

Ensuring Equitable Access to Infertility Care in the United States: Guiding Principles for Policies Mandating Insurance Coverage



**Assisted
Reproduction**

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Laws and policies that promote equitable access to infertility care, including those that mandate insurance coverage, help to ensure the full spectrum of reproductive rights, including the rights to make decisions about one's reproductive life, health, equality and non-discrimination, and benefit from scientific progress. Human rights principles should guide the development of such policies.

INTRODUCTION

Inequities in health and access to health-care, including infertility care, are pervasive in the United States. Well-documented disparities in access to infertility care reveal that people of color, low-income people, people with disabilities, and the LGBTQ community receive infertility treatment at disproportionately low rates.¹

Deeply entrenched racial and ethnic disparities in health disproportionately impact Black women of all socioeconomic backgrounds,² including in rates of infertility. Black women in the United States are nearly twice as likely to experience infertility than non-Hispanic white women³ yet are 20% less likely than white women to receive infertility care.⁴ Below-average rates of infertility care use have also been found among Hispanic and American Indian/Alaska Native non-Hispanic women, while Asian/Pacific Islander and Black non-Hispanic women have reported longer periods of infertility and accessing ART at later ages compared to their non-Hispanic white counterparts.⁵

Likewise, having low-income and lacking access to insurance can be major barriers to infertility care. Indeed, women without insurance are three times more likely than women with insurance to discontinue infertility care after a single cycle of treatment.⁶ Even when insured, many public and private insurers require patients to prove clinical infertility before providing IVF coverage. That is, patients must demonstrate they have tried to become pregnant by having unprotected sex for six months or a year, depending on their age.

Such insurance eligibility requirements are not inclusive of or sensitive to the experiences of single individuals and individuals in same-sex couples, who are required to undergo six to twelve unsuccessful cycles of IUI, depending on their age, to receive the required clinical diagnosis.

In recent years, legislatures across the country have recognized infertility as a public health concern and acted to make infertility care affordable and accessible. They have done so by enacting legislation establishing state insurance mandates requiring some or most private health insurance plans to include certain minimum levels of coverage for infertility diagnosis and treatment, including IVF. Such legislation addresses an important need given that, in the United States, a single IVF cycle can cost upwards of \$20,000 in out-of-pocket costs and the chances of live birth increase with each cumulative cycle.⁷

However, the limited number of private insurance markets and public programs covering infertility care, combined with high out-of-pocket expenses result in significant economic barriers to needed infertility treatment. State insurance mandates have been shown to increase infertility care use nearly three times and to result in more positive health outcomes for individuals, couples, and their children.⁸ This increase, however, has been most notable among a subgroup of “older, more educated women” who may have a “higher probability of having private health insurance.”⁹ Human rights-based legislation to establish or expand infertility care insurance mandates is critical to address these and other remaining barriers to access.

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It should be noted that increasing access to infertility care through insurance mandates alone will not address the disparities, including racial and ethnic disparities, in infertility incidence or in access to care in the United States. Doing so requires a deeper investment to address disparities in access to broader reproductive health education and services, and a commitment to addressing personal bias and institutional racism in medicine.

It also requires a greater understanding of the scale of infertility incidence and of what groups are disproportionately impacted. There is a dearth of recent, accurate data on how many people are impacted by infertility in the United States. Investing in funding research on how and why infertility is more prevalent in some communities than in others and in practicing inclusive research participation by impacted communities is imperative. Likewise, researching whether existing infertility treatment meets the needs of people impacted by infertility is important. Research has shown that even when care is accessed, infertility treatment like IVF has poorer success rates in Black women as compared to their non-Hispanic white counterparts.¹⁰ Filling the research gaps in infertility incidence, access to care rates, and treatment success rates is critical to ensuring not only that people impacted by infertility can equitably access care, but that the care they access successfully meets their family formation goals.

To learn more about infertility, access to care, and disparities in the United States, see [Infertility and IVF Access in the United States: A Human Rights-Based Policy Approach](#).

GUIDING PRINCIPLES

The principles outlined here are based on core human rights norms and standards, including the rights to reproductive autonomy, health, and equality and

Infertility

The Centers for Disease Control and Prevention (CDC) defines infertility as the inability to become pregnant after six months of unprotected sexual intercourse if 35 or more years of age or 12 months if under 35 years of age. By this metric, infertility impacts approximately 12% of women ages 15-44 years in the United States,¹¹ while almost 9% of men ages 25-44 years report that they or their partner saw a doctor for an infertility issue. This definition, often incorporated into legislation regulating insurance coverage for infertility care, describes the physiological conditions underlying the inability to reproduce and assumes that a person is engaging in procreative sex with their partner. As such, it fails to address social infertility, defined as the inability to reproduce due to social factors such as a person's lack of a partner or because of a person's sexual orientation.

Intrauterine Insemination (IUI)

A method of assisted reproduction whereby sperm is transferred directly into a person's uterus to facilitate fertilization.

In Vitro Fertilization (IVF)

An assisted reproductive technology wherein sperm and an egg are combined in a laboratory to create an embryo that can then be transferred into a uterus where it may implant in the uterine lining.

Ovulation Stimulation (OI)

A method of assisted reproduction most used in an IVF cycle that uses hormone medications to stimulate follicular development and induce oocyte maturation to ensure that during a menstrual cycle one or more mature oocytes are released.

non-discrimination, which respect, protect, and fulfill the rights of every individual to reproductive health care. Infertility care is part of the full spectrum of reproductive health care and as such, these principles apply human rights norms and standards to ensure that individuals, couples, and families have equitable access to infertility care without discrimination. Lawmakers should consider these principles when developing proactive legislation to require insurance coverage for infertility care, including diagnosis and treatment such as IVF.

Every person has the right to make autonomous decisions about their reproductive life, including whether to have children, when to have children, and how many children to have.¹² This right includes an individual's right to decide whether to grow their family using assisted reproduction, including assisted reproductive technologies such as IVF. IVF is time-sensitive and requires frequent ultrasound monitoring, blood tests, medication, and

availability for egg retrieval. Insurance mandates to provide coverage for infertility care should not require individuals to undergo other forms of assisted reproduction, such as IUI, before becoming eligible for IVF. While less expensive than IVF, a single cycle of IUI can cost between \$150 and \$4,000 out-of-pocket depending on whether it includes hormone treatment and medical monitoring.¹³ Notably, the rates of success for IUI are lower than for IVF.¹⁴

Governments must ensure that every person has the right to the highest attainable standard of physical and mental health, including sexual and reproductive health.¹⁵ As such, governments must provide access to infertility care that is available, accessible, acceptable, and of good quality.¹⁶ Limited information, restrictive laws and policies, stigma, high cost, and other barriers put infertility care, including IVF, out of reach for many, especially people of color, low-income people, people with disabilities, and the LGBTQ commu-

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nity. To guarantee that infertility care and facilities are available, governments must ensure that there is a sufficient number of trained infertility care providers and facilities throughout the country.¹⁷ To ensure that infertility health care is accessible, it must be physically accessible, including for people living in rural areas and people with disabilities. It must also be economically accessible, i.e. affordable for all, and evidence-based information on infertility must be made easily accessible and provided in a manner consistent with the needs of the individual and the community.¹⁸ To ensure that infertility care is acceptable, it must respect principles of confidentiality and informed consent and be culturally appropriate and respectful.¹⁹ Finally, infertility care, including facilities, services, and information must be of good quality, meaning that they “are evidence-based and scientifically and medically appropriate and up-to-date.”²⁰

Insurance mandates can help to ensure that infertility care meets the requirements of availability, accessibility, acceptability, and good quality. To do so, and to reach the widest number of insured individuals, insurance mandates should apply to individual, small, and large group insurance markets.²¹ Likewise, laws and policies should consider how to ensure infertility care insurance coverage for employees of self-insured employers, whose plans are exempt from state insurance mandates under the Federal Employee Retirement Income Security Act Laws.²²

Laws and policies should also look beyond the private insurance market. Medicaid, an income-restricted health insurance program and the largest source of public funding for medical and health-related services for low-income people and families in the United States, rarely covers diagnostic testing for infertility or infertility care.²³ This makes receiving a diagnosis of infertility and most forms of infertility care prohibitively expensive for the nearly 75 million people enrolled in the program. Likewise, laws and policies should con-

sider the needs of people insured under TRICARE, an insurance-like benefit plan used in the Department of Defense’ (DoD) military health system, the Department of Veterans Affairs, and the Federal Employee Health Benefit Program, which does not currently cover IVF for its over 8 million enrollees.²³

Laws and policies relating to access to infertility care must not discriminate against people on prohibited grounds, including sex, gender identity, sexual orientation, race, disability, marital or relationship status, nationality, or other status.²⁵ Record numbers of people are seeking infertility care in the United States. In 2018, one third of U.S. adults reported either using some form of infertility care to try to grow their family or knowing someone who had.²⁶ To better ensure that every person can afford and access the infertility care they need, laws and policies should be inclusive. For example, laws and policies should be gender neutral and not predicate eligibility for infertility coverage solely on an individual’s inability to procreate with their partner. Instead, they should recognize social infertility and the need for assisted reproduction by single people and people in same-sex couples through an inclusive definition of “infertility” which recognizes a person’s inability to reproduce either as an individual or with their partner.²⁷ Alternatively, legislation should include a definition of “infertility patient” as anyone who requires medical intervention to become pregnant.²⁸

Laws and policies should also not require an individual to be married or to use their spouse’s sperm to be eligible for coverage. Such a requirement excludes single individuals, individuals in same-sex partnerships, married same-sex couples, and individuals in non-traditional family units impacted by infertility. Additionally, they should not require individuals or families to use their own gametes to be eligible for coverage as is currently required of U.S. military servicemembers and veterans. Instead, infertility insurance coverage should allow for individuals and couples to use gametes or embryos provided by others²⁹ thereby better recognizing how different individuals and couples experience infertility and the kind of infertility care they need to grow their family.

To learn more about infertility incidence and access to care for service-

members and veterans, see [Serving Those Who Serve? Access to IVF for Servicemembers and Veterans.](#)

Every person has the right to comprehensive, unbiased, and evidence-based information and services and has the right to consent to or to refuse treatment.³⁰ To make informed decisions, individuals seeking infertility care should be well-informed about how infertility may present itself, what care is available to address infertility, and the risks associated with infertility care, including but not limited to ovulation stimulation, intrauterine insemination, IVF, and fertility preservation as well as the risks associated with any medication used in combination with these. Laws and policies mandating coverage for infertility care should require the dissemination of accurate and evidence-based information on infertility and on the availability of infertility care. This information should be accessible to all individuals seeking infertility care, including via the internet and primary health care providers.

Governments must ensure that persons directly impacted by infertility can effectively and meaningfully participate in the development, adoption, and implementation of laws and policies governing access to infertility care.³¹ Impacted people are best positioned to understand how infertility is experienced and what solutions are needed to address it. Laws and policies should be drafted following a consultative process with stakeholders so that resulting laws and policies are responsive to the needs identified and prioritized by those communities most impacted by infertility.

Public and private actors have a responsibility to respect the human rights of people seeking or receiving infertility care.³² Governments must ensure that laws, policies, and practices requiring insurance coverage for infertility care, including IVF, promote accountability and transparency in decision-making by private actors and at the local, state, and federal level. One way to do this is to incorporate accountability mechanisms that oversee and hold accountable the actions of third parties, including fertility clinics, should they fall short of established guidelines, best practices, or licensing schemes.

Endnotes

- ¹ American Society for Reproductive Medicine, *Disparities in Access to Effective Treatment for Infertility in the United States: An Ethics Committee Opinion*, 116 FERTIL STERIL 54 (2021), [https://www.fertstert.org/article/S0015-0282\(21\)00137-0/fulltext](https://www.fertstert.org/article/S0015-0282(21)00137-0/fulltext); Angela Kelley et al., *Disparities in Accessing Infertility Care in the United States: Results from the National Health and Nutrition Examination Survey, 2013-16*, 112 FERTIL STERIL 562 (June, 28, 2019), [https://www.fertstert.org/article/S0015-0282\(19\)30423-6/fulltext](https://www.fertstert.org/article/S0015-0282(19)30423-6/fulltext); National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children* at chapter 11 (2012), https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf.
- ² See generally Monique Tello, *Racism and Discrimination in Health Care: Providers and Patients*, Harvard Health Publishing: Harvard Health Blog (Jan. 16, 2017), <https://www.health.harvard.edu/blog/racism-discriminationhealth-care-providers-patients-2017011611015>; David Williams & Toni Rucker, *Understanding and Addressing Racial Disparities in Health Care*, 21 HEALTH CARE FIN. REV. 75 (2000), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194634/>; Ursula Bauer & Marcus Plescia, *Addressing the Disparities in the Health of American Indian and Alaska Native People: The Importance of Improved Public Health Data*, 104 AM. J. PUB. HEALTH S255 (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4035867/>.
- ³ Anjani Chandra et al., *Infertility and Impaired Fecundity in the United States, 1982-2010: Data From the National Survey of Family Growth* (2013), <https://www.cdc.gov/nchs/data/nhsr/nhsr067.pdf>.
- ⁴ Anjani Chandra et al., *Infertility Service Use in the United States: Data from the National Survey of Family Growth, 1982-2010*, NATL HEALTH STAT REPORT (2014), <https://pubmed.ncbi.nlm.nih.gov/24467919/>.
- ⁵ Ada C. Dieke et al., *Disparities in Assisted Reproductive Technology Utilization by Race and Ethnicity, United States, 2014: A Commentary*, 26(6) JOURNAL OF WOMEN'S HEALTH 605 (June 2017), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5548290/>.
- ⁶ Bronwyn Bedrick et al., *Factors Associated with Early In Vitro Fertilization Treatment Discontinuation*, 112 FERTIL STERIL 105 (2019), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7299162/>.
- ⁷ FertilityIQ, *IVF – In Vitro Fertilization*, <https://www.fertilityiq.com/ivf-in-vitro-fertilization/costs-of-ivf> (last visited June 9, 2021); National Institute for Health and Care Excellence, *The Importance of 3 Full Cycles of IVF* (Oct. 31, 2014), <https://www.nice.org.uk/news/blog/the-importance-of-3-full-cycles-of-ivf>.
- ⁸ Tarun Jain et al., *Insurance Coverage and outcomes of In Vitro Fertilization*, THE NEW ENGLAND J OF MED (2002), https://www.nejm.org/doi/10.1056/NEJMs013491?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0www.ncbi.nlm.nih.gov.
- ⁹ Marianne Bitler & Lucie Schmidt, *Utilization of Infertility Treatments: The Effects of Insurance Mandates*, 49 DEMOGRAPHY 125 (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5833298/pdf/nihms926829.pdf>.
- ¹⁰ See e.g., Dana McQueen et al., *Racial Disparities in In Vitro Fertilization Outcomes*, 104 FERTIL STERIL 398 (2015), [https://www.fertstert.org/article/S0015-0282\(15\)00359-3/fulltext](https://www.fertstert.org/article/S0015-0282(15)00359-3/fulltext); Tarun Jain, *Racial Disparities and In Vitro Fertilization (IVF) Treatment Outcomes: Time to Close the Gap*, Reprod Biol Endocrinol 18, 112 (2020), <https://rbej.biomedcentral.com/articles/10.1186/s12958-020-00672-2>.
- ¹¹ Centers for Disease Control and Prevention (CDC), *2017 Assisted Reproductive Technology Fertility Clinic Success Rates Report* (Oct. 2019), <https://www.cdc.gov/art/reports/2017/fertility-clinic.html>. While this study does not report accounting for respondents' gender identity and thus appears to be based on cisgender respondents, infertility also impacts transgender and gender nonconforming people.
- ¹² Convention on the Elimination of All Forms of Discrimination Against Women, *adopted* Dec. 18, 1979, art. 16(e), G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, at 193, U.N. Doc. A/34/46 (1980), 1249 U.N.T.S. 13 (*entered into force* Sept. 3, 1981) [hereinafter CEDAW]; Convention on the Rights of Persons with Disabilities, *adopted* Dec. 13, 2006, art. 3, 23(1)(b), G.A. Res. A/RES/61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/61/611 (1980) (*entered into force* May 3, 2008) [hereinafter CRPD]. The reproductive justice framework, which aims to transform disparities so that “all people have the social, political, and economic power and resources to make healthy decisions” about their “gender, bodies, sexuality, and families,” is complementary to the human rights framework. Reproductive justice stands for the right of every person to personal bodily autonomy, to have children, to not have children, to parent children in safe and healthy communities, and to control one's birthing options. In this context, the reproductive justice framework advocates for the right of every person not only to *decide* to use assisted reproduction to parent but also to access assisted reproduction to achieve one's desired family size. Forward Together, *What is Reproductive Justice?*, <https://forwardtogether.org/what-is-reproductive-justice/>; Loretta Ross, *What is Reproductive Justice?* IN REPRODUCTIVE JUSTICE BRIEFING BOOK: A PRIMER ON REPRODUCTIVE JUSTICE AND SOCIAL CHANGE, <https://www.protectionchoice.org/downloads/Reproductive%20Justice%20Briefing%20Book.pdf>.
- ¹³ FertilityIQ, *The Cost of IUI*, <https://www.fertilityiq.com/iui-or-artificial-insemination/the-cost-of-iui> (last visited June 9, 2021).
- ¹⁴ Christina Caron, *Getting Pregnant with IUI: What You Need to Know*, THE NEW YORK TIMES (Apr. 18, 2020), <https://www.nytimes.com/article/getting-pregnant-iui.html>.
- ¹⁵ Universal Declaration of Human Rights, art. 25, GA Res 217A (III), UNGAOR, 3rd Sess., Supp. No. 13, U.N. Doc A/810 (1948) [hereinafter UDHR]; International Covenant on Economic, Social and Cultural Rights, *adopted* Dec. 16, 1966, art. 12, G.A. Res 2200A (XXI), U.N. GAOR, Supp. No. 16, U.N. Doc. A/6316 (1996) (*entered into force* Jan. 3, 1976) [hereinafter ICESCR]; CEDAW, *supra* note 12, art. 12; International Convention on the Elimination of all forms of Racial Discrimination, art. 5., *adopted* Dec. 21, 1965, G.A. Res. 2016 (XX), Annex, U.N. GAOR 20th Sess., Supp. No. 14 at 47, U.N. Doc. A/6014 (1996), 660 U.N.T.S. 195 (*entered into force* Jan. 4, 1969) [hereinafter CERD]. Committee on Economic, Social and Cultural Rights, *General Comment No. 22: on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights)*, para. 1, U.N. Doc. E/C12/GC/22 (2016) [hereinafter ESCR Committee, *General Comment No. 22*].
- ¹⁶ ESCR Committee, *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)*, (22nd Sess., 2000), U.N. Doc. E/C12/2000/4 (2000) [hereinafter ESCR, *General Comment No. 14*].
- ¹⁷ *Id.* at para. 12(a); ESCR Committee, *General Comment No. 22, supra* note 15, at para. 12-13.
- ¹⁸ ESCR, *General Comment No. 14, supra* note 16, para. 12(b); ESCR, *General Comment No. 22, supra* note 15, para. 15-19.
- ¹⁹ ESCR, *General Comment No. 14, supra* note 16, para. 12(c); ESCR, *General Comment No. 22, supra* note 15, para. 20; Committee on the Convention on the Elimination of Discrimination against Women, Gen-eral Recommendation No. 24, para. 22, (20th Sess., 1999), U.N. Doc. A/54/38/Rev.1 (1999) [hereinafter CEDAW, *General Comment No. 24*].
- ²⁰ ESCR, *General Comment No. 22, supra* note 15, para. 21.
- ²¹ Colo. Rev. Stat. § 10-16-104(23) (2020); An Act to Provide Access to Fertility Care, ME LD 1539 (HP 1144) (2020), <http://www.mainelegislature.org/legis/bills/getPDF.asp?paper=HP1144&item=1&snum=130>.
- ²² Nearly 60% of private-sector employees in the United States are covered by a plan that is fully or partially self-insured. One of the largest self-insured employers in the United States is Walmart, which is also the country's largest private employer with approximately 1.5 million employees.
- ²³ In June 2019, New York announced that its Medicaid fee-for-service and Medicaid Managed Care benefits would include “medically necessary” ovulation enhancing drugs and attendant medical services for members between 21 and 44 years of age. Coverage includes up to three cycles of ovulation induction. *New York State Department of Health, New York State Medicaid Update* (June 2019), https://www.health.ny.gov/health_care/medicaid/program/update/2019/2019-06.htm; Utah enacted legislation in 2020 to provide coverage for IVF and genetic testing to Medicaid patients who have a genetic trait associated with cystic fibrosis, spinal muscular atrophy, Morquio Syndrome, myotonic dystrophy, or sickle cell anemia and who intend to undergo IVF with a partner who is diagnosed with the same qualifying condition. Utah Code Annotated § 26-18-420 (2020).
- ²⁴ Office of Personnel Management, *Healthcare & Insurance – FEHB Program Handbook Introduction*, <https://www.opm.gov/healthcare-insurance/healthcare/reference-materials/fehb-handbook/> (last visited June 3, 2021).
- ²⁵ UDHR, *supra* note 15, art. 1, 2, 7; International Covenant on Civil and Political Rights, *adopted* Dec. 16, 1966, art. 2, 3, 26, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (*entered into force* Mar. 23, 1976); ICESCR, *supra* note 15, art. 2, 3; CEDAW, *supra* note 12, art. 1; CERD, *supra* note 15, art. 1; CRPD, *supra* note 12, art. 5.; ESCR, *General Comment No. 14, supra* note 16.
- ²⁶ Gretchen Livingston, *A Third of U.S. Adults Say They Have Used Fertility Treatment or Know Someone Who Has*, PEW RESEARCH CENTER (July 17, 2018), <https://www.pewresearch.org/fact-tank/2018/07/17/a-third-of-u-s-adults-say-they-have-used-fertility-treatments-or-know-someone-who-has/>. Note that the survey's wording may have resulted in double-counting participants.
- ²⁷ Colo. Rev. Stat. § 10-16-104(23) (2020).
- ²⁸ An Act to Provide Access to Fertility Care, ME LD 1539 (HP 1144) (2020), <http://www.mainelegislature.org/legis/bills/getPDF.asp?paper=HP1144&item=1&snum=130>.
- ²⁹ Veterans Infertility Treatment Act of 2021, H.R. 1957, 117th Cong. (2021); Veteran Families Health Services Act of 2021, S. 1280, 117th Cong. (2021).
- ³⁰ CRPD, *supra* note 12, art. 25(d); ESCR, *General Comment No. 14, supra* note 16, para.8; ESCR, *General Comment No. 22, supra* note 15, para. 18, 21, 47; CEDAW, *General Comment No. 24, supra* note 19, para. 22; Juan E. Mendez, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, Human Rights Council, para. 47, U.N. Doc A/HRC/22/53 (Feb. 1, 2013). Involuntary sterilization has been recognized as a human rights violation, including of a person's right to informed consent and to refuse treatment.
- ³¹ ESCR, *General Comment No. 14, supra* note 16, para. 11.
- ³² *Id.* para. 35.