INFERTILITY AND HUMAN RIGHTS: A JURISPRUDENTIAL SURVEY

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I. Introduction

A. The Importance of a Human Rights Framework for Infertility

Infertility—defined as “a disease of the reproductive system”—is a global health challenge affecting millions of individuals.¹ Yet, evidence-based and scientifically accurate information about infertility, as well as infertility treatment, is difficult or impossible to access for many of the affected individuals. Impediments may include a government’s refusal to allocate resources to address the issue, the expense of infertility treatment, the stigma experienced by infertile individuals, and the discriminatory exclusion of some infertile individuals from access to treatment. Systemically poor health care infrastructures and inadequate training may also contribute to increased incidences of infertility.²

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² Willem Ombelet, Is Global Access to Infertility Care Realistic? The Walking Egg Project, 28 REPROD. BIO MEDICINE ONLINE 267 (2014) (noting role of poor primary care in increased infertility in developing countries); see also OFF. OF THE OMBUDSMAN, GOV’T OF MALAWI, WOES OF THE WOMB: AN INVESTIGATION INTO ALLEGATIONS OF MEDICAL MALPRACTICE RESULTING IN REMOVAL OF UTERUSES FROM EXPECTANT WOMEN IN PUBLIC HEALTH FACILITIES (2019),
While this paper focuses on the disease of infertility, individuals and couples experiencing childlessness for other reasons are often burdened by the same social and emotional harms. Childlessness arising from legal, regulatory, or social constraints is no less consequential for individuals than disease-based childlessness. For purposes of this paper, we identify childlessness outside of infertility, sometimes called “social infertility,” as “conditional childlessness.” We believe that the phrase “conditional childlessness”—more fully defined below—is a better descriptor of the distinctions between infertility as defined by the World Health Organization (WHO), and other conditions giving rise to childlessness. The human rights norms applicable to conditional childlessness are not fully explored in this paper, but where there are overlaps between the jurisprudence concerning infertility and conditional childlessness, we analyze the pertinent human rights norms applicable to both circumstances.

We believe that human rights norms can guide jurisdictions in structuring their responses—both proactive and reactive—to infertility (as well as conditional childlessness). A number of studies and commentaries have identified the relevant human rights concerns raised by infertility and have examined the ways in which human rights concepts map on to clinical, social, and epidemiological observations of childlessness—whatever its cause. Based on this body of analysis, there is no question that the failure to prevent infertility, treat infertility, and recognize and respond to infertility and conditional childlessness raises human rights concerns. In particular, infertility implicates the right to health (e.g., International Covenant on Economic Social and Cultural Rights (ICESCR)), the right to equality and non-discrimination (e.g., International Covenant on Civil and Political Rights (ICCPR), Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)), the equal

3 See Anna Louie Sussman, The Case for Redefining Infertility, NEW YORKER, June 18, 2019 (describing challenges to disease-based definition of infertility).


right to determine freely and responsibly the number and spacing of one’s children (e.g., CEDAW), the right to benefit from scientific progress (e.g., ICESCR), and the rights to privacy and to form a family (e.g., ICCPR). Conditional childlessness may also be analyzed with reference to these rights, particularly the rights to equality and non-discrimination, the right to benefit from scientific progress, and the right to privacy and to form a family. These core human rights are set out in international human rights texts as well as regional human rights instruments such as the African Charter on Human and Peoples’ Rights and the European Charter of Human Rights.6

While human rights texts clearly articulate a set of norms that are relevant to infertility, the question remains whether international and national-level decisionmakers charged with interpreting and implementing these rights have employed human rights frameworks. This survey focuses on that open question: What is the evolving human rights jurisprudence relating to infertility?

To answer that question, we examine international and national practices as they exist. Our purpose is not to offer critiques, but to illuminate the extent to which international and national policies and practices regarding infertility have already engaged with human rights norms, and to explore the future implications of that approach.

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For purposes of this survey, we take the position that the term “jurisprudence” goes beyond the text of international instruments and reflects the idea that human rights law becomes fully realized as it is applied to particular issues and fact patterns. Accordingly, this global survey acknowledges relevant human rights texts, but focuses on human rights law “as applied” to issues of infertility by both international and domestic bodies, including courts and other adjudicative bodies, human rights monitoring bodies, human rights commissions, ombuds, and other policymakers. Further, this survey takes into account the understandings of human rights and infertility urged by advocates in the context of human rights monitoring. We believe that this comprehensive approach can most accurately determine the extent to which international, regional, and domestic jurisdictions have addressed issues of infertility through a human rights lens and can help ascertain whether—and how—a more consistent application of human rights frames might address gaps in human rights protections for affected individuals.

As described below, using this wide lens to explore the human rights jurisprudence relating to infertility, we find that both international and national bodies have recognized human rights issues raised by infertility. Beyond simply recognizing the connections, some bodies have gone farther to address and apply the nuances of human rights frames in particular situations involving infertility law and policy. While more challenges remain—and we describe some of these challenges at the end of this article—the human rights framework holds considerable promise as a basis for further developing international and national policies concerning infertility and, by extension, human rights-based approaches to conditional childlessness.

B. Definitions

Several key terms play an important role in this analysis.

1. Infertility

The WHO defines infertility for clinical purposes as “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse.” The WHO adopted this definition in 2009 as part of its general Glossary of definitions, and we use it here as a common point of

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7 WORLD HEALTH ORG., supra note 1.
Though the WHO’s definition is widely cited as a clinical description of infertility, it is not the only possible definition, and there are variations used in clinical practice, infertility research, and policymaking. Some definitions, for example, identify longer or shorter time periods of trying for pregnancy before achieving a diagnosis of infertility. Definitions may also vary with the age and gender of the individuals.

Importantly, a clinical definition of infertility may not be the operative legal definition adopted by policymakers within a jurisdiction. For example, in some jurisdictions, a diagnosis of infertility is reserved for individuals attempting to conceive or sustain a pregnancy within marriage. This legal limitation of the term “infertility” to married couples is not clinically dictated, but rather reflects a legislative choice. Case law may also determine the legal definition of infertility in a given jurisdiction. For example, some adjudicators have rejected legislative definitions of infertility that could limit the ability of same-sex couples to gain access to assisted reproduction.

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8 F. Zegers-Hochschild et al., International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary of ART Terminology, 92 FERTILITY & STERILITY 1520 (2009).


10 Gurunath, supra note 9, at 576.

11 For example, the U.S. Centers for Disease Control (CDC) suggest that for some providers, six months of unprotected sex without pregnancy may trigger infertility treatments for women over thirty-five. See Centers for Disease Control, Infertility Facts: What is Infertility? (Jan. 16, 2019), https://www.cdc.gov/reproductivehealth/infertility/index.htm [https://perma.cc/YYU6-EK6J].


13 YZ v Infertility Treatment Authority (Vic) [2005] VCAT 2655 (Austl.).
2. Primary and Secondary Infertility

Primary infertility is the inability to have any live birth, while secondary infertility is the inability to have a live birth after previously successful procreation. For purposes of our investigation of human rights jurisprudence, we do not distinguish between primary and secondary infertility, but the terms appear in this report when citing other materials recognizing the distinction.

3. Conditional Childlessness

While this paper focuses on the disease of infertility, individuals and couples experiencing childlessness for other reasons are often burdened by the same social and emotional harms. Childlessness arising from legal, regulatory, or social constraints on access to fertility treatments may be as consequential for individuals as disease-based childlessness. For purposes of this paper, we propose defining childlessness attributable to legal or social conditions, rather than medical factors, as “conditional childlessness.”

Same-sex couples, single individuals of either sex who wish to become parents in the absence of a partner, and couples in which one or both partners are transgender are most commonly identified with this category. In some instances, these couples or individuals are fertile in the sense of being disease-free but may require medical assistance to procreate on their own terms. We note that the legal and social conditions constraining reproduction are not limited to sexual orientation, gender identity, or partnering choices. While infertility itself is a disability, otherwise fertile disabled individuals or people living with HIV may experience conditional childlessness because of laws or practices limiting their access to reproductive technologies. Age—a factor that has physiological components but would not be characterized as a disease—may also give rise to

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14 WORLD HEALTH ORG., supra note 1; see also Mascarenhas et al., supra note 1.


conditional childlessness based on provider policies that impose age-based restrictions on infertility treatments.\textsuperscript{17}

Our use of the phrase “conditional childlessness” does not in any way represent an agreed definition proposed by the WHO or any other organization. We are proposing the phrase in the belief that “conditional childlessness” usefully distinguishes between the disease of infertility as defined by the WHO and classified in the International Classification of Diseases (ICD) and other conditions giving rise to childlessness of individuals and couples, which range from gender identity to discriminatory constraints on disabled individuals’ reproduction. We realize that our proposal requires further consideration and agreement with key stakeholders including affected communities, and so offer this definition to stimulate further discussion.

4. Assisted Reproductive Technology

This survey utilizes the WHO’s definition of assisted reproductive technology (ART), i.e., “all treatments or procedures that include the in vitro handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy. This includes, but is not limited to, in vitro fertilization and embryo transfer, gamete intrafallopian transfer, zygote intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation, and gestational surrogacy.”\textsuperscript{18} According to the WHO, “ART does not include assisted insemination (artificial insemination) using sperm from either a woman’s partner or a sperm donor.”\textsuperscript{19}

5. In Vitro Fertilization

The WHO defines in vitro fertilization (IVF) as an “ART procedure that involves extracorporeal fertilization, i.e., fertilization of an egg(s) outside of the human body.”\textsuperscript{20}

\textsuperscript{17} Robert L. Klitzman, \textit{How Old is Too Old? Challenges Faced by Clinicians Concerning Age Cutoffs for Patients Undergoing In Vitro Fertilization}, 106 FERTILITY & STERILITY 216 (2016).

\textsuperscript{18} F. Zegers-Hochschild, \textit{supra} note 8.

\textsuperscript{19} Id.

\textsuperscript{20} Id.
C. Survey Methodology

The methods employed for this survey consisted of desk research and key informant interviews.21

1. Desk Research

To begin the research, we developed search terms tailored to generate information relating to both domestic and international human rights jurisprudence. The following terms were utilized in online searches. Searches proceeded by combining a term from the list of Instruments and Documents with a term from the list of Concepts.

a. Instruments and Documents

- Universal Declaration of Human Rights
- International Covenant on Economic, Social, and Cultural Rights
- International Covenant on Civil and Political Rights
- UN Convention on the Elimination of All Forms of Discrimination Against Women
- UN Convention on the Rights of Persons with Disabilities
- UN Convention on the Elimination of All Forms of Racial Discrimination
- UN Convention on the Rights of the Child
- UNESCO Universal Declaration on the Human Genome and Human Rights
- International Conference on Population and Development Programme of Action
- European Convention on Human Rights
- Council of Europe Convention on Human Rights and Biomedicine
- Treaty of Rome provisions: freedom of movement to seek medical services, freedom of movement of goods
- African Charter on Human and Peoples’ Rights
- Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa
- Abuja Declaration
- Maputo Protocol
- Artavia Murillo et al. v. Costa Rica (IACHR 2012)
- American Convention on Human Rights

21 Key informant interviews are “in-depth interviews of a select (nonrandom) group of experts who are most knowledgeable of the organization or issue.” Key Informant, ENCYC. OF SURVEY RESEARCH METHODS (2008).
b. Concepts

- The right to reproduce
- The right to found a family
- The right to decide freely and responsibly on the number and spacing of children
- The right to procreate
- The right to privacy
- The right to science
- The right to health
- Fertility treatments for prisoners
- Childlessness
- Medical infertility
- Social infertility
- HIV and infertility
- Sterilization
- Medically Assisted Reproduction (MAR)
- Assisted Reproduction Technology (ART)
- In-Vitro Fertilization (IVF)

These terms were employed in the fall of 2019 in searches of the following databases: Westlaw, LexisNexis, JSTOR, Hein Online, vLex, escr-net, the Global Health and Human Rights database, the Oxford Reports on International Law, SCC Online, and UT Austin Translated Decisions. Searches were also conducted in online databases maintained by: (1) the Office of the United Nations High Commissioner for Human Rights; (2) the Organization of American States, the InterAmerican Court of Human Rights and the InterAmerican Commission of Human Rights; (3) the Council of Europe and European Court of Human Rights; (4) the European Court of Justice and the European Agency for Fundamental Rights; (5) the African Court of Justice and Human Rights and the African Commission on Human and People’s Rights; (6) CARICOM, the Caribbean Community; (7) Forum-Asia, the forum for Asian human rights and development associated with ASEAN; and (8) the University of Toronto International Reproductive and Sexual Health Law Program. In addition, we surveyed materials from National Human Rights Institutions accessed through the Global Alliance of National Human Rights Institutions and the Danish Human Rights Institute. Searches conducted in Google and Google Scholar also identified relevant legal and background material.²²

²² The authors are grateful to the Northeastern University School of Law Library for assistance in identifying relevant databases and search terms.
II. Background: Why Examine Infertility and Why Now?

A. Consequences of Infertility and Conditional Childlessness

Infertility can impose special harms on individuals and families. The circumstances in which infertility and conditional childlessness arise, and their consequences, are unique to each individual and vary based on social circumstances. The examples below illustrate several social factors that can exacerbate the harms of infertility, conditional childlessness, and the lack of access to ART.

1. Infertility Can Lead to Polygyny

Recent studies have identified polygyny as one of the major by-products of infertility, leading to financial and emotional difficulties for many women. The inability to conceive is generally assumed to be a women’s issue, and men respond by taking additional wives, sometimes without any consultation with their initial spouse. Women


24 On the assumption that women are responsible for infertility, see Marcia C. Inhorn, “The Worms Are Weak”: Male Infertility and Patriarchal Paradoxes in Egypt, 5 MEN AND MASCULINITIES 236 (2003) (observing that “women typically bear the social burden of childlessness when their husbands are infertile”). On the “normalization” of polygyny in Malawi as a response to infertility, see B.C. de Kok, “Automatically you become a polygamist”: “Culture” and “Norms” as Resources for Normalization and Managing Accountability in Talk about Responses to Infertility, 13 HEALTH 197, 212 (2009).
dealing with infertility and polygyny react to these stresses by seeking out external support, and for some, by living separately from their husbands or initiating divorce.\textsuperscript{25} Women participating in one study recommend more comprehensive reproductive health care, since overcoming their childlessness was one way of ensuring that they continued to receive material support from their husbands.\textsuperscript{26}

2. Infertility Treatment May Be Stigmatized

Despite high-level commitments to sexual and reproductive health and reproductive rights from the International Conference on Population and Development of 1994 and the Sustainable Development Goals embedded in the United Nations’ 2030 agenda, a number of national strategies and plans still do not recognize infertility as an issue of concern.\textsuperscript{27} In some instances, infertility remains poorly understood, creating an environment of stigma and discrimination against infertile individuals.\textsuperscript{28} Misconceptions include the widespread belief that smoking or women’s use of oral contraceptives causes infertility. Similarly, studies indicate that women are typically blamed as the cause of a couple’s infertility.\textsuperscript{29}

\textsuperscript{25} Dierickx, supra note 23, at 1–2.

\textsuperscript{26} Id.


Infertility treatments themselves are often stigmatized. According to one study of an Islamic population, “[d]onor technologies are considered haram, or religiously forbidden and highly sinful. Sperm donation is particularly sinful, because it violates patrilineal genealogy, inheritance, and descent, which is an Islamic mandate.” Beyond specific religious prohibitions, there is often a generally-held view that IVF and other ART procedures are simply “socially unacceptable.”

3. Same-Sex Couples or Singles Seeking Treatment May Experience Discrimination

Same-sex couples and single persons often face additional barriers to receiving fertility services, even when they are available free of charge to heterosexual couples. For example, in some contexts, national guidelines state that women should be offered three cycles of IVF if they are under forty years old and have been trying to conceive naturally for two years, or have had twelve attempts at artificial insemination. As a practical matter, a single person or same-sex couple that is otherwise eligible for IVF may have no alternative but to undertake twelve attempts at artificial insemination at their own expense in order to qualify for IVF through the public health care system, since they will not be in a position to “try” natural conception for two years.

There are also reports of providers denying single women access to public funding for IVF altogether, on the ground that their family composition is undesirable. IVF is

30 Immigration and Refugee Bd. of Can., supra note 28.

31 Id.; see also Shanna Logan et al., Infertility in China: Culture, Society and a Need for Fertility Counselling, 8 ASIAN PAC. J. REPROD. 1 (2019) (indicating that some Chinese couples hide their infertility and withdraw from society due to feelings of shame); Rebecca Cook & Bernard Dickens, Reducing Stigma in Public Health, 125 INT’L J. GYNECOLOGY & OBSTETRICS 89 (2014) (discussing sources of stigma, including resort to medically assisted reproduction).


available to these women only if they can pay private providers significant sums out of pocket. Many simply cannot afford the costs without the subsidies offered through the public health system. For single women, it may be irrelevant whether they are infertile or conditionally childless, since discriminatory practices ensure that treatment is effectively unavailable in any case.

4. Infertility’s Emotional Consequences

The consequences of infertility may also be emotional. As the Constitutional Court of South Africa opined in 2016 concerning the effects of experiencing infertility, “grief; sadness; despair; panic; helplessness; and isolation are but a few of the feelings that often ensue.” According to researchers, the most common effects of “involuntary childlessness”—whether or not disease-based—are “distress, depression, anxiety, reduced self-esteem, somatic complaints, reduced libido and a sense of blame and guilt.”

For conditionally childless individuals, an additional effect is the impact of being treated differently based on one’s sexual orientation, gender identity, or family composition. While the harms of such policies may not be readily visible, the impacts are no less real.

B. Infertility is Receiving Increased Attention on Both the National and International Levels

Growing awareness of harms such as those described above, along with evidence of high rates of infertility in many places around the world and expanded ability to treat the

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35 AB and Another v. Minister of Social Development 2016 (3) SA 570 (CC) at 3 para. 2 (S. Afr.).


issue, has increased attention to infertility both domestically and internationally.38 For example, in 2015, the U.S. Centers for Disease Control issued a National Public Health Action Plan for the Detection, Prevention, and Management of Infertility.39 In its National Health Plan 2005–2015, the nation of Moldova specifically identified “prevention and management of infertility” as a priority issue.40 Malawi’s National Sexual Health and Reproductive Rights Policy for 2017–2022 similarly articulates a policy goal to “reduce incidence of infertility among men and women.”41 Likewise, a 2017 policy audit of nine European countries—Poland, Sweden, the Czech Republic, the United Kingdom, Italy, Romania, Spain, Germany, and France—found that all nine had legislation in place providing for access to infertility treatments, though criteria varied across borders.42

An important aspect of domestic legal regulation is the question of financial access to infertility treatment. In 2017, to aid the Irish government’s consideration of the issue, the Irish Health Research Board conducted a broad survey examining funding mechanisms for ART internationally. The report found that “[w]ithin Europe, six countries offer full public funding, and outside Europe, Israel, New Zealand, and Ontario (Canada) offer full funding. Within Europe, nineteen countries offer partial public funding, and outside


Europe, Australia provides partial funding. Based on this study, in 2018, the Irish legislature set aside funding to assist couples with the costs of IVF treatment, with a plan expected to be implemented by 2021.

Not surprisingly, increased attention to infertility on the national stage has been accompanied by greater attention to the issue internationally, as nations worldwide engage in high-level exchanges on human rights issues and sound public policies. Some governments reporting on their progress toward achieving the UN Sustainable Development Goals for 2030—particularly the goals relating to good health (SDG 3) and equality (SDG 5)—have connected these long-term goals with their domestic agenda to expand awareness regarding, and access to, infertility treatments. Some nations also identify infertility issues as a component of their reporting to human rights treaty monitoring bodies, such as the UN Human Rights Committee or the CEDAW Committee. International courts may also be called on to consider issues related to infertility, such as treatment of embryos, surrogacy, and circumstances of conditional childlessness.

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45 See Republic of Serb., infra note 144; Ministry of Foreign Affairs & Trade of Hung., infra note 145; Gov’t of Lat., infra note 146; Republic of Port., infra note 147.


III. Key Human Rights Are Realized Through Efforts to Address Infertility and Conditional Childlessness

As national and international attention to infertility grows and develops, and as technology to address infertility becomes more accessible, the rights at issue—to basic health care, to infertility information, and to infertility treatment—also become more concrete. Nations’ reporting on infertility issues in the context of human rights monitoring and SDG reporting is one indication that the contours of these rights are becoming clearer through the application of human rights norms. Below, we discuss how specific human rights have been applied in the contexts of infertility and conditional childlessness.

A. Right to Health

Article 25 of the Universal Declaration of Human Rights (UDHR) declares that “[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including . . . medical care.”48 The right to health also appears in the International Covenant on Economic, Social and Cultural Rights (ICESCR), which recognizes “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”49 The scope of the human right to health—which is also identified in the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), the UN Convention on the Elimination of All Forms of Racial Discrimination (CERD), the UN Convention on the Rights of People with Disabilities (CRPD), and regional human rights conventions—is thoroughly discussed in Fact Sheet 31 prepared by WHO and the OHCHR.50

The right to health encompasses reproductive health, including issues of infertility. Of particular note are (1) the African Charter on Human and Peoples’ Rights, which provides that States Parties “shall take the necessary measures to protect the health of

their people," and (2) the Maputo Protocol to the African Charter, which states that States Parties “shall ensure that the right to health of women, including sexual and reproductive health is respected and promoted.” The ICESCR also recognizes that the right to sexual and reproductive health is “an integral part of the right to health.” The General Comment 22 issued by the ICESCR directly addresses infertility, requiring States Parties to provide information about fertility treatments, take measures to ensure the universal access to infertility diagnosis and treatment, and work to eliminate social misconceptions regarding infertility.

Responding to calls from international and regional human rights bodies, some national health agencies have taken steps to address infertility as part of their efforts to achieve the human right to health. For example, when Iran participated in the UN Human Rights Council’s Universal Periodic Review (UPR) in 2016, the country reported that its steps to realize women’s human right to health included expanded access to infertility treatments. The number of clinics increased, and, under the new initiatives, infertile couples might qualify for government funding of up to eighty-five percent of their expenses for treatment.

Beyond infertility-specific measures, many of the initiatives undertaken to achieve the human right to health focus on improving basic health care to prevent occurrences of infertility. Where infertility rates are very high, such as in sub-Saharan Africa, preventable disease or infection often plays a significant role. In their 2015 literature survey, Inhorn and Patrizio observed that “[h]igh rates of African infertility are largely due to the sequelae of poorly managed or untreated RTIs [reproductive tract infections]; more than eighty-five percent of infertile women in sub-Saharan have a diagnosis of infertility attributable to an infection, compared with thirty-three percent of women.

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54 Id. ¶¶ 18, 40, 45.

This high rate of sexually transmitted infections contributes to increased infertility among both men and women.\textsuperscript{57}

Many countries have appreciated the connection between human rights and infertility prevention. For example, Angola addressed the issue of infertility prevention in response to recommendations from the African Commission on Human and Peoples’ Rights. When Angola was reviewed for its compliance with the African Charter on Human and Peoples’ Rights in 2012, the African Commission recommended that Angola “[s]trengthen reproductive health programmes and policies to ensure greater access to family planning by adolescent women and girls.” Responding to the Commission in a 2017 submission of two combined periodic reports, Angola underscored, among other things, that its domestic initiative on the “[p]revention and treatment of female and male infertility and sexual disorders” was an effort to realize human rights in this area.\textsuperscript{58}

International treaty bodies often reinforce this emphasis on prevention. For example, in 2017, Nigeria was reviewed for its CEDAW compliance. In Concluding Observations, the CEDAW Committee noted with concern high rates of obstetric fistula and lead contamination, both factors that could lead to infertility. The Committee recommended that the Nigerian government address these situations and “ensure” access to health care for those affected.\textsuperscript{59}

The following case study of Malawi indicates that domestic actors in that country have recognized a strong connection between the human right to health and infertility prevention.


\textsuperscript{57} Id.


1. Malawi Case Study: Infertility Prevention Through a Human Rights Lens

Infertility is a “significant public health problem in African countries like Malawi.” Godfrey Kangaude—gender equality and sexual and reproductive rights advocate—argues that the most common cause of infertility in Malawi is a lack of access to high quality health care, resulting in untreated and undetected STIs. For this reason, Kangaude and other public health advocates recommend addressing infertility issues by advocating for a broader human right to health care.

This approach is apparent in a report titled Woes of the Womb, in which the Malawi Office of Ombudsman employed a human rights lens to examine the practice of removing uteruses from expectant women in public health facilities. The Ombudsman found that from January to July 2018, three hospitals in Malawi registered a total of 160 hysterectomies, most conducted in conjunction with a caesarean delivery. Upon investigation, the Ombudsman determined that the Ministry of Health’s failure to provide sufficient staff to Obstetrics and Gynecology Departments compromised the quality of reproductive and sexual health services. The problem is systemic, with shortages of medical professionals, ward space, beds, drugs, medical equipment, and ambulances listed among the causes of preventable hysterectomies.

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63 OFF. OF THE OMBUDSMAN, GOV’T OF MALAWI, supra note 2. The Office of Ombudsman is an independent institution established by the 1994 Republican Constitution of Malawi.

64 Id. at 7–8.

65 Id. at 18–19.
Citing the fact that Malawi is a party to the ICESCR, a signatory to the Constitution of the World Health Organization, and a party to the Maputo Protocol, the Ombudsman concluded that “[i]t is the State’s obligation to provide quality health care to its citizens.” 66 Further, the Ombudsman noted, the Malawi government is obliged under Section 13(c) of its national constitution “to actively promote the welfare and development of the people of Malawi by progressively adopting and implementing policies and legislation aimed at achieving the goal of providing adequate health care, commensurate with the health needs of Malawian society and international standards of health care.” 67

Beyond its health effects, the prevalence of infertility in Malawi has serious social and cultural consequences. Kangaude notes that infertility is a common cause of divorce; it also leads to polygamy and extramarital affairs. 68 Although women disproportionately experience social stigma for being infertile, infertile men are also shamed and may be unable to access treatment. 69 In sub-Saharan Africa, diagnosis of male-factor infertility threatens men’s sense of self-worth given the prevalence of patrilineal descent and social pressure to become polygynous. 70 Yet polygyny is not a benign solution, since as Malawians increase their number of sexual partners, they may also increase the spread of HIV, creating additional public health concerns. 71

The Merck Foundation has organized an awareness campaign in Malawi to reduce the stigma of infertility while advocating for improved access to high quality fertility care. 72 This campaign appears to be effective, but Kangaude suggests going beyond

66 Id. at 19.
67 Id. at 6.
68 Kangaude, supra note 61.
69 Id.
70 Fiona R. Parrott, ‘At the Hospital I Learnt the Truth’: Diagnosing Male Infertility in Rural Malawi, 21 ANTHROPOLOGY & MED. 174, 176 (2014); see also DE KOK, supra note 60, at 3.
71 Georges Reniers & Rania Tfaily, Polygyny and HIV in Malawi, 19 DEMOGRAPHIC RES. 1811, 1825 (2008) (observing that “HIV prevalence rates in Malawi are higher among those who have been in a polygynous union compared to those who have been in monogamous marriages only”).
72 See Merck Foundation, Merck Foundation Partners with the First Lady of Malawi to Build Healthcare Capacity and Break Infertility Stigma in the Country, AFRICANEWS (Jan. 19, 2019),
education campaigns. Kangaude argues that a combination of higher quality health care, greater access to IVF technology, and more infertility treatment research can help reduce the incidence of infertility among men and women. Thus, the realization of a broader human right to health care may be the key to addressing this challenge.

B. Rights to Equality and Non-Discrimination

1. Gender, Sexual Orientation, and Gender Identity

Equality and non-discrimination are core human rights principles enshrined in the UDHR, ICCPR, ICESCR, CEDAW, CERD, and CRPD, in addition to regional human rights instruments. These principles have been explicitly applied to discrimination on the basis of gender, sexual orientation, and gender identity in the area of infertility.

Considering women’s equality, the UN Working Group on the Issue of Discrimination Against Women in Law and Practice stated in its 2016 Annual Report to the Human Rights Council that “[d]enial of access to essential health services with respect to . . . infertility treatment has particularly serious consequences for women’s health and lives.”\(^73\) The expert group noted that the denial comes in many forms, including “criminalization, reduction of availability, stigmatization, deterrence or derogatory attitudes of health-care professionals.”\(^74\) They also found that denial of access to health services “drives service provision underground into the hands of unqualified practitioners. This increases the risks to the health and safety of the affected women.”\(^75\)

Importantly, the ICESCR’s General Comment 14 explains that the right to non-discrimination in health care includes providing “those who do not have sufficient means with the necessary health insurance and health-care facilities.”\(^76\) This has particular significance for health systems relevant to fertility, since “investments should not


\(^74\) Id.

\(^75\) Id.

disproportionately favour expensive curative health services which are often accessible only to a small, privileged fraction of the population, rather than primary and preventive health care benefiting a far larger part of the population.  

The human rights to equality and non-discrimination are also implicated through the predicate causes of infertility, which may be correlated with gender. For example, human rights bodies have noted the connection between practices of Female Genital Mutilation (FGM) and infertility, connecting the dots between gender-based violence and infertility.

Beyond gender, the right to equality extends to sexual orientation and gender identity. While there is no specific treaty addressing sexual orientation or gender identity, several existing treaties, including CEDAW and the ICCPR, encompass those concepts. In addition, the widely-cited Yogyakarta Principles, while aspirational, speak to equality and non-discrimination based on sexual orientation and gender identity. Regional human rights instruments have also been construed to encompass discrimination on the basis of sexual orientation and gender identity.

Still, despite efforts to establish clear principles supporting equality in access to infertility treatment, as well as responses to conditional childlessness, judicial rulings have not always added clarity.

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77 Id.


Both the European and Inter-American human rights courts have considered allegations that restrictions on access to ART are discriminatory with varying results. In 2012, in *Gas and Dubois v. France*, the European Court of Human Rights considered a French law barring same-sex couples from receiving artificial insemination by an anonymous donor, a procedure that was available to infertile heterosexual couples. The applicants, a lesbian couple, claimed violations of Articles 8 and 14 of the European Convention on Human Rights—respectively, the right to privacy and the right to non-discrimination in realizing the rights of the Convention. However, the court never reached the Article 8 issue, because it concluded under Article 14 that the law was not discriminatory. According to the court, a fertile homosexual couple’s situation could not be deemed comparable to that of an infertile heterosexual couple, and therefore the law did not violate equality principles.\(^82\) While the European Court’s ruling still stands, in 2018, France’s top administrative court recommended amending French law to allow single women and lesbian couples access to IVF—a recognition that conditional childlessness requires a rights-based response.\(^83\)

In contrast to the European Court ruling in *Gas and Dubois*, when the Inter-American Court of Human Rights considered Costa Rica’s IVF ban, it credited the ban’s discriminatory impacts in assessing the severity of the restriction.\(^84\) The ban was challenged by several married heterosexual couples and one unmarried heterosexual couple, who argued that the law violated the American Convention on Human Rights. The court disallowed the IVF ban, concluding that the interference with privacy and other human rights “had a differentiated impact on the victims owing to their situation of disability, gender stereotypes, and, for some of the victims, to their financial situation.”\(^85\) The disabled applicants were subject to discrimination because the operative definition of infertility identified it as a disease, putting the burden on the state to help them overcome their condition.\(^86\) As to women, the court stated that the ban was based on and reinforced


\(^85\) *Id.*, ¶ 314.

“gender stereotypes [that] are incompatible with international human rights law.”

The poor were subject to discrimination because they could access IVF treatments only by travelling abroad, at significant expense.

Other countries have put forward their equality-based approaches to infertility treatment programs—including those for conditionally childless individuals—to international bodies as an indication of their human rights progress. For example, in a submission to the CEDAW Committee, Montenegro’s Human Rights Institution highlighted its 2009 law providing for equality in infertility treatments. Similarly, a 2019 Shadow Report filed with the CEDAW Committee by civil society groups in Uruguay noted favorably that the country’s national law allows both partnered and single women to access low-complexity fertility treatments through public health providers, and high-complexity fertility treatments with partial financial assistance.

Recognition of the discriminatory impacts of restricting access to fertility treatments appears to be growing. For instance, in one survey, a number of National Human Rights Institutions in Asia identified IVF access to sexual minorities as an important issue for domestic attention. Similarly, in its 2017 review of Italy’s compliance with the ICCPR, the Human Rights Committee noted that Italian law “[denies] access to in vitro fertilization under Law No. 400/2004 . . . to lesbian, gay, bisexual, transgender, and intersex persons.” Describing this as a “principal matter[,] of concern,” and identifying


91 Anne Gallagher, Presentation at the Regional Consultation on Reproductive Rights, Hosted by the APF and UNFPA (June 20, 2011), https://www.asiapacificforum.net/resources/presentation-anne-gallagher-apf-unfpa-regional-consultation-2011/ [https://perma.cc/R92N-JDU9].

the law as constituting discrimination on the basis of sexual orientation and gender, the Human Rights Committee opined that Italy should “provide for equal access to in vitro fertilization.”

2. Disability

Disabled individuals may be particularly susceptible to discriminatory violations of their rights to reproductive and sexual health, either because they are subjected to forced sterilization or because they are denied access to treatments for infertility or conditional childlessness. The CRPD speaks directly to both of these issues in Article 23, which obligates States Parties to eliminate discrimination against persons with disabilities in matters relating to family and parenthood, while also noting that “[p]ersons with disabilities, including children, retain their fertility on an equal basis with others.” The CRPD’s General Comment 3 identifies a specific concern regarding the human rights abuses inherent in the involuntary sterilization of disabled women and girls. The Comment also states that disabled individuals have an equal right to information about infertility and an equal right to make decisions about their fertility.

Several UN agencies have come together to jointly condemn involuntary sterilization. A number of civil society groups have made similar points in their UN submissions. For example, the International Disability Alliance, the feminist organization Creating Resources for Empowerment in Action (CREA) (India), and FiLiA (U.K.) have submitted materials on sterilization and more general reproductive issues for consideration by treaty bodies. In 2015, the Committee on the Rights of Persons with

93 Id. ¶ 11.
96 See id.
98 See Andrea Parra, Director of Advocacy, CREA, Speech at the Committee on the Rights of People with Disabilities Day of General Discussion on art. 5 (Aug. 25, 2017); INT’L DISABILITY ALLIANCE (IDA),
Disability’s list of issues for its review of Mongolia specifically focused on the forced abortion and sterilization of disabled individuals. The Disabled People’s Organizations of Mongolia reported to the Committee that forced sterilization was permitted in cases where a doctor determined that a woman had “psychosocial or intellectual disorders.” In its Concluding Observations on Mongolia, the Committee expressed concern about permitting sterilization without an individual’s informed consent and urged that the law be repealed. In another reporting sequence, the Committee criticized Cyprus for failing to maintain safeguards that would allow disabled women to retain their fertility.

Nevertheless, domestic-level application of these human rights norms continues to face some resistance, particularly when affirmative treatments are at issue. For example, Denmark has developed a review process for determining whether a disabled person will be allowed to receive ART, as described in the state party’s report to the CRPD Committee. A Danish civil society shadow report, however, objects to the lack of guidelines and seemingly arbitrary nature of the decision-making processes through which disabled individuals will be allowed to receive fertility treatment, expressing concern about the effects of these restrictions on access to reproductive assistance.

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C. The Right to Determine Freely and Responsibly the Number and Spacing of Their Children

Article 16 of CEDAW guarantees women equal rights in deciding “freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.” 104 The CRPD likewise recognizes the equality rights of persons with disabilities “to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education . . . and the means necessary to enable them to exercise these rights.” 105 This right is also articulated in Paragraph 7.3 of the International Conference on Population and Development (ICPD) Programme of Action, which recognizes “the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health.” 106 At the regional level, Article 14(1) of the African Women’s Protocol mandates that States Parties “shall ensure that the right to health of women . . . is respected and promoted,” including “the right to decide whether to have children, the number of children and the spacing of children.” 107

The terms of these provisions are pertinent to both infertile and conditionally childless individuals, yet international bodies have applied them infrequently. However, the CEDAW Committee’s General Recommendation No. 19 on violence against women recognizes that compulsory sterilization violates individuals’ right to decide on the number and spacing of one’s children. 108 Citing the General Comment, in 2006 the

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105 G.A. Res. 61/106, supra note 94.


CEDAW Committee concluded that the Hungarian government’s sterilization of a Roma woman without her consent violated Article 16 of CEDAW.  

D. The Right to Enjoy the Benefits of Scientific Progress and Its Applications

Article 27(1) of the Universal Declaration of Human Rights states that “[e]veryone has . . . the right to share in scientific advancement and its benefits.”  

This aspirational provision of the UDHR is reinforced in Article 15(1)(b) of the International Covenant on Economic, Social and Cultural Rights, which affirms that “[e]veryone has] the right to enjoy the benefits of scientific progress and its applications.” The right to benefit from scientific progress is also recognized in the Charter of the Organization of American States, the Protocol of San Salvador, the Arab Charter on Human Rights, the Charter of Fundamental Rights of the European Union, and the American Declaration of the Rights and Duties of Man. In addition, the right appears in the UN Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind, the Universal Declaration on the Human Genome and Human Rights, the Universal Declaration on Bioethics and Human Rights, and the UNESCO Recommendation on the Status of Scientific Researchers. The texts of these provisions, which repeatedly guarantee the right to “everyone,” are relevant to both infertile and conditionally childless individuals.

The right to science figured in the Inter-American Court’s consideration of Costa Rica’s absolute ban on IVF treatment in Murillo v. Costa Rica. Finding the ban to be in violation of the American Convention on Human Rights, the court drew a clear connection between access to science and the exercise of other protected rights.

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110 G.A. Res. 217 (III) A, supra note 48, art. 27(1).


112 G.A. Res. 3384 (XXX), Declaration on the Use of Scientific and Technological Process in the Interests of Peace and for the Benefit of Mankind (Nov. 10, 1975); G.A. Res. 53/152, Universal Declaration on the Human Genome and Human Rights art. 12(a) (Dec. 9, 1998); UNESCO Res. 29C/17, Universal Declaration on the Human Genome and Human Rights art. 15 (Nov. 11, 1997); UNESCO Res. 18 C/Res.40, Recommendation on the Status of Scientific Researchers art. 19 (Nov. 20, 1974).
According to the court, “the right to private life and reproductive liberty is related to having access to the medical technology necessary to exercise that right.”113

Following the Inter-American Court’s 2012 decision in Murillo, there was a prolonged political process in Costa Rica that ultimately resulted in an Executive Decree ordering compliance with the Inter-American Court’s decision.114 While reviewing the Costa Rican President’s Executive Decree in 2016, however, the UN Committee on Economic, Social, and Cultural Rights (CESCR) lodged concerns about the policy under the heading “Benefits of Scientific Progress.” The Committee recommended that the State Party continue efforts to “ensure, in practice, access to in vitro fertilization technology and to guarantee the right of persons who need to use this technology to enjoy the benefits of scientific progress and its applications.”115

E. Right to Privacy and Autonomy, Including the Right to Form a Family

The human right to privacy is recognized in the UDHR, the ICCPR, the ICESCR, the Convention on the Rights of the Child (CRC), the CRPD, the European Convention, and the American Convention.116 The right has been construed broadly and would apply to circumstances of both infertility and conditional childlessness. As interpreted by the Inter-American Court of Human Rights, the human right:

. . . goes beyond the right to privacy. The protection of private life encompasses a series of factors associated with the dignity of the individual, including, for example, the ability to develop his or her own


114 Ligia De Jesus Castaldi & Maria Ines Frank, Inter-American Court Judgment Against Costa Rica on In Vitro Fertilisation (IVF): A Challenge to the Court’s Enforcement Authority, OXFORD HUM. RTS. HUB: OXHRH BLOG (Apr. 28, 2016),
https://tbinternet.ohchr.org/Treaties/CESCR/Shared%20Documents/CRI/INT_CESCR_ICO_CRI_22872_E.pdf [https://perma.cc/USK6-WY33].


116 The right does not figure in the African Charter.
personality and aspirations, to determine his or her own identity and to define his or her own personal relationships. The concept of private life encompasses aspects of physical and social identity, including the right to personal autonomy, personal development and the right to establish and develop relationships with other human beings and with the outside world.  

Based on this reasoning, the Inter-American Court explained that “the decision of whether or not to become a parent is part of the right to private life and includes . . . the decision of whether or not to become a mother or father in the genetic or biological sense.”  

While they share a common core, international instruments vary in their articulation of the right to privacy. The ICESCR addresses this right in two provisions: Article 10 states that “[t]he widest possible protection and assistance should be accorded to the family,” and Article 17 prohibits “arbitrary” interference with the family. Likewise, the American Convention addresses family-related privacy in two provisions that track the ICESCR: Article 11(2) (barring arbitrary interference with the family) and Article 17 (identifying the family as a fundamental group entitled to protection). In contrast, the European Convention connects the right to privacy and family life in one section of text, Article 8, which provides that “[e]veryone has the right to respect for his private and family life, his home and his correspondence.”  

It is difficult to derive general principles from the case law under these provisions. On the one hand, courts often grant a wide margin of appreciation to uphold national

\[117\] Murillo, No. 257, ¶ 143.

\[118\] Id.


restrictions on ART. On the other hand, courts have required evidence that the balance reached by a state does not unduly restrict individual human rights.

The European Convention’s Article 8 figured prominently in Evans v. United Kingdom, a 2007 case before the European Court of Human Rights that concerned the treatment of a couple’s embryos. The couple had created the embryos during the course of their relationship. When they subsequently split up, the male partner withdrew his consent to use of the embryos and sought to have them destroyed, while his ex-partner, Ms. Evans, sought to preserve them. Because the case focused on the proper treatment of the embryos, it did not concern infertility per se, but the court’s interpretation of Article 8 is pertinent to the consideration of the states’ obligations in the infertility context. According to the Evans court, the term “private life” in Article 8 “incorporates the right to respect for both the decisions to become and not to become a parent.” Further, stated the court, Article 8 “does not merely compel the State to abstain from such interference [in private life]: in addition to this primarily negative undertaking, there may be positive obligations inherent in an effective respect for private life.” But, admitted the court, “[t]he boundaries between the State’s positive and negative obligations under Article 8 do not lend themselves to precise definition.”

The European Court directly addressed the application of Article 8 to infertility in Dickson v. United Kingdom, also decided in 2007. In that case, an incarcerated individual who could only conceive through assisted reproduction sought the state’s acquiescence and assistance in securing artificial insemination at his own expense. The U.K. refused to accommodate Dickson’s request, and he sought review by the European Court of Human Rights.

In its decision, the European Court noted that the right to privacy encompassed both positive and negative obligations, but determined that in the Dickson’s case, the question was whether an appropriate balance was achieved between competing public and private interests. Reviewing the specific circumstances—that Dickson’s partner was out of prison, that the costs imposed on the state would not be significant, and that the

122 The margin of appreciation is a judicial doctrine that allows states to have a measure of diversity in their interpretation and application of human rights treaty obligations. See generally ANDREW LEGG, THE MARGIN OF APPRECIATION IN INTERNATIONAL HUMAN RIGHTS LAW: DEFEENCE AND PROPORTIONALITY (2012).


124 Id. ¶ 75.

The underlying goal of prison is rehabilitation—the court concluded that the U.K. policy of denying ART put too great a burden on Dickson’s procreative rights and violated Article 8.\footnote{Dickson v. The United Kingdom: Summary of Facts, UNITE FOR REPROD. RIGHTS, https://uniteforreprorights.org/resources/dickson-v-united-kingdom/ [https://perma.cc/LH7T-8QLW].}

The European Court took a more deferential approach in 2011 when considering government restrictions on IVF in \textit{S.H. and Others v. Austria}.\footnote{S.H. v. Austria, 2011-V Eur. Ct. H.R. 295, 325 (discussed in greater detail in Part III.F infra).} There, the court concluded that the State’s prohibition of egg and sperm donation for in vitro fertilization was within the government’s margin of appreciation and therefore compatible with the European Convention. According to the court, the Austrian national legislature carried out a careful balancing of competing interests and allowed other forms of medically assisted procreation. The court further observed that there was no strong European consensus on whether donations for in vitro fertilization should be allowed.\footnote{Id. at 323–26.}

In contrast, in 2012 in \textit{Costa and Pavan v. Italy}, the European Court of Human Rights found violations in Italy’s law restricting access to IVF to sterile or infertile couples, or couples in which the men have STIs.\footnote{Case of Costa & Pavan v. Italy, App. No. 54270/10, EUR. CT. OF HUM. RTS. (Aug. 28, 2012), http://hudoc.echr.coe.int/eng?i=001-112993 [https://perma.cc/EK42-EAFK].} The applicants, a heterosexual married couple who had previously had a child, were carriers of cystic fibrosis. They sought to use ART to select an embryo that was free of the disease, but Italy’s law barred them from using that technique. Finding the law in violation of Article 8 of the European Convention, the court concluded that restrictions constituted a disproportionate interference with the applicants’ right to respect for private and family life.\footnote{Id.}

As discussed above, the Inter-American Court likewise determined that Costa Rica’s complete prohibition of in vitro fertilization violated the American Convention, including its provisions on privacy and rights to a family. According to the court, the prohibition was a disproportionately “severe interference in relation to [the couples’] decision-
making concerning the methods or practices they wished to attempt in order to procreate a biological child” and offered only “very slight” protection of prenatal life.\textsuperscript{131}

The CESCR has adopted a similar view, stating in its 2016 Concluding Observations concerning Costa Rica that denial of access to in vitro fertilization adversely affects, \textit{inter alia}, Article 10 of the ICESCR, “the right to form a family.”\textsuperscript{132}

\textbf{F. The Human Rights Identified as Pertinent to Infertility Appear in Every Major Human Rights Instrument and Are Subject to General Jurisprudential Principles}

As the above discussion underscores, infertility has been identified with a set of human rights that are endorsed in virtually all human rights instruments. The rights to equality and non-discrimination, to health, to privacy, to form a family, to determine the timing and spacing of children, and to science all appear in multiple human rights treaties and declarations. To varying degrees, international bodies have also discussed these rights with respect to conditional childlessness.

However, this roster of rights, while deeply intertwined, do have some important jurisprudential differences. In general, civil and political rights—such as equality, non-discrimination, and privacy—are deemed to be immediate obligations of States Parties to the treaties addressing these rights.\textsuperscript{133} In contrast, economic, social and cultural (ESC) rights—such as the right to health or to the benefits of science—are subject to progressive realization; that is, a State Party must respect, protect, and fulfill these rights over time, making steady progress, but is not immediately responsible for achieving these rights.\textsuperscript{134}

Still, even within the context of progressive realization, States Parties must take some immediate action irrespective of available resources. Discrimination in the delivery of


\textsuperscript{132} Comm. on Economic, Social and Cultural Rights, Concluding Observations: Costa Rica \textit{supra} note 115, ¶ 64.


ESC rights must be immediately addressed. In addition, States Parties are not permitted to adopt retrogressive measures that would move the government further away from meeting its human rights obligations. And the States Parties must at all times meet minimum core obligations, including essential health care.

As noted above, particularly within regional human rights systems, national policies may also be analyzed with reference to a “margin of appreciation” which credits the reasoned conclusions of national bodies, particularly when there is no region-wide (or international) consensus on the issue. A pertinent example is the European Court of Human Rights’ decision in S.H. and Others v. Austria. There, the court considered an Austrian law forbidding use of donated ova for IVF under all circumstances, and barring sperm donation unless the sperm was directly placed in the womb of a woman (in vivo artificial insemination). Two Austrian couples complained about this regulation. In upholding the policy as permissible under Article 8 of the European Convention, the court stated:

[T]he central question in terms of Article 8 of the Convention is not whether a different solution might have been adopted by the legislature that would arguably have struck a fairer balance, but whether, in striking the balance at the point at which it did, the Austrian legislature exceeded the margin of appreciation afforded to it under that Article. In determining this question, the Court attaches some importance to the fact that, as noted above, there is no sufficiently established European consensus as to whether ovum donation for in vitro fertilisation should be allowed.

At the same time, the court noted that the Austrian legislature would be expected to revisit the policy as conditions changed in the future. In fact, in 2015, Austria relaxed its rules in several respects to allow lesbian couples to use donated sperm for IVF and to

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135 OHCHR FAQ, supra note 133, at 15.

136 Id. at 15–17.


138 Id.

permit egg donation in certain circumstances. Similarly, after scrutiny by the European Court, Italy has altered its laws on gamete donation.

While there is a substantial paper trail demonstrating governments’ attention to infertility through submissions to international bodies and amendments to domestic laws, some expert observers remain cynical about national commitments to addressing infertility. According to the 2018 report of the Guttmacher-Lancet Commission—an international body assembled to develop an actionable agenda on sexual and reproductive health and rights—national rhetoric about infertility is not always backed up with action. The report asserts:

[An absence of political concern combined with the high cost of assisted reproductive technologies have resulted in a huge divide between high-income and low-income nations in the availability of fertility care. Much more could be done . . . to raise awareness about and prevent infertility, to research low-cost solutions, and to make access to new technologies more equitable across the globe.

Certainly, as the report concludes, there are times when nations seem merely to pay lip service to the human rights issues raised by infertility. However, the reporting on SDG implementation suggests that not all national promises to address infertility are empty.

Reports on nations’ progress toward achieving the SDGs indicate that a number of national governments (generally in Europe) appreciate the connection between infertility and human rights and are able to report concrete steps as part of their progress toward SDG goals. Examples include:


141 Guiseppe Benagiano et al., Italian Constitutional Court Removes the Prohibition on Gamete Donation in Italy, 29 REPROD. BIOMED. ONLINE 662, 662–63 (2014).


Serbia, which identifies the “fight against infertility” as part of its national strategy to encourage childbirth in pursuit of Target 3.7 on reproductive health;\(^{144}\)

- Hungary, which reports on an increase in state funding for infertility treatment, including IVF;\(^{145}\)
- Latvia, which reports on the introduction of publicly funded fertility treatment programs as part of its efforts under SDG 3;\(^{146}\) and
- Portugal, which has expanded its basic health services for pregnant women, a move that will likely also improve infertility outcomes.\(^{147}\)

### IV. Continuing Challenges

International bodies, national governments, and civil society have repeatedly recognized the relationships between infertility and human rights. Still, there remain many conceptual challenges underlying the human rights analyses that have not been fully addressed. These challenges are explored below.


A. The Definition of Infertility

A threshold challenge is the definition of infertility. Definitions matter because they shape the protections offered by courts, affect available funding streams, and are critical for ensuring that human rights are respected as governments respond to the issue.148

As set out above, the WHO defines infertility as a “disease.”149 Recognizing that many experiences of infertility are disease-based triggers a particular response, including access to medical services, insurance coverage, and critical funding that targets disease prevention, treatment, and management. Yet, it is also true that many individuals experience childlessness in the absence of any recognized disease. As key informant Elly Leemhuis-de Regt observed, “infertility has more than one face and many causes.”150

At least two domestic courts in Australia have already been asked to apply an equality lens to the question of whether infertility services can be limited only to individuals who experience infertility as a disease. In the earlier of the two cases, McBain v. Victoria, a Melbourne-based doctor initiated a court proceeding to determine whether he might administer IVF to an unmarried woman who wished to have a child.151 The court ruled that the Infertility Treatment Act of 1995 (Vic.), which prohibited administering IVF to unmarried women, violated the Sex Discrimination Act and the Australian Constitution. In rejecting the limitation of IVF to married women, the court refuted claims made by the Catholic Church that the limitation was supported by international treaty law focusing on the family unit.152

The Infertility Treatment Act was subsequently repealed, and the new law, the Victorian Assisted Reproductive Treatment Act of 2008, laid out prohibited grounds of discrimination in administering IVF.153 Notably, disability was omitted from these

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149 WORLD HEALTH ORG., supra note 1.

150 Interview by Martha Davis with Elly Leemhuis-de Regt (Sept. 13, 2019) (notes on file with the author).


152 Id. ¶¶ 11–13.

153 A more recent case, EHT18 v Melbourne IVF, held that a woman was not required under the 2008 Act to obtain her estranged husband’s consent to undergo IVF treatment using donor sperm, and that such a requirement would discriminate on the basis of marital or relationship status. [2018] FCA 1421 (Austl.).
grounds based on the assertion that in some instances, a mother’s disability might create risks for the child.154

Further, it is important to note that while the judicial opinions and legislation in this area expanded opportunities to access ART, these developments have not altered the disease-based model used to trigger Medicare coverage for the services. As set out in a 2014 report on women with disabilities:

In Australia, Medicare covers the treatment of IVF for medical infertility, but for women who are deemed not to be ‘medically infertile’ (such as single women and lesbian couples), then no Medicare rebate is available.155

Similarly, in Scotland, the National Health Service funds IVF only for couples, and same-sex couples are eligible for funding only after six to eight unsuccessful cycles of donor insemination.156 These hurdles to obtaining public funding severely restrict, or even deny, treatment to lesbians and single women as a practical matter.157

In these jurisdictions, then, general concepts of equality are applied to permit doctors to assist individuals with IVF regardless of the causes of their childlessness, but public funding for medical care is available only to those who are “medically” infertile. As discussed in Part III above, the human rights frame has already been applied in some instances to address inequality issues and may prove to be an approach that, for policy purposes, bridges the definitional distinction between infertility and conditional childlessness.

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155 FROHMADER, supra note 154, at 32.


157 HUMAN FERTILISATION & EMBRYOLOGY AUTH., FERTILITY TREATMENT 2017: TRENDS AND FIGURES 3 (2019) (noting that in the U.K., single patients made up only three percent of all treatment cycles).
B. Government Responsibilities to Address the Costs of Infertility Treatments

Taken to its endpoint, infertility treatment can be very expensive. Repeated cycles of infertility treatments, and even public funding for surrogacy, may be seen to take scarce funding away from other important priorities, including basic health care that might prevent infertility in the first instance. Yet, if no public funding is provided for infertility treatments, economic inequalities can dramatically skew who has access to these reproductive services. In such circumstances, human rights considerations can be an important touchstone for allocating resources, though they may not provide complete answers when a number of important priorities are competing for limited funds.

Inequalities in infertility treatment are particularly stark because of the steep costs associated with some types of treatments. Andrea Whittaker and her co-authors have written, for example, about the inequalities in the surrogacy market. As they note, “[g]iven the problems of ART access, individuals and couples are increasingly travelling across national borders in search of assisted reproductive services.” The costs of such travel, often involving repeated trips, are significant. That LGBTQ or single individuals may not have access to more local reproductive choices compounds the myriad inequalities in these arrangements.

In some places, donating eggs or serving as a surrogate may be a route to an individual’s economic stability. In those circumstances, nations may have little

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159 Andrea Whittaker et al., Globalised Quests for Assisted Conception: Reproductive Travel for Infertility and Involuntary Childlessness, 14 GLOBAL PUB. HEALTH 1669, 1670 (2019).

160 While travel costs will vary widely, typical costs common to individuals will include time, stress, and the cost of the procedure itself. See Alex Wu et al., Time Costs of Fertility Care: The Hidden Hardship of Building a Family, 7 FERTILITY & STERILITY 2025, 2028–29 (2013).


incentive to regulate a practice that is either bringing in tourist dollars or serving pro-
natalist policies.163

While these tourist markets flourish in some locations, low-income individuals who
reside in the country may still be unable to afford infertility services.164 And in countries
where infertility treatment is highly regulated and particularly costly to deliver, those
who cannot afford to travel internationally may not have access to infertility treatments
and reproductive technologies at all.165

Because of this, key informant Bernard Dickens sees the issue of public funding as
critical to protecting human rights.166 The CEDAW Committee has likewise urged
adoption of laws providing greater public subsidies for assisted reproduction.167

The following case study of India highlights the complex interplay between
reproductive autonomy, public funding, and the regulation of infertility treatments such
as surrogacy.

163 SAMA RES. GRP. FOR WOMEN & HEALTH, CALL FOR INPUTS—REPORT OF THE SPECIAL RAPPORTEUR ON THE
SALE AND SEXUAL EXPLOITATION OF CHILDREN, INCLUDING CHILD PROSTITUTION, CHILD PORNOGRAPHY AND
HealthIndia.docx [https://perma.cc/8UXS-6WJW] (noting that “surrogacy operates in a legal vacuum”);
Anastasia Paraskou & Babu P. George, The Market for Reproductive Tourism: An Analysis with Special
Reference to Greece, 2 GLOBAL HEALTH RES. POL’Y 1, 11 (2017) (arguing that “assisted reproductive tourism
is probably a way out to [Greece’s] current economic crisis”).

164 Sarojini Nadimpally, Unravelling the Fertility Industry: ARTs in the Indian Context, in
RECONFIGURING REPRODUCTION: FEMINIST HEALTH PERSPECTIVE ON ASSISTED REPRODUCTIVE TECHNOLOGIES 92, 94 (Sarojini
Nadimpally & Vrinda Marwah eds., 2014) (noting the “unresolved questions of access to these expensive
technologies for the majority in third world countries”).

165 Ombelet, supra note 5.

166 Telephone Interview with Bernard Dickens, Professor Emeritus, University of Toronto, Faculty of Law
(Sept. 16, 2019).

167 See, e.g., Comm. on the Elimination of Discrimination Against Women (CEDAW), Concluding
Observations on the Fifth and Sixth Period Rep. of Costa Rica, U.N. Doc. CEDAW/C/CRI/CO/5-6, ¶ 33
(July 11, 2011) (urging Costa Rica to “ensure access to assisted reproductive services”); CEDAW Comm.,
(July 24, 2014); (“The committee regrets that . . . assisted reproductive treatment is not subsidized [in
Lithuania]”). For information on the 2016 change in the law, see Valentinas Mikelėnas & Rasa Mikelėnait, Is
1. Case Study: Reproductive Autonomy or Under-Regulation?

In some countries, under- or unregulated fertility businesses are common, providing substandard care at high prices. These jurisdictions have become destinations for medical tourism. In fact, countries may see the provision of such services in an unregulated setting as a route to national economic stability.

The result may be that local women’s reproductive capacities are exploited in order to resolve the infertility issues of others. This concern is particularly acute for persons with disabilities, who may be exploited without providing their fully-informed consent to procedures.

At the same time, according to the Sama Resource Group for Women and Health in New Delhi, for those who can afford it, “the decision to enter a surrogacy arrangement by the intending parents is founded on reproductive autonomy.” In India, national courts have articulated a strong defense of reproductive autonomy. In Suchita Srivastava v. Chandigarh Administration, for example, the Supreme Court of India held that a woman’s right to reproductive choices is integral to personal liberty and the right to life. This right, the court wrote, includes the right to have children and to not have children, and derives from the rights to privacy, dignity, and bodily autonomy. Likewise, in Justice K.S. Puttaswamy v. Union of India, the Supreme Court held that privacy includes decisional autonomy of individuals to make personal reproductive decisions.

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169 Paraskou & George, supra note 163, at 8.


172 SAMA RES. GRP. FOR WOMEN AND HEALTH, supra note 163.


174 See id. ¶ 11.
choices. In other words, when a state interferes with an individual’s right to procreate through surrogacy, the state is directly encroaching on an individual’s privacy.

Ultimately, the extensive use of ART in India, Israel, and elsewhere is grounded in social pressure to conceive and raise a child that is “biological/natural.” The ready availability of ART through the under-regulated private sector supports these efforts to conceive, at least for those who can pay, while also attracting tourist dollars.

C. Limits of Government’s Positive Obligations

Whether or not infertility treatment receives public funding, the question remains whether, and in what circumstances, the government must take affirmative steps to make infertility services available to individuals. One of the strongest cases for such an affirmative obligation occurs when the individual seeking the services is in government custody. This was the very situation in Dickson v. United Kingdom, discussed above, where an incarcerated individual sought access to IVF in order to procreate with his non-incarcerated wife. Dickson agreed to self-fund the procedure, but the government would incur some minor costs and inconvenience as it accommodated the prisoner’s request. The European Court of Human Rights’ decision requiring the U.K. government to provide such assistance to the prisoner included as one factor in its calculus that the costs in that instance would not be significant.

However, this ruling leaves the door open for a different result if costs are greater. This has potential implications for female or LGBTQ incarcerated individuals seeking IVF or other infertility treatments, since accommodating their needs will require more extensive and expensive arrangements in the context of their incarceration. To date, the European Court has simply indicated that the expense of the requested procedure can be considered as part of a balancing test, without identifying whether the balance might tip away from accommodating the individual if the expenses were sufficiently great.

175 Justice K.S. Puttaswamy v. Union of India, (2017) 10 SCC 1, 201 (India).


There are other ways that states may seek to cabin their positive obligations, including setting limits on the state’s material expenditures in addressing infertility. For example, many national health programs limit the number of cycles eligible for public funding, with tacit approval from international and domestic human rights bodies. New Zealand also restricts obese individuals from receiving publicly-funded IVF, justifying the limitation as necessary to minimize the risk of poor outcomes.

Nation states have also frequently imposed different, more stringent, criteria on disabled people or individuals living with HIV who are seeking access to infertility assistance, raising the question of how far the affirmative obligation extends. In 2011, for example, Croatia reported to the UN Committee on the Rights of Persons with Disabilities that medical fertilization was available only to married couples “who have work capacity” and the capacity to provide adequate parenting, among other criteria.

And as recently as 2018, medical regulations in the Ukraine forbade doctors from providing IVF to women living with HIV.

At the extreme, far from extending fertility assistance, some nations continue to force the sterilization of individuals who are deemed to be deviant—such as transgender persons, disabled individuals, or those living with HIV—in likely violation of the Convention Against Torture.

https://qmro.qmul.ac.uk/xmlui/bitstream/handle/123456789/12980/Yarwood_Mary_PhD_Final_070316.pdf?sequence=1&isAllowed=y


regarding the persistence of these cruel and inhumane domestic laws and practices.\(^{184}\) In 2011, the ASEAN Civil Society Conference and ASEAN People’s Forum issued a statement calling on ASEAN member nations to end such practices.\(^{185}\) Likewise, the WHO and UN agencies have stated that sterilization is appropriate only with full and informed consent.\(^{186}\)

Finally, in some nations the concept of “embryonic personhood” has shaped access to IVF and other infertility treatments in ways that may violate human rights norms.\(^{187}\) In particular, opponents of IVF have argued that eggs are persons from the moment of fertilization, using that claim to support legal limitations on the number of eggs that can be fertilized using IVF.\(^{188}\) However, at least one UN expert has been critical of such limitations when examining them through a human rights lens.\(^{189}\)

**CONCLUSION**

Comprehensive rights-based approaches to addressing infertility are still difficult to identify on the national level. Instead of a human rights focus, many national laws adopt policies that (1) include discriminatory measures based on sex, sexual orientation, gender identity, disability, or HIV status; (2) disadvantage low-income people seeking infertility treatment.


\(^{185}\) Statement of Representatives of the 2011 ASEAN Civil Society Conference (ACSC)/ASEAN People’s Forum (APF) to the Informal Meeting Between ASEAN Leaders and Civil Society, FORUM-ASIA (May 6, 2011), https://www.forum-asia.org/?p=6941 [https://perma.cc/Y43X-PBB8].

\(^{186}\) World Health Org., Eliminating Forced, Coercive and Otherwise Involuntary Sterilization – An Interagency Statement, at 1 (May 2014).


treatments by restricting public funding; (3) fail to appropriately identify and rectify basic health and treatment gaps that lead to infertility; and (4) privilege conservative religious interpretations over contemporary understandings that acknowledge gender-based rights and scientific advances.

But, while few exemplars exist, the international community has steadily expanded its recognition of human rights norms’ applications in the context of both infertility and conditional childlessness. Further, detailed human rights-based approaches have been developed in related areas, such as maternal morbidity and mortality, and could serve as a model for similar guidance in the area of infertility. Development of such models may be the next stage in implementing human rights approaches in the context of both infertility and conditional childlessness.