

Infertility and IVF Access in the United States:

A Human Rights Based Policy Approach

Infertility impacts millions of people in the United States. Nevertheless, limited information, restrictive laws and policies, stigma, high cost, and other barriers put infertility care, including in vitro fertilization (IVF), out of reach for many, especially people from marginalized communities. Well-documented disparities in access to infertility care reveal that people of color, low income people, people with disabilities, and LGBTQ communities receive treatment at disproportionately low rates.¹

Laws and policies that protect and promote equitable access to infertility care help to ensure the full spectrum of reproductive rights, including the right to make decisions about one's reproductive life, to health, and to equality and non-discrimination. This fact sheet presents the global and U.S. incidence of infertility and explores access gaps and barriers to infertility care in the United States. It also outlines human rights-based policy recommendations to address disparities in access to infertility care, including IVF, particularly among communities most impacted.

Infertility Incidence and Global Response

Infertility is a globally recognized public health concern. The World Health Organization (WHO) estimates that clinical infertility impacts 186 million women in developing countries.² The WHO emphasizes that research on safe and cost-effective solutions and increased access to infertility diagnosis, management, and treatment is necessary, particularly in developing countries where the burden of infertility is the greatest.³ In 2019, the United Nations Population Fund included the “capability to reproduce” in its definition of sexual and reproductive health, and advocated for expanded access to infertility treatments that delinks access from ability to pay.⁴ It also noted that infertility can result in psychological distress, intimate partner violence, and social stigma.⁵ Most recently, on the occasion of the 25th anniversary of the International Conference on Population and Development – a 1994 meeting where governments adopted a Programme of Action calling for all people to have access to comprehensive reproductive health care, including family planning – sexual and reproductive health and rights organizations from around the world identified infertility and involuntary childlessness as a global area of unmet need that governments and United Nation agencies should address.⁶

In the United States, clinical infertility impacts approximately 12% of women ages 15-44,⁷ while almost 9% of men ages 25-44 report that they or their partner

saw a doctor for an infertility issue.⁸ A 2009 study found that only 24% of people seeking infertility care were able to access it in the United States.⁹ These numbers do not account for people who do not meet the narrow definition of clinical infertility adopted by the Centers for Disease Control and Prevention (CDC). (see Definitions)

In 2014, the CDC issued a National Public Health Action Plan for the Detection, Prevention, and Management of Infertility.¹⁰ The Action Plan focused on promoting healthy behaviors to maintain and preserve fertility and on promoting its prevention, including by reducing exposure to environmental and occupational agents that can threaten one's fertility.¹¹

Insurance Coverage

Infertility care can include a variety of treatments and services, including but not limited to diagnosis, management, and treatment including ovulation induction, intrauterine insemination (IUI), and IVF. While this section focuses primarily on access to IVF, it also includes information on other forms of infertility care where available.

Private Insurance Market

As of 2019, 17 states in the United States have insurance laws, also known as state mandates, requiring insurance companies to include coverage for infertility diagnosis and

treatment in their policies.¹² Of these, only 11 specifically require coverage for IVF.¹³ These mandates vary from state to state, but many include eligibility requirements that limit access to IVF. All of these, for example, require a clinical diagnosis of infertility (see Definitions), often requiring all people seeking coverage, including single people and people in same-sex partnerships, to demonstrate clinical infertility by undergoing a pre-determined number of unsuccessful rounds of IUI. Mandates include other limitations, as well. For example, Maryland, Arkansas, and Hawai'i require the person seeking coverage for IVF to use their spouses' sperm.¹⁴ Where policies cover IVF, coverage is limited by either a dollar limit that an enrollee may spend in a lifetime or a maximum number of IVF cycles that is covered.

Access to infertility care under these mandates is further limited by exemptions for certain employers. The Federal Employee Retirement Income Security Act (ERISA) governs self-insuring employers, that is employers who do not purchase insurance coverage but rather pay for health coverage out of pocket.¹⁵ ERISA supersedes state laws so that such employers are not required to comply with state mandates and thereby not required to provide coverage for infertility care.¹⁶ Mandates may also exempt small business.¹⁷ Under some mandates, employers can refuse to provide infertility coverage to employees if they claim that doing so violates their religious beliefs.¹⁸

Public Plans

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 infertility care, including IVF.¹⁹ Thus, the nearly 75 million people enrolled in Medicaid in the United States may not be able to access such care.²⁰ And while a recent study found that publicly-funded family planning clinics provide some infertility information and care to patients, this varies depending on whether or not the clinic receives funds through the Title X family planning program, a federal program established in 1970 to provide low-income individuals and families with comprehensive family planning health services.²¹

Servicemembers also have limited access to infertility care, including IVF. Under TRICARE, an insurance-like benefit plan used in the Department of Defense' (DoD) military health system, "non-coital reproductive procedures, services or supplies, including in vitro fertilization" are excluded from coverage.²² Pursuant to a 2012 memorandum that modified

Definitions

Infertility

Definitions of infertility generally refer narrowly to clinical infertility. The Centers for Disease Control and Prevention (CDC), for example, defines infertility as the inability to become pregnant after six months or one year of unprotected sexual intercourse. This definition, often incorporated into legislation to establish or expand IVF insurance coverage, fails to address social infertility, defined as the inability to reproduce via sexual intercourse due to social factors such as a person's lack of a partner or because of a person's sexual orientation.

The World Health Organization (WHO) distinguishes between primary infertility, which refers to women who have not previously had a pregnancy and live birth, and secondary infertility, which refers to women who have already had at least one pregnancy and live birth. Based on WHO's estimates, secondary infertility impacts more women globally than does primary infertility. For the purposes of this fact sheet, infertility refers to both primary and secondary infertility.

Intrauterine Insemination (IUI)

Also known as artificial insemination, IUI is a method of assisted reproduction whereby sperm is transferred directly into a person's uterus to facilitate fertilization.

In vitro Fertilization (IVF)

IVF is an assisted reproductive technology wherein sperm and eggs 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 Induction

Ovulation induction is a medical treatment that uses hormone medication to stimulate the ovaries to produce multiple mature follicles and ova. It can be used in combination with IUI to increase the likelihood of pregnancy.

DoD policy, however, an eligible servicemember or the lawful spouse of such a servicemember may receive access to assisted reproductive technologies, including up to three completed cycles of IVF from either a military treatment facility or a civilian provider.²³ The eligibility requirements to receive IVF, however, are narrow. Currently, only servicemembers who 1) are on active duty, 2) experienced a serious illness or injury while on active duty, 3) lost natural reproductive ability due to that illness or injury, 4) can provide their own genetic material to produce a pregnancy, and 5) have a lawful spouse who can also provide their own genetic material are eligible to have their IVF care covered.²⁴ These requirements exclude unmarried servicemembers, those in same-sex marriages, and those who cannot prove that a service-connected illness or injury caused their clinical infertility.

The Veterans Health Administration's (VHA) medical benefits package specifically excludes coverage for IVF services.²⁵ However, pursuant to a provision first attached to the annual appropriations bill in 2016 and included every year since then, the VHA currently funds IVF for veterans who had a service-connected condition that led to their inability to procreate with their spouse.²⁶ This funding is limited to the current fiscal year and must be renewed by Congress with every appropriations cycle. Moreover, these narrow eligibility requirements mirror those under TRICARE, limiting IVF access to a narrow subset of veterans – driving non-eligible individuals from both groups to seek care from out-of-network providers if they have the financial resources to do so.

Disparities in Access

The limited number of private insurance markets and public programs covering infertility services, combined with high out-of-pocket expenses, result in significant economic barriers to needed infertility treatment. Indeed, while state insurance mandates requiring infertility care coverage have been shown to significantly increase its use, this increase has been most notable among a subgroup of “older, more educated women” who may have a “higher probability of having private health insurance.”²⁷ A person's race, marital status, sexual orientation, and disability also impact their access to infertility information and care.

Income

The median cost of a single IVF cycle in the United States is \$19,200.²⁸ Although success rates vary based on multiple factors, including the patient's age and infertility

diagnosis, 2016 national data from the Society for Assisted Reproductive Technology reports that the rate of live births following first-use IVF for women under the age of 35 using their own oocytes is only 37%.²⁹ This leads to increased costs for women who require multiple cycles in order to achieve a live birth. A recent study found that nearly 34% of women surveyed discontinued treatment after their first IVF cycle due to its high cost.³⁰ Another study found that women without insurance coverage were three-times more likely to do the same.³¹ Other forms of infertility care, such as IUI, may also be cost-prohibitive for people in the United States with median or below median income levels.³² In addition, high costs and lack of insurance coverage may act as an incentive to patients and providers alike to transfer multiple embryos per cycle, which may lead to a multiple pregnancy (a pregnancy with more than one fetus) and attendant increased health risks to both the pregnant person and the fetuses.³³

Race

Racial disparities in rates of infertility and access to infertility care are well-documented in the United States. While Black women of reproductive age are 80% more likely to report infertility, they are 20% less likely than white women to receive infertility care.³⁴ Below-average rates of infertility care use have also been found among Hispanic and American Indian/Alaska Native non-Hispanic women.³⁵ This may be explained in part by the prohibitive costs of infertility care. The U.S. median income for Hispanic households in 2017 was \$50,486 and \$40,258 for Black households, putting even one cycle of IVF at a median cost of \$19,200 out of reach for many.³⁶

Delays in accessing infertility care have also been documented for Asian/Pacific Islander and Black non-Hispanic women who reported longer periods of infertility.³⁷ This may be driven in part by the stigma associated with infertility. Indeed, Black women have been shown to be “three to four times more likely [than White non-Hispanic women] to be concerned about having ‘failed’ to conceive, using science to conceive, the social stigma of infertility, and disappointing their spouse.”³⁸

Marital Status and Sexual Orientation

As mentioned above, single people and people in same-sex couples may also face barriers in accessing infertility care, including IVF. Indeed, public and private insurers can, and many do, require evidence of clinical infertility before

providing IVF coverage. That is, people must demonstrate they have tried to become pregnant by having unprotected sex for six months or a year, depending on their age. Such eligibility requirements are not inclusive of or sensitive to the experiences of single people and same-sex couples, who may be required to undergo six to twelve unsuccessful cycles of IUI in order to receive the required clinical diagnosis of infertility and become eligible for IVF coverage. While less expensive than IVF, a single cycle of IUI can cost between \$150 and \$4,000 depending on whether it includes hormone treatment and medical monitoring.³⁹ This does not include the cost of obtaining sperm.

Disability

The American Society for Reproductive Medicine (ASRM) issues guidelines for member fertility providers in the United States, yet there is no overarching regulatory framework in place. This means that individual providers, who act as gatekeepers to infertility treatment, may determine care for prospective patients based on criteria that may or may not align with ethical guidelines.⁴⁰ In this environment, fertility clinics have reportedly denied care to single people, people in same-sex couples, people with disabilities, and other marginalized groups based on harmful preconceptions about who can and should be able to have children and parent.⁴¹ For example, the National Council on Disability (NCD) reported on a case in which a fertility clinic denied infertility care to a blind woman based on the provider's perception that her blindness would present a direct threat to her future child.⁴² Provider bias has also been documented against persons who are HIV positive, have an intellectual disability, or are bipolar.⁴³

A Human Rights-Based Policy Approach

Infertile people must be able to equitably access the infertility information and care they need. Access to such information and care not only addresses infertile people's reproductive health needs but may also have a positive impact on the stigma associated with infertility. Advocates and policymakers developing laws and policies to expand access to infertility information and care in the United States should look to fundamental human rights, including the rights to personal and bodily autonomy, to equality and non-discrimination, to health, and to informed consent. In this way, infertility information and care will be part and parcel of basic reproductive health care.

Consistent with these principles, policies should ensure that

The Stigma of Infertility

Across all demographics, the stigma of infertility disproportionately affects women. This is true even though male-factor infertility accounts for an estimated 50% of all clinical infertility cases.⁴⁴ Infertility strikes at the core of the societal expectation that women are innately born to bear children and become loving mothers. Any deviation from this norm, whether intentional or not, may not only engender societal stigma or personal shame, but also lead to societal isolation and result in high levels of anxiety and depression that mirror those experienced by people dealing with cancer, heart disease, and H.I.V.⁴⁵ Society may stigmatize infertile women, including by undermining their value and questioning their gender identity, based on their inability or unwillingness to become pregnant and have a child. In some cases, infertility may lead to marital or interpersonal conflict⁴⁶ or domestic or intimate partner violence.⁴⁷

Increasingly, infertility is being recognized as a complex physical and mental trauma based on its negative personal impact on people's life expectations.⁴⁸ Some characterize it as an invisible loss – a complicated grief process for involuntarily childless people.⁴⁹

persons seeking infertility care are provided comprehensive, unbiased, and evidence-based information about the services they seek. More states should expand their insurance mandates to cover infertility care, including IVF. Likewise, Medicaid should include coverage for infertility care as part of its essential health benefits so that access to care is not dependent on a person's financial resources. IVF insurance eligibility requirements, whether for civilians or military members, should be inclusive of single people and people in same-sex couples. Ultimately, such laws and policies should be developed, adopted, and implemented with the effective and meaningful participation of persons directly impacted by infertility. In this way, such laws and policies will be responsive to the needs identified and prioritized by those communities most impacted by infertility.

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