving many of its employees unable to access the benefit.58 (Note: even when egg freezing is a covered benefit, the marketing of the service may not always provide accurate information regarding

56. Bellloni G. 2023. "States Pursue Small Expansions to Medicaid Fertility Coverage." Bloomberg Law.
57. Weigel G, Ranji U, Long M, Salganicoff A. 2020. "Coverage and Use of Fertility Services in the U.S." Kaiser Family Foundation.
58. U.S. Office of Personnel Management. 2021. FEHB Program Carrier Letter.

success rates). However, some employers are increasingly providing fertility coverage for their employees. In 2021, a national survey⁵⁹ of benefits plans provided by large employers found that, of companies with 20,000 or more employees, 73% covered evaluation by an infertility specialist; 53% covered drug therapy; 42% covered IVF; and 38% covered IUI. While this is a step in the right direction, employees of smaller companies still face significant employer-related challenges to accessing fertility evaluation, diagnosis, and treatment.

There are legislative efforts to support equitable leave policies for employees dealing with infertility. In 2021, Senators Tammy Duckworth (D-IL) and Ayanna Pressley (D-MA-07) introduced the Support Through Loss Act in Congress. The bill would ensure that employers provide paid time off for employees to cope following pregnancy loss, unsuccessful assisted reproductive technology procedure, failed adoption or surrogacy arrangement, or medical

diagnosis that impacts pregnancy or fertility. Although the bill did not pass, Senators Duckworth and Pressley renewed their support for the measure in 2023.

In terms of fertility, I think there needs to be a lot more research. There's just so little research into the causes of infertility. First, a lot more dedication needs to be put to that, with women or birthing folks being some of the lead researchers so that vou can focus on the lived experience and ask the right questions. Second, some deep ethical conversations need to happen. Particularly around things like surrogacy, and the development of assisted reproductive technologies. What does it mean in terms of who has bodily autonomy when it comes to surrogacy? When it comes to the types of technologies that are developed and recommended? Who participates in that research? There are so many ethical areas we haven't really delved into.

Khye Tyson, Kuluntu Reproductive Justice Center

DISABILITY JUSTICE

The U.S. has a deplorable history of discrimination, racism, ableism, abuse, and state-sanctioned eugenics policy and practice toward people living with disabilities, including institutionalization, sexual violence, and forced or coerced sterilization. These eugenic practices have also extended to women of color, immigrants, low-income women, and women in prisons as a tool of population control, as referenced earlier in this paper. People living with disabilities experience invisibilization, stigma and denial of the right to conceive, bear, and parent children, and a wide range of systemic barriers to access reproductive health, and maternity care. People living with disabilities and chronic conditions also often face barriers to comprehensive sex education, as well as restricted access to contraceptives and to the full range of reproductive health services. Moreover, they often experience doctors' and clinicians' prejudices and biased assumptions that they are uninterested in sex and childbearing.⁶¹

Research shows that women and nonbinary people with disabilities are equally likely to want to have children as those without disabilities; however, they are less likely to intend to have a baby in the future. There may be many reasons for this gap; women with disabilities are often pressured not to have children, and experience significant disparities in access to family planning services.⁶² Furthermore, as parents, people living with disabilities must contend with discriminatory state laws and policies that can authorize removal of children through child welfare services solely based on the rationale that one or both parents live with a disability. 63

The right to parent is a key disability and reproductive justice issue and people living with disabilities deserve access to programs and services to support the right to parent to their fullest capacity. Currently, with the impact of the Dobbs ruling curtailing reproductive health services nationwide, people living with disabilities face more systemic barriers to accessing care. A disability justice perspective is crucial to provide equal access and reduce barriers for those with chronic conditions and other disabilities to pursue fertility services as a component of comprehensive reproductive health and rights. Organizations such as Sins Invalid and other grassroots groups are working in communities at the intersection of reproductive justice and disability justice to provide leadership, analysis, and advocacy so that reproductive justice is a reality for people living with disabilities.

51. DiMatteo E, Ahmed O, Thompson V. 2022. "Reproductive Justice for Disabled Women: Ending Systemic Discrimination." Center for American

Progress.
62. Bloom TL, Mosher W, Alhusen J, et al. 2017. "Fertility Desires and Intentions Among U.S. Women By Disability Status: Findings from the 2011-2013 National Survey of Family Crowth." Maternal Child Health Journal, 21(8): 1606-1615.
63. National Council on Disability. "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children" (Washington: 2012)

FGAL CONTEXT

In June 2022, the Supreme Court issued the Dobbs v. Jackson Women's Health Organization ruling, which overturned Roe v. Wade and ended the Constitutionally-protected right to abortion access. As a result, the authority to regulate abortion was returned to state legislatures. As of January 2024, 21 states either banned or restricted access to abortion,64 and some of those states also extended restrictions to encompass various aspects of ART. For example, Louisiana, Oklahoma, Virginia, and West Virginia have laws on the books that define embryos as human children and that legally bar their destruction.65

In February 2024, Alabama's Supreme Court ruled that embryos are "extrauterine children," 66 prompting a fertility clinic to halt IVF services, and additional clinics and treatment centers similarly suspending services.⁶⁷In response to the swift public outcry, at the end of February, the Alabama state legislature backtracked and introduced a narrow bill to protect IVF patients and providers with immunity from possible prosecution under the new law. The bill passed and was signed into law in early March and fertility services resumed. However, one AL hospital system has already announced it will cease to provide services at the end of December 2024, due to ongoing litigation concerns.⁶⁸ The broader conservative goal to establish personhood, fetal rights, and outlaw abortion have not been resolved by the short-term fix, and therefore pregnant people's rights continue to be subverted and threatened by criminalization.

The New York Times. 2024. "Tracking Abortion Bans Across the Country."
Adashi EY, O'Mahony DP, Cohen IG. 2023. "Assisted Reproduction post-Dobbs: The Prospect of Legislative Protection." FS Rep 4(2): 128-129. Walker A. 2024. "Alabama Supreme Court Rules Frozen Embryos Are 'Children'". The Guardian.
Vagianos A. 2024. "Alabama IVF Clinic Halts Services After State Rules Frozen Embryos Are 'Children'". Huffpost.
Timotija, F. "Alabama Hospital to Stop IVF Treatments At the End of 2024 Due to 'Litigation Concerns'" The Hill.

Prior to the Alabama ruling, members of Congress have responded to personhood claims, proposing federal legislation that would protect access to IVF and related treatments.

In 2022, Senator Patty Murray (D-WA) and Representative Kim Schrier (D-WA-8) separately introduced the Let Doctors Provide Reproductive Health Care Act, which protects health care providers who offer a variety of legal reproductive health services, including IVF. Later that year, Senators Tammy Duckworth (D-IL), Patty Murray (D-WA), Tammy Baldwin (D-WI), and Kirsten Gillibrand (D-NY) introduced the Right to Build Families Act of 2022, which prevents states from preventing patients from accessing ART or completing ongoing ART procedures.⁶⁹ In January 2024, The Access to Family Building Act was introduced in the Senate by Senators Tammy Duckworth (D-IL), Patty Murray (D-WA), and in the House by Susan Wild (D-PA). The bill would establish a right to access IVF and other ART services and ensure they remain legal and available everywhere in the U.S.

In the wake of the Alabama ruling, Duckworth attempted to bring up a vote under unanimous consent in March, but was blocked by Senate Republicans.

69. Vagianos, A. 2024.



CONCLUSION

We are currently living in the midst of a contentious political environment that is quickly shifting and exacerbated by a polarizing election year in which American democracy will be tested. Major ripple effects impacting a broad range of reproductive health services will continue to be felt across the country from the reversal of Roe v. Wade, new state rulings such as Alabama's IVF law, Arizona's recent state supreme court's passage of an 1864 near-total ban on abortion, and many more regressive bans and laws related to bodily autonomy and gender. The additional barriers and constraints placed upon people's reproductive freedom will be felt most acutely by women and nonbinary people of color living at the intersection of multiple systems of oppression. As of the time of this paper's publication, we are also awaiting another landmark Supreme Court ruling in June, Alliance for Hippocratic Medicine v. Food and Drug Administration (FDA), on access to mifepristone, which could again significantly alter the landscape of abortion access via telemedicine and medication abortion pills, and potentially undermine the authority of the FDA as a regulatory institution by allowing special interest groups, including organizations with no legal standing, to substitute their own unscientific claims about the safety of any medicines.

The issue of infertility is critical to the reproductive justice and birth justice movement and demands increased funding, attention, awareness, and advocacy now more than ever, given the interconnected links between current attacks on reproductive freedom, gender, bodily autonomy, and democracy that are being orchestrated and coordinated by similar political actors. This landscape analysis provides an introductory overview of the structural and systemic barriers facing women and nonbinary people of color by highlighting the racial, ethnic, gender, ability, and class-based disparities that fertility challenges bring, as well as the stigmas and biases inherent within our health care systems and social, political and cultural contexts. Ms. Foundation's recommendations and additional research needs are as follows.

Support holistic approaches among women and nonbinary people of color-led reproductive justice and birth justice organizations to address family building, maternal health care including fertility information, awareness, and education; evaluation, testing, and diagnosis; and culturally competent and gender-affirming treatment.

Recognize and fund infertility issues as part of an intersectional birth justice and reproductive justice movement, connected to economic justice, LGBTQ+ justice, racial and gender justice, parenting justice, disability justice, immigrant justice, climate justice, and many additional social justice issues.

Support integrated, holistic policy advocacy to expand state-based and federal insurance mandates for infertility coverage, including Medicaid coverage, and specific cost barriers and access needs for immigrant, disability, and LGBTQ+ communities.

Support advocacy work addressing disparities in fertility treatment services, particularly in regions like the South, and address access barriers within immigrant, disability, and LGBTQ+ communities.

Support organizations working on culture change and narrative shift strategies focused on increased dialogue and awareness to counter stigma, address harmful myths and stereotypes, and acknowledge individuals' feelings of isolation and shame.

MORE RESEARCH NEEDED

In addition to considerations above, this paper points to the need for additional research into infertility, impaired fecundity, and a range of related conditions. Specifically, we illuminate the need to support research funding in the following areas:

Expand financial and capacity building resources for reproductive justice organizations to lead community-based fertility conversations and research on lived experiences of infertility, impaired fecundity, miscarriage, and related experiences, centering queer and trans communities.

Expand qualitative research on the experiences of women and nonbinary people of color, people living with disabilities, and LGBTQ+ individuals experiencing infertility and impaired fecundity.

Expand and increase parity National Institutes of Health and basic research investments in women's health focused on infertility among under-studied communities, including AAPI and Indigenous women, as well as women's health conditions impacting infertility including autoimmune conditions, endometriosis, PCOS, sickle cell disease, etc.

Increase research into fertility-related health conditions that disproportionately impact women and nonbinary people of color, including fibroids, adenomyosis, and PCOS as well as the reproductive and fertility-based impacts of chronic health conditions, such as sickle cell disease, that disproportionately affect women and nonbinary people of color.

Expand basic education and public awareness about reproduction, fertility, pregnancy, miscarriage, stillbirth, and the range of health conditions that may impede fertility.

Increase policy analysis and research into the costs and benefits of providing fertility treatment in public and private insurance health plans.

Increase research studies on equity and the impact of cost barriers, access to financing, insurance, private grants or other funding sources, on use of fertility treatment services.

Expand research on the pregnancy and birthing outcomes of people living with disabilities, chronic conditions and other disabilities.

ABOUNDATION FOR WOMEN

For more than 50 years, the Ms. Foundation for Women has shaped women's philanthropy in the United States, providing a blueprint for the establishment of hundreds of local and regional women's funds, influencing mainstream culture through nationwide projects such as Take Our Daughters to Work Day, and making grants totaling over \$90 million to more than 1,600 grassroots organizations across the country.

Ms. Foundation's mission is to build women's collective power in the U.S. to advance equity and justice for all. Through research, advocacy, and grantmaking, the Ms. Foundation is the national model for sustainable, trust-based philanthropic support of women of color-led movements.

ABIRTHJUSTICE INITIATIVE

The Ms. Foundation launched our Birth Justice Initiative in 2022 as a grantmaking strategy to advance equitable birth outcomes and experiences; strengthen the capacity, organizational infrastructure, and financial stability of grassroots women and nonbinary people of color-led birth justice organizations; and expand the frame of birth justice to support intersectional movements and strategies that recognize the full spectrum of experiences and identities in birthing, parenting, and family building. To date, Ms. Foundation has invested approximately \$5 million dollars in support of 60+ grassroots organizations led by women and nonbinary people of color to build power within the birth justice movement and address race-based health disparities in birth experiences and birth outcomes.

Ms. Foundation believes that women and nonbinary people of color are key experts and should be decision-makers in shaping policy and culture change around birth justice. By investing directly into organizations led by and for women and nonbinary people of color, we are ensuring that the movement to address race-based disparities in healthcare, including birth outcomes and experiences, is led by those who are impacted most. Strengthening the collective power of communities of color is critical to addressing the root causes of these disparities and advancing birth justice for all.

The U.S. has one of the highest maternal mortality rates of all developed nations, and Black women die in birth at three to four times the rate of white women – one of the widest racial disparities in women's health. Systemic racism, implicit bias, and anti-Blackness all contribute to the significant disparities in birth outcomes among Black, Indigenous and birthing people of color. And yet, philanthropy has significantly underfunded and underinvested in organizations led by and for women and nonbinary of color, as revealed in Ms. Foundation's <u>Pocket Change research series</u>.

Given these findings, the Birth Justice Initiative supports driving greater philanthropic investment, understanding, and engagement toward organizations led by and for women and nonbinary people of color.

The initiative builds upon the Ms. Foundation's decades of experience supporting grassroots leaders fighting for reproductive justice and aims to build power within the birth justice movement, increase connectivity and collaboration between organizations and movement leaders, and provide philanthropic advocacy to influence the movement of more resources for birth justice.

Recognizing that the spectrum of intersectional issues that comprise birth justice and the ability to have children and parent with dignity are not only limited to the birth process, the Ms. Foundation's Birth Justice Initiative invests in organizations that represent the full spectrum of birth experiences including, but not limited to: preconception health, mental health and wellness; infertility; abortion access and abortion care; comprehensive sex and sexuality education; non-racist, culturally affirming, and gender-expansive healthcare; access to birth workers of color; access to lactation support and services; postpartum health and wellness; grief and loss care and support; and sexual assault prevention and survivor support services.

Organizations supported through this initiative collectively utilize a range of movement-building strategies to advance birth justice —such as narrative change, policy and systems change, advocacy, leadership development, and direct service, among others. And finally, they work at the intersection of birth justice and other movements, such as disability justice, youth justice, LGBTQIA+ justice, environmental justice, economic justice, and criminal legal reform. To learn more about the Birth Justice Initiative and organizations we currently support, click here.



THANK HYOU!

DEEPEST GRATITUDE TO
THE EXPERTS AND
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Appendix: Organizations Addressing Reproductive Justice, Birth Justice, and (In)fertility

<u>Akin</u>: Network of practitioners providing support from preconception through postpartum, including pregnancy loss.

<u>All Options Pregnancy Resource Center</u>: Full spectrum organization promoting unconditional, judgement-free support for people in all of their decisions, feelings, and experiences with pregnancy, parenting, abortion, and adoption. Centers those most impacted by reproductive injustices.

<u>Ancient Song Doula Services</u>: Brooklyn, NY, offers doulas and childbirth services to women of color and low-income families.

<u>Black Mamas Matter Alliance</u>: Black women-led alliance working to change policy, cultivate research, advance care, and shift the cultural narrative and amplify voices of Black mamas.

<u>The Broken Brown Egg, Inc.</u>: Empowers, informs, and advocates for those questioning or experiencing infertility, with an emphasis on Black women.

<u>Everthrive Illinois</u>: Addresses the most pressing health problems facing women, children, and families; works to dismantle systemic racism and inequality to pave the way for greater health equity in Illinois.

<u>Endo Black</u>: Advocates for African American women and women of color affected by endometriosis.

<u>Family Equality</u>: Family Equality is fighting to protect and support LGBTQ+ families. By fighting for a world where everyone can experience the unconditional love and belonging of family.

<u>Fertility for Colored Girls</u>: provides education, awareness, support, funding, and encouragement to African American women, couples, and other women of color experiencing infertility.

<u>Fertility Within Reach</u>: Increases access to fertility treatment and benefits by educating patients, policymakers and service providers with proprietary and evidence-based data.

<u>In Our Own Voice</u>: National Black Women's Reproductive Justice Agenda is a national-state partnership focused on lifting up the voices of Black women leaders at the national and regional levels in our fight to secure Reproductive Justice for all women, girls, and gender-expansive individuals.

<u>Irth: App providing prenatal, birthing, postpartum and pediatric reviews of care from black and brown women.</u>

<u>Kindbody: Offers gynecology, fertility, and family-building care, delivering clinical</u> excellence with accessible pricing. Special education and support programs for women of color and LGBTQ+ persons.

<u>Kuluntu Reproductive Justice Center: Reproductive justice services and events hub that centers the needs of Black women, girls, non-binary folx, and femmes.</u>

<u>Lawyers for Good Government, Reproductive Health Legal Assistance Project</u>: With state and local laws changing rapidly this database helps patients access medical care post Dobbs by providing legal guidance to reproductive healthcare providers.

<u>Life After 2 Losses</u>: Champions perinatal care. Promotes birth advocacy and birth justice by empowering women, families, and communities to build confidence in their decision-making abilities during conception, pregnancy, labor, childbirth, and postpartum.

<u>Loom</u>: Empowers women with sexual and reproductive health education through using empathy, inclusivity, and science.

<u>Ms. Foundation for Women Birth Justice Initiative</u>: Find a complete list of current Ms. Foundation grantee partners here.

<u>National Asian Pacific American Women's Forum</u>: Mobilizes and builds power across the U.S. to create social, political, and economic change for Asian/Pacific women and girls using a reproductive justice framework.

<u>RH Impact formerly, National Birth Equity Collaborative</u>: Creates transnational solutions that optimize Black maternal, infant, sexual, and reproductive wellbeing. Work centers on training, research, technical assistance, policy advocacy, and community-centered collaboration.

<u>Resolve, The National Infertility Association</u>: is dedicated to ensuring that all people challenged in their family building journey reach resolution through being empowered by knowledge, supported by community, united by advocacy, and inspired to act.

<u>Sickle Cell Red</u>: Sickle Cell Reproductive Health Education Directive (SC RED) advocates for high quality reproductive and maternal health care for individuals living with all types of sickle cell disease.

<u>Sister Song</u>: Strengthens and amplifies collective voices of indigenous and women of color to achieve reproductive justice.

<u>Sisters in Loss</u>: Black woman-led maternal health education organization that replaces silence with storytelling around infertility, pregnancy, and infant loss. Provides grief and bereavement doula services and trainings.

<u>Sins Invalid</u>: Sins Invalid is committed to social and economic justice for all people with disabilities – in lockdowns, in shelters, on the streets, visibly disabled, invisibly disabled, sensory minority, environmentally injured, psychiatric survivors – moving beyond individual legal rights to collective human rights.

<u>Sol and Love</u>: Resources on love, pregnancy and infant loss, and grief for black Angel Parents, including books, affirmations, and a podcast.

<u>Vios Fertility Institute (now Kindbody)</u>: Offers fertility treatments including IVF, IUI, genetic testing, egg freezing, etc.

The White Dress Project: Provides support, education, and hope for people living with uterine fibroids.

Ms. FOUNDATION FOR WOMEN



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